University of Alberta

Breaking the Silence: Adolescents' Experience of Living with a Sibling who has Cystic Fibrosis

by

Sylvie Larocque

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the

Doctor of Philosophy

Faculty of Nursing

Edmonton, Alberta

Spring 2006

Your file Votre référence
ISBN: 0-494-14005-4
Our file Notre référence
ISBN: 0-494-14005-4

I would like to dedicate my thesis to my parents for their love and commitment to their children. Je vous aime énormément!

Abstract

Purpose: To date, the primary focus of research on siblings of a child with a chronic illness has been on the effects of living with the demands of the illness. The results were inconsistent and include negative effects, positive effects, mixed effects and no effects. These conflicting results are largely due to methodological limitations such as the lack of in-depth qualitative inquiries with the siblings as informants instead of solely with their parents. The purpose of this study, informed by Gadamerian hermeneutics, was to develop an in-depth understanding of the experience of adolescents living with a sibling who has Cystic Fibrosis.

Methods: The convenience sample consisted of 10 adolescents between the ages of 12 and 22 years who had a sibling living with CF. Following the first in-depth interviews, 8 adolescents were interviewed again using a variety of interactive activities. Interviews were audiotaped and transcribed. Hermeneutic interpretation was conducted by using an ongoing systematic analysis of the whole text, as well as a systematic analysis of parts of the text, and a comparison of the two interpretations for understanding the whole in relation to the parts. Whole cases were compared to other cases in order to find commonalties in meanings.

Findings: The invisibility of the illness enabled the adolescents to perceive their lives as **normal**; yet, the adolescents were able to recognize **the illness challenges**. Thoughts of their sibling's illness were mostly in the **background** thereby allowing them to have typical adolescents concerns such as homework. Thoughts about their siblings' illness emerged in the **foreground** when faced with external reminders or illness exacerbations which forced them to respond to different concerns and feelings. The

majority of the adolescents **wanted to know more** about their siblings' illness based on personal motives.

Recommendations: The Shifting-Progressive-Relapsing Perspective with illness-in-the foreground or illness-in-the background depending on the illness progression was developed as a model to understand what it is like for adolescents to have a sibling who has CF. With this new perspective in mind, I recommend that future nursing researchers shift towards a trajectory and developmental perspective to understand the experience of living with a progressive-relapsing fatal illness and that health care professionals use a family centered care approach to meet the siblings' emotional and informational needs.

Acknowledgements

I would first like to acknowledge Dr. Lynne Ray, my supervisor, for her understanding, continuous support and her shared commitment to children and their families who live with chronic conditions. She has given me research opportunities within her program of research and has guided me through my own research process for this dissertation. I also want to thank Dr. Margaret J. Harrison who has also facilitated invaluable research opportunities and who has never stopped believing in me. I also want to recognize Dr. Ronna Jevne for challenging me to be creative and to acknowledge my pre-understandings of what it was like for me to live with two chronically ill siblings. Thank you also Dr. Joyce Magill-Evans for her valuable contributions to my project through her challenging questions and attention to detail. I also want to thank Dr. Magdalena S. Richter for her interest and support in my research and to Dr. Anne Neufeld for chairing my candidacy and final oral examination. I was honored to have Dr. Janet Deatrick as my external examiner. Her in depth feedback will have an ongoing influence on my research in childhood and family nursing.

This study would not have happened without the support of the health care professionals at the Pediatric CF Clinic, University of Alberta Hospital. Special thanks to Joan Tabak, clinical nurse specialist, for her help in recruiting adolescents and in accessing information. I am grateful to the teens who gave generously of their time. Without them this study would not have been possible.

I have been privileged to study with an extraordinary group of women. We have shared moments of joy, accomplishment, discouragement and fear. We have laughed and

cried over good food, wine and most of all great company. A special thanks to Gwen Rempel whose generosity and friendship I will cherish forever.

My final thanks is to my family for their love, support, commitment to seeing through this (although intellectually stimulating and enriching) extremely emotionally challenging experience. Without my parents' proud-encouraging words and prayers, the laughter and joyful nature of my boys and the confidence of my friends and family in my ability to succeed, this journey would not have been possible.

I would like to acknowledge the financial support that I received throughout my doctoral program: The Canadian Nurses' Respiratory Society, the University of Alberta including the Faculty of Graduate Studies and the Perinatal Research Centre, the Centre national de la formation en santé, Laurentian University and the Registered Nurses Association of Ontario, Pediatric Nursing Interest Group.

Table of Contents

Figures

CHAPTER ONE

TO BE A SIBLING OF A CHILD WHO HAS A CHRONIC CONDITION

Cystic Fibrosis (CF) is a progressive disease with no known cure. However, evolving diagnostic measures and treatments have resulted in patients living longer. Families are thus expected to manage the illness' challenges for a longer period of time. Although the ill children and their parents have captured the interest of researchers, siblings have rarely been included in research designs. Thus, the purpose of this study is to understand the experience of adolescents living with a sibling who has CF. A Gadamerian hermeneutic lens was chosen to inform this study. In research informed by this philosophic perspective, the researcher's prior understandings of a chosen object of inquiry are examined. My understanding of my object of inquiry stems in part from my personal experience of having two chronically ill brothers, and from my knowledge of the literature on siblings of children who have a chronic condition.

Siblings of Children Living with a Chronic Condition

Childhood chronic conditions have often been defined in the sibling literature, explicitly as well as implicitly, as illnesses or disabilities with long-term trajectories. Childhood chronic conditions have also been associated with a range of added responsibilities and restrictions which markedly change everyday life for each member of the family (Chesler & Barbarin, 1987; Jessop & Stein, 1989; Strauss & Glaser, 1975; Trahd, 1986; Wright & Leahey, 1987). In addition, when there is uncertainty about the course of the illness it can cause anxiety and other emotional responses in every family member (Coyne, 1997a; Turk, 1964; Meyerowitz & Kaplan, 1967). Most of the research has focused on the experience of the child with a chronic condition and the stress faced by parents; however, there has been much less inquiry into the experiences of the ill child's siblings (Faux, 1993). It is possible that many of the family stresses and changes accompanying chronic childhood conditions affect siblings' well-being. It is also possible that

children who have a chronically ill sibling are able to manage with the changes imposed by the illness in ways that help them grow and develop in positive directions.

When one child has CF, changes in family patterns related to the demands of the illness include disruption of personal and family routines such as chores, meals, bedtime rituals, play patterns and family outings (Bluebond-Langner, 1996; Coyne, 1997b). One reported source of change and consequent risk to siblings' welfare is rooted in parental preoccupation with the ill child. In some studies siblings described their parents as being overindulgent, overprotective, and more lenient in discipline with the chronically ill child (Bendor, 1990; Feeman & Hagan, 1990). It has long been argued that siblings may feel rejected or resentful if they believe that their parents focus most of their physical or emotional attention on the ill child (Iles, 1979). Siblings' perception of differential treatment can increase conflict between siblings (Boer, 1990), which can threaten the integrity of sibling relations. Furthermore, decreased parental energy and attention can lead to feelings of isolation and loneliness for siblings (Williams et al., 1997). In one study, siblings exhibited more behavioral problems and depression than the ill child (Lee, Phoenix, Brown & Jackson, 1997).

Sibling relationships have attributes common to all interpersonal relationships but also have unique characteristics that enhance the strength of the sibling bond. The sibling relationship is typically 1) the longest relationship that an individual will experience in his/her lifetime, 2) one of close daily contact as siblings interact within the home, and 3) one which has shared as well as non-shared experiences contributing to the siblings' individual differences (Bank & Kahn, 1975; Cicirelli, 1995). Within the sibling subsystem, children learn to share, compete, and compromise with others of similar status. This socialization process has a profound influence on the siblings' lives (Powell & Gallagher, 1993) and is a foundation on

which brothers and sisters prepare for experiences with people outside the family system. The effects siblings have on each other's development may be increasingly important as the numbers of two-working-parent and single-parent families increase (Nelms, 1990). According to Rollins (1990), siblings of children with a chronic illness often perceived their mothers, especially single mothers, as unavailable.

A critical life event such as a child's chronic condition may significantly alter the sibling relationship and the sibling's life experiences (Dunn, 1988). Some siblings may experience a loss in their physical and emotional relationship with the afflicted sibling because of, for example, their desire to protect the ill child from physical harm through play (Fanos, 1996). Since the ill child often requires more time and attention from parents, it may interfere with the sibling bond, which often results in resentment. Fanos (1996) found that siblings frequently hope for a little illness for themselves, believing that illness brings increased parental attention.

Parents are often preoccupied with their own internal struggles (i.e. the need to protect their children) and external struggles such as receiving the needed support from community and health care services. When parents are preoccupied with their own struggles, siblings may take on increased household activities and parental roles (Chesler, Allswede & Barbarin, 1991) that are often resented by younger siblings (Bank & Kahn, 1982; Fanos, 1996) and that may become overwhelming for siblings. The most consistent factor to emerge from Damiani's (1999) literature review is that girls continue to have more home- and ill-child-care responsibilities than boys. This may be related to the findings that older sisters exhibit more behavior problems than other siblings (Silver & Frohlinger-Graham, 2000; Stawski, Auerbach, Barasch, Lerner, Zimin, 1997).

Despite these concerns, few researchers have addressed the experiences of siblings of a child with a chronic condition. In 1975, Bank and Kahn identified two major reasons for the lack of systematic research on siblings: (1) our culture values the parent-child relationship more than the sibling relationship, and (2) siblings have systematically been excluded from our health care delivery structure. These reasons seem to remain an issue thirty years later. I have chosen to study the experience of siblings to address the lack of systematic research and because of my experience of living with two chronically ill brothers. In the following sections, I will offer an historical account of my personal experience of living with two chronically ill brothers which was strongly influenced by my religious faith. Italic font will be utilized throughout the thesis when *referring to my personal experience.* My interpretation of how researchers have addressed the effects of chronic illness on siblings will follow my personal perspective.

A Personal Perspective

Although I have seldom spoken about my own experience of living with two chronically ill brothers, my earliest memory is of being only five years old, laying in bed at night and praying to God. I pleaded for Him to make my brothers' illness and sufferings disappear. I had watched my mother and grandmother pray, and they made what they called "sacrifices" in order to have their prayers answered. I decided that I would ask God to give me my brothers' illnesses and sufferings; that is, I would offer my health in exchange for my brothers' health. I thought my sacrifice would even surpass the ones I had seen my grandmother and mother make. God could not refuse me. I prayed every night because I feared that if I missed even one night, it would be the one when God had come to listen to my plea. I was very patient because I knew God had a lot of work to do and that it took a long time for Him to listen to everyone's prayers and wishes.

Five years went by and nothing happened. My soul was full of unbearable guilt, the guilt of being healthy as I watched my brothers suffer. I decided that my chosen sacrifice was not enough for what I was asking. How could one healthy body replace two ill bodies? I decided to ask God to take my life in exchange for my brothers' health. I prayed and waited for years for God to grant me my wish. He never did.

In my early teens, I became aware of the horrible injustices and sufferings that people were experiencing around the world. I was overcome with shame as I compared my wish to the needs of others. I came to realize that God would not grant me my wish because He was needed desperately elsewhere. I had to find an alternate solution to deal with my unbearable guilt. I did not feel that I could talk to my parents about what I was experiencing because they worried and cared so much for my brothers that I did not want them to have to worry about me. They had given so much of themselves to keep our family together and to give their children every opportunity to develop to their full potential. How they did so, I do not know. They received minimal help from external resources. I believe that their strong love and commitment to each other and to their children got them through what my father refers to as something he would not even wish on his worst enemy.

I was determined to find a way to lessen my guilt. I decided to live my life for one of my brothers. I didn't think I had the strength to do it for both. I chose Luc over Paul because Luc was suffering the most. He had experienced health for the first five years of his life. He then started having grand mal seizures, which became worse as he got older. The seizures were being barely controlled by medication, but their side effects and the seizures themselves were slowly eating away at his life. When he could no longer use words to describe his pain and suffering, they were clearly communicated with his eyes. Paul has also suffered cruelly, but in

spite of his severe mental challenges, he was usually very happy, laughing and easily contented. Although six years older than me, he had become my younger brother and I his older protective sister. However, the suffering I witnessed in Luc was unconceivable. For this reason, before writing an exam or starting any dance competition, I would say to myself, "This one's for you, Luc". I would make sure to study and practice very hard in order to succeed because I did not want to let him down. I also felt that by working hard and succeeding, I could make my parents happy and lessen some of their loss that came from having two ill children.

Sometimes, I did not succeed as I had planned, and the shame and guilt became even more unbearable. I would promise Luc and myself that I would never fail again. I worked harder than any teenager I knew in order to be successful in everything I did. Doing so helped decrease the guilt somewhat; however, this guilt was ultimately overshadowed by his death. Although he lived ten years longer than expected, our family never spoke of his potential death; I believe this was because it was too difficult for my parents.

He died at the age of 28. I was 20. I could not, would not accept his death. I had lived his life for the past six years. He could not leave me now. I could not live without him. How could I? Everything I had done was for him. To accept his death would mean to accept my own. I repressed the funeral from my mind and refused to visit the burial site. By doing so, I could pretend he was alive and could go on living. Two years later during a course on Death and Dying, our professor stated that we could not help others with their loss if we had not been able to grieve our own. She asked us to choose a loss that we had not grieved yet and said that she would guide us through the grieving process. I decided it was time to let go of my brother and to find myself. Through this grieving process, I felt extreme anger towards my brother for leaving

me, cried endlessly at his burial site, came to accept his death, and found comfort because he was no longer suffering.

The journey to find myself and to learn to live for myself was long and difficult but also the most enriching experience of my life. I no longer live my life for him, but he will never be forgotten. In fact, my eldest son's middle name is "Luc". Although I can now talk to my parents about my experience, I continue to limit the amount of information I share with them in order to protect them. Although my parents, through their love and commitment, were instrumental in our ability to adapt, no formal support was available for my healthy brother or myself. My brother and I rarely speak about our experience, and I have often wondered why. Are we silent because we continue to live in the comfort of the silence, or are we trying to avoid the effects it may have had on us?

In planning my future, I anticipate caring for my aging parents, who have given so much of themselves to their children, and I also anticipate caring for my severely mentally challenged brother when my parents are no longer capable. Many of the decisions I have made in my life have been influenced by my experience of having chronically ill siblings. I followed through on a childhood promise and became a health care professional. I decided to become a pediatric nurse in order to help children and families (including siblings) deal with the challenges of illness. I have pursued an academic career and have taught nursing students the importance of including families in the planning of care for ill children. I have focused my research on the impact of chronic childhood illness on siblings and the importance of family-centered care. I have also chosen to share my experience of living with two chronically ill brothers in order to respect the hermeneutic philosophy that I have chosen to guide my inquiry into the experience of adolescents living with a sibling who has a chronic illness.

A Perspective from the Literature

Researchers studying sibling adjustment have often mixed both illnesses and disabilities when studying and describing sibling adjustment to chronic conditions, making it at times impossible to separate illness from disability. For example, a study by Williams et al (1997) included siblings who were living with a sibling who had cancer, cystic fibrosis, diabetes or spina bifida in their sample. Thus, the following literature reflects this mix of illness and disability, recognizing the long-term nature of the condition as its defining factor. Overall, research on sibling adjustment has concentrated specifically on the chronic nature of the ill child's condition as a stressor with subsequent effects on the siblings. The range of study results varied widely, including negative effects, positive effects, the absence of effects and a mixture of positive and negative effects.

Studies in the 1970s and early 1980s frequently reported negative effects and cited various behavioral problems and somatic complaints (Taylor, 1980; Tew & Laurence, 1973). These studies based their findings on anecdotal, projective or psychological testing data, and used inadequate controls to measure psychological adjustment in siblings, which resulted in findings of questionable validity. The following signs of poor sibling adjustment were described by nurse researchers: fatigue, weakness, poor appetite, overeating, enuresis, nightmares, irritability, impatience, restlessness, over activity, lack of initiative, social withdrawal, poor school performance, school phobia, increased sibling rivalry, self-blame, and preoccupation with thoughts of the affected child (Craft, 1979; Everson, 1977).

Later, more controlled studies, which used comparison groups and reliable and valid measures to examine sibling adjustment, generally demonstrated less dramatic rates of sibling maladjustment. Despite these methodological improvements, siblings were found to have

internalizing and externalizing behavior problems and lower social competence (Achenbach & Edelbrock, 1983; Dyson, 1989). Other negative effects on siblings found in the literature were low self-esteem (Ferrari, 1987; Hefferman & Zanelli, 1997), withdrawal or shyness (Tritt & Esses, 1988), poor peer relations and delinquency (Breslau & Prabucki, 1987), feelings of loneliness and isolation, anxiety, depression, vulnerability, anger, school problems and a decrease in school grades (Faux, 1991; Vance, Fazan, Satterwhite & Pless, 1980; Williams, Lorenzo & Borja, 1993). According to Williams et al. (1997), many of the siblings' adjustment problems resulted from them feeling physically and emotionally isolated from their parents. Furthermore, many siblings worried about the illness, the ill sibling and their parents (Chesler et al., 1991; Derouin & Jessee, 1996; Engstrom 1992; Kramer, 1984). Sharpe and Rossiter (2002) conducted a meta-analysis with 51 published studies from 1976 to 2000 studying siblings (n=2 500) of children with a chronic condition. The authors adopted William's (1997) definition of chronic illness (a medically diagnosed condition with duration of 6 months or longer showing little change or progression) yet the sample of the study included illness that have varying progression, such as cancer, cystic fibrosis and spina bifida. Sharpe and Rossiter (2002) found a statistically significant and negative overall effect size of -.20 for having a sibling with a chronic illness.

In contrast, other studies found that siblings of chronically ill children did not experience a significantly higher incidence of behavior and social competence problems than other siblings (Dyson, 1989; Gallo, Breitmayer, Knafl & Zoeller, 1992). Some researchers found positive sibling behaviors in families with a child who has a chronic condition. These behaviors have included less sibling aggression and teasing (Fanos, 1996; Faux, 1993), increased sensitivity to the needs of others, increased empathy (Gallo, Breitmayer, Knafl & Zoeller, 1991; 1992;

Hefferman & Zanelli, 1997) and increased family unity (Derouin & Jessee, 1996). In her review of the literature on the siblings of children with cancer, Walker (1990) found evidence of positive effects as "increased ability for empathy and sensitivity, enhanced personal maturation and self-concept, and increase in family cohesion, and perceived ability to cope with negative changes" (p. 358).

Other studies found no effect on siblings of children with a chronic condition. According to Gallo, Breitmayer, Knafl and Zoeller (1992) siblings of children with a variety of chronic illnesses such as diabetes, juvenile rheumatoid arthritis and asthma did not experience a significant higher incidence of behavior and social competence problems than a normative sample. Dyson (1989) also found that siblings of handicapped children displayed the same level of self-concept, behavior problems and social competence as matched siblings of non-handicapped children. Thompson, Curtner and O'Rear (1994) concluded that siblings of children with a chronic illness are not at greater risk for more psychosocial adjustment problems than other siblings.

Researchers are starting to recognize the possibility of mixed effects on siblings of children with a chronic illness. For example, according to Gallo, Breitmayer, Knafl and Zoeller (1993), five of the 11 siblings who participated in their study were considered very well-adjusted while five others were viewed as poorly adjusted. Williams et al. (1997) found that although the siblings of children with cancer, CF, diabetes and spina bifida experienced isolation and resentment, they did not experience fear. Rollins (1990) used projective drawing techniques in case studies to assess siblings and found that one sibling created an adaptive drawing while the two other participants had maladaptive drawings. As early as 1986, Kupst argued that: "while the experience of serious illness in a brother or sister may present several upsetting and

uncomfortable situations for a child, most of them appear to be able to cope with it, especially over time" (p. 84).

There are many possible explanations for the conflicting results related to sibling impact. All studies reflect the investigators' motivation, background and training. In my education, illness was viewed as a stressor requiring adaptation. This perspective has shaped my pre-understandings of what it is like for a family member who has a chronically ill sibling. Researchers who are interested in studying siblings are often clinicians wanting to improve the siblings' lives as well as clinical practice. Given their orientation and their background as well as the prevailing theoretical and methodological norms, it is not surprising that some researchers have relied on controlled studies with large samples and clearly defined and delimited predictors of outcomes in order to make recommendations based on those findings. However, the conflicting results appear to indicate that not enough is known about the situations of siblings of children with a chronic condition to guide the choice of outcome measures for large quantitative studies.

The few studies that have examined siblings' interpretations did not address the importance of respecting developmental stages (Van Riper, 2003) and siblings from a variety of age groups were included in one study. This might mean that the responses of siblings from four to 18 years would be interpreted as one. This approach does not consider the unique struggles and coping processes of each childhood developmental stage and could also explain the conflicting results found in the sibling literature.

Furthermore, research conclusions are often based on observational or self-report data provided by parents, teachers and health care professionals. Such second-hand data, although interesting, cannot accurately represent the lives of siblings. Moreover, these data probably tell

us more about the parental and professional observers than about the siblings. For example, Menke (1987) reported that parents and siblings did not agree about the nature of the worry experienced by the siblings. Other investigators found that parents of children with chronic illnesses may not accurately perceive how their other children are coping (Haverman & Eiser, 1994).

Several studies have attempted to explain the variation found in the psychosocial adjustment of siblings by examining non-disease-related factors that may interact with the demands of the chronic illness and contribute to the siblings' adjustment. Since the family provides the primary context in which children and adolescents acquire ways of coping with stress (Compas, Worsham & Ey, 1992), it is not surprising that Williams (1997) in her review of the literature found the following predictors of positive adjustment: absence of parental depression, good marital adjustment, high levels of family resources, family cohesion, low interpersonal conflict, parental responsiveness and effective parent-sibling communication about the illness. Researchers in these studies used standardized measures of both sibling behavior and family functioning, such as the Child Behavior Checklist and the Psychiatric Screening Inventory for mothers, to examine relationships between sibling adjustment and family context. While measures of family and individual functioning provide standardization, they may have limited clinical/predictive utility because the information provided is global in nature and is not necessarily related to the experience of living with the challenges of childhood chronic illness.

Families with high levels of internal and external resources may be able to cope more effectively than other families (Van Riper, 2000); however, we cannot ignore the magnitude of the challenges that a childhood chronic illness presents for the parents. For example, they undertake new and different roles, as well as changes in activities and responsibilities, due to the

ill child's treatments and hospitalizations (Coyne, 1997a; Gallo et al., 1991). Therefore, they may have less capacity for supportive, sensitive, and involved parenting with their healthy children. Siblings themselves choose not to talk to their parents about the illness because they do not want to impose their worries on their parents (Bluebond-Langner, 1996; Hefferman & Zanelli, 1997). As well, siblings' concern about their parents' welfare leads them to provide practical and emotional support to their parents (Chesler et al., 1991). Because of this role reversal, siblings might not receive the support they need.

The implicit assumption that the disease or illness is a stressor that has predetermined effects has lead many investigators to focus on children's and adolescents' adjustment. Looking at any chronic illness in this way is inappropriate and explains why we are still, in the words of Anselm Strauss (1984, p. 110), "in the realm of terra incognita" in our understanding of siblings' experience of living with their siblings' illness. We have no complete comprehensive answers to the question of how chronic illness affects siblings. I argue that the absence of satisfactory answers results from the way researchers have approached their investigations.

Other researchers have also identified the need for qualitative descriptive data to understand the siblings' interpretation and the complexity of living with a brother or a sister who has a chronic condition (Chesler et al., 1991; Damiani, 1999; Derouin & Jessee, 1996; Madan-Swain, Sexson, Brown & Ragab, 1993). After conducting an integrative review of the nursing research on the sibling experience of living in a family that includes a child with a chronic illness or disability, Van Riper (2003) concluded that "future research concerning the sibling experience of chronic illness should be guided by a holistic perspective..." (p. 297), thus recognizing and more accurately capturing the complexity of human experiences.

Key methodological reasons exist for the inconsistent findings in research with siblings. First, studies have relied on parents as secondary informants for sibling data. Second, there has been insufficient qualitative research to elucidate fully the relevant sibling factors. Third, the potential impact of developmental stages in siblings experiences has not been respected. Last, specific illness or disability characteristics or demands such as onset, course, outcome and incapacitation (Rolland, 1993) have not always been considered when studying sibling adjustment. The first step to address these methodological limitations is to conduct in-depth interpretive inquiry with the siblings themselves. The second step is recognizing the importance of specific illness-characteristics on the experience of a specific age group of siblings.

Purpose of the Study

The purpose of this study was to develop an in-depth understanding of the experience of adolescents living with a sibling who has CF. I sought to explore, from the adolescent siblings' frame of reference, what it was like growing up with a sibling who has a chronic life threatening illness: what are their feelings, concerns, struggles, joys, hopes, reward, and what they find helpful as well as unhelpful in meeting the challenges of the illness. I also sought to understand what perceived impact CF had on their family life and how family and other contacts outside the family have influenced the adolescents' interpretations.

This level of understanding is a critical prerequisite to developing nursing interventions that target the specific issues identified by siblings as opposed to those identified by secondary informants. The findings will be useful for designing and testing appropriately targeted interventions that minimize risk behaviors and encourage health enhancing behaviors (Stewart, 2000).

CHAPTER TWO

THE QUESTION

To question is to have already a sense that one does not know, and that one seeks understanding. Understanding begins, writes Gadamer (1989), "when something addresses us" (p. 266). The intent of asking a question is to "bring into the open. The openness of what is in question consists in the fact that the answer is not settled. ...The revelation of the questionability of what is questioned constitutes the sense of the question" (Gadamer, 1982, p. 326). The inconsistencies and contradictions found in the literature have brought the need to understand the experience of siblings' living with a chronically ill child into the open. Answers about the feelings, concerns, struggles, joys, hopes, rewards of siblings of children who have chronic illness and what they found helpful as well as unhelpful in meeting the challenges of the illness are not settled. Thus, I seek to understand "What is it like for adolescents to live with a sibling who has Cystic Fibrosis?"

In research informed by Gadamerian hermeneutics, researchers must demonstrate the awareness that they have chosen a research question, a situation, or phenomenon because of its perceived effect on history (Gadamer, 1989). Thus, the purpose of this chapter is to explain the importance of giving voice to siblings, adolescents in particular, to explain why I have identified family as an important influence in adolescents' lives and to explain why I have chosen Cystic Fibrosis (CF).

Giving Voice to Siblings

I chose to give voice to siblings because previous research has relied on parental or health care professionals' interpretations and has rarely given siblings the opportunity to tell their stories. I also question the accuracy of the parents' and health care professionals' interpretations

because health care professionals do not often interact with siblings and because siblings rarely speak about their feelings. Siblings are also reluctant to openly discuss their concerns about the ill child's condition with their parents because they are concerned that open communication might upset their parents, and they want to protect parents from such pain and discomfort (Chesler et al., 1991; Carpenter & Sahler, 1991; Haverman & Eiser, 1994). In Bluebond-Langner's study (1996), when a sibling is asked, "Who do you talk to about your sister's condition? He responded, M*yself. I think about it in my head. I don't talk to nobody about it"* (p. 226).

As a pediatric nurse, I have often observed health care professionals planning their care according to the needs of the ill child and of their parents while those of the siblings are forgotten. Health care professionals may assume that parents have the internal and external resources to manage the illness and care for the ill child as well as for the other children. In order to contain the intrusion of the chronic illness, parents often use strategies of normalcy and control (Faux, 1991; Bluebond-Langner, 1996) and are encouraged to do so by society and health care professionals. Thus, open communication is fraught with risk to what families see as essential for the conduct of everyday life and family relationships. Parents often think that they are protecting their children by not talking about the illness, or they may also be preoccupied by its challenges and lack time and commitment for communicating. Children and adolescents have identified their parents' reluctance or inability to talk about the illness as one of the most important stressors when dealing with the challenges of their siblings' illness (Henley & Hill, 1990; Weir, 1999). Gardner (1998) found that poor parental response to healthy children's needs and questions was a key factor that exacerbated the impact of a sibling's illness.

A lack of discussion about the ill siblings' condition can lead to misinformation and misunderstanding, as well as a sense of isolation that comes from holding inside what one fears cannot be revealed to another. *I recall thinking that nobody, not even my brother, could possibly understand what I was going through: the thoughts, the pain and the struggles.* In a retrospective study with siblings of children who had died of a chronic illness (Fanos, 1996), the clearest message from survivor siblings was that they wished they had been prepared for the possibility that their sibling might die. Furthermore, siblings believed that it would have been helpful if their parents had been able to discuss the illness with them. Although siblings have difficulty sharing their concerns with their ill brother or sister and parents, they do, on occasion, share them with others. According to Fanos (1996), siblings were aware that there were many ways for distressed parents to communicate the news inappropriately and they regretted that no professional had been available to tell them the truth and to help them process their emotional reactions.

Many scholars now agree that to learn more about children's or adolescents' experiences with illness, we need to elicit their representations. Thus, the focus is shifting from seeking information about children/adolescents to seeking information directly from them because children/adolescents are now considered the best sources of information about their lives (Bearison, 1991; Thompson & Gustafson, 1996). As an illustration of this shift, in my master's thesis (Larocque, 1995), I attempted to give voice to adolescent siblings by using an adolescent coping scale A-COPE (McCubbin & Patterson, 1981) to elicit coping behaviors that they believed to be helpful in dealing with the demands of their siblings' chronic illness. I was initially offended when many of the adolescents in my study scribbled in the margins of the instrument. Did they not know that margins on a piece of paper are meant to limit what is

desirable or possible and are to be left clean? I had chosen what I believed was a reliable instrument with clear instructions on how to complete the Likert scale. All the adolescents had to do was circle 1, 2, 3, 4 or 5. Why did they have to go beyond the limits set in the instrument?

This striking incident called for understanding (Heidegger, 1968). "Understanding begins ... when something addresses us" (Gadamer, 1989, p. 299). The comments that were added by the adolescents were reactions to the coping behaviors on the instruments or were new strategies not found on A-COPE. These included obtaining information about the illness and helping with the treatments. Their comments suggest that standardized measures, such as A-COPE which was designed to examine siblings' ability to cope with the challenges of life events, are limited in their ability to capture the coping behaviors needed by siblings to deal with such a complex situation.

But, more importantly, what I believe the adolescents were trying to tell me was that the questionnaire was too limiting to capture their reality. I also believed that once again, adolescents were being asked to be quiet. I understood the scribbling as an opportunity to ask the siblings if they wanted to add anything else, which thus allowed them to break free from the silence. The majority of the siblings spoke for over an hour about their feelings, concerns and struggles. I was excited about the richness of their stories but did not include them in my research findings because they were not part of my research proposal. I knew then that quantitative approaches were not appropriate for studying the experience of siblings because "we must remain strictly within the parameters of the methods of severance we have enacted, for any other interconnections would despoil or defile the instance we have so carefully and methodically isolated and purified" (Jardine, 1998, p. 36). The interest of such a quantification of significance is not to understand better this instance and its meaning as a feature of human

life, but to be better able to control, predict, and manipulate its future reoccurrences (Habermas, 1972). Only if we attend to the actual experiences of adolescent siblings of children with a chronic illness can we understand how to serve these siblings better and how to help them cope.

Studying Adolescent Siblings

Of the possible age groups, I chose to study adolescents. Adolescents experience profound developmental changes (Patterson & McCubbin, 1987) which make them especially vulnerable to stress in the family environment. In addition to managing the challenges of their sibling's illness, adolescents are expected to: 1) accept their changing body size, shape, and function; 2) learn to maintain good health; 3) achieve a satisfying and socially accepted feminine or masculine role; 4) establish themselves as a member of one or more peer groups and develop skills in relating to a variety of people; 5) achieve independence from parents; 6) select an occupation and prepare for economic independence; 7) prepare to settle down; 8) develop intellectual and work skills and the social sensitivities of a competent citizen; 9) desire and achieve socially responsible behavior in the cultural setting; 10) develop a workable philosophy, a mature set of values and worthy ideals, and assume standards of morality (Bee, 1998; Duvall & Miller, 1986). According to Fanos (1996), siblings who were adolescents when their brother or sister died of a chronic illness were more anxious and depressed, and experienced more survival guilt than those who were either preadolescent or adult when their sibling died. Nursing researchers have not focused specifically on adolescent siblings (Van Riper; 2003), and since adolescence is an important time for developmental change, studies should focus more on this age group.

Although adolescents may be more vulnerable than other age groups to stressful life events such as the death of a sibling (Fanos, 1996; Patterson & McCubbin, 1987), I believe that

adolescents are also able to use strategies or behaviors to cope with individual family life events, such as a sibling's chronic illness. According to Gardner (1998), when siblings see themselves as able to cope effectively and as having some control over the illness-related changes in their lives, the impact of these changes decreases. Wright, Watson and Bell (1996) argue that what one believes about illness contributes dramatically to how one experiences and manages an illness. Thus, it is important to understand what adolescents find helpful and unhelpful in managing the challenges of their siblings' illness.

Families' and Parents' Contribution to Adolescent Coping

I concur with Compas, Worsham and Ey (1992) that the family provides the primary context in which children and adolescents acquire ways of coping with stress even though adolescents acquire coping behaviors and styles from a variety of sources which include: 1) internal resources such as personality; 2) previous personal experience in handling similar situations; 3) vicarious experience associated with observing the success or failure of others, especially family members; 4) perceptions of their own physiology and inferences they make about their vulnerability; and 5) social persuasion, particularly by parents, peers, and significant others.

Contrary to expectations, parents' involvement in the lives of their adolescents does not decrease as they grow older (Peterson & Leigh, 1990). Rather, relational patterns change and become more egalitarian. Parental acceptance, empathy, and support remain an essential foundation for developing social competence during adolescence. Families contribute to adolescent coping with life experiences in many ways including: parental coaching and modeling of coping behaviors, parental-child attachment, parental support, family climate, and family communication patterns.

Parental Coaching

When using a coaching perspective, parents give their children direct instruction on how they might think about (appraise) stressful events or what strategies they might use to deal with stressful events (Kliewer & Lewis, 1995). Coaching can involve both positive messages that enhance self-efficacy and active attempts to deal with a problem, as well as negative messages that could encourage blaming or avoiding dealing with a problem. Work in developmental psychology literature supports parental coaching as a means to influence coping processes. For example, in a study with 39 children ranging from seven to 16 years of age and diagnosed with Sickle Cell Disease, Kliewer and Lewis (1995) found that parents' active coping suggestions were positively associated with children's levels of hopefulness.

Parental Modeling

A second way in which parents may influence their children's/adolescents' coping processes is through modeling; that is, children learn to interpret, appraise, and respond to stressful situations by watching and imitating their parents. Social learning theory suggests that the more overt the coping behavior, the more likely it is to be imitated by children/adolescents. Gil, Williams, Thompson and Kinney (1991) found a significant positive association between parental passive adherence coping (following the doctor's instructions) and negative thinking (focusing on fear and anger) in the children's and adolescents' attempts to manage chronic pain. According to Shulman (1993), when parents are willing to accept help from others and show the ability to evaluate events encountered by the family, their adolescent children demonstrate a higher level of internal and active coping. Thus, parental behaviors may serve as models for adaptive or maladaptive coping and directly encourage certain modes of coping.

Parental-Child Attachment

Ainsworth (1989) suggested that attachment or bonding with parents provides the child with a secure base from which to explore the world and to develop an individual identity. Although the typical adolescent is busy establishing autonomy from his or her parents, findings (Ryan & Lynch, 1989; Smith & Smith, 1976) support Ainsworth's contention that strong parental bonding actually facilitates adolescents' individuation process. Armsden and Greenberg (1987) found that parental attachment was an effective buffer against the stress associated with adolescent developmental tasks. They also found that adolescents who were securely attached to their parents demonstrated fewer negative effects from life stress than adolescents with weaker attachments to their parents. In a study with 60 undergraduate students, Brack, Gay and Matheny (1993) expanded on the work of Armsden and Greenberg (1987) and examined the relationship between adolescent coping resources and attachment to parents and peers. As anticipated, the researchers found that in late adolescence, relationships with family were significantly correlated with perceived coping resources. Attachment to the mother was significantly correlated with eight of the twelve subscales of the Coping Resources Inventory for Stress, whereas attachment to the father was correlated with five of the subscales and attachment to peers to four of the subscales. These findings suggest that a secure parental bonding, especially with the mother, facilitates the development of important adaptation skills and resources.

Parental Support

Parental support consists of gestures or behaviors such as general support, physical affection, acceptance, or companionship that communicate warmth, affection, and rapport (Barber & Thomas, 1986). In a study to test an integrative predictive model to examine

interrelationships among parental support, adaptive coping strategies, and psychological adjustment among late adolescents, Holahan, Valentiner, and Moos (1995) found that parental support was related to psychological adjustment both directly and indirectly through adaptive coping responses. According to Compas (1987), parental support in the form of giving information and advice can encourage more constructive and less avoidant styles of problem-solving. Parental support may also foster adaptive coping by enhancing adolescents' perceived self-efficacy and sense of mastery (Bandura, 1982). Frey and Rothlesberger (1996) examined social support in a representative sample of 141 healthy adolescents. Parental support rather than peer support was considered essential for both day-to-day matters as well as for emergency situations.

Family Climate

The notion of family climate was introduced by Moos (1974) to assess the individual's perceptions of the family milieu. Moos subsequently developed the Family Environment Scale (FES) to measure family climate. In a study of 187 Israeli adolescents aged 15 to 17, Shulman, Seiffge-Krenke, and Samet (1987) found that when family climate was perceived to be cohesive, organized, and respectful of individual development, adolescents demonstrated higher functional coping. Stern and Zevon (1990) found similar results in their study of the relationship between adolescent coping and perceived family climate. Furthermore, a negative perception of the family climate was associated with the use of more emotion-based coping strategies such as withdrawal, denial, and tension reduction. From their studies on adolescent coping and family climate, Seiffge-Krenke (1995) concluded that a supportive and committed family contributes to a lower level of stress, especially relationship stressors. However, to develop functional coping styles characterized by an active approach, Seiffge-Krenke argued that two additional

requirements must be met: family life must be clearly organized and structured by providing rules and procedures that may also guide adolescent coping behavior, and a family climate must encourage the adolescent's autonomous behavior and sense of responsibility. Thus, a sense of family cohesion and support in asserting individuality are the precursors of adolescent adaptive coping.

Family Communication Patterns

The specific ways that family members communicate with one another are a final factor associated with the development of adolescent coping. According to Olson (1993), "communication" is the mediating factor contributing to levels of cohesion and adaptability within families. That is, supportive communication tends to facilitate spontaneous problem-solving, genuine information giving and information seeking, empathic understanding, and equity between family members. In my previous study with adolescent siblings of children with CF, adolescents found that talking to their parents about the illness was one of the most effective coping behaviors when dealing with the demands of the illness (Larocque, 1995). Despite its purported effectiveness, the adolescents did not frequently choose to use this coping behavior.

Although studies have demonstrated the contribution of a family to adolescent coping, families of children with a chronic illness may have limited internal and external resources to contribute to adolescent sibling's coping. Most children with a chronic illness are cared for at home and this has considerable impact on the family system due to the time and energy needed to meet the multiple challenges of the illness. According to Knafl, Breitmayer, Gallo and Zoeller (1996), making sense of the illness in terms of its meaning for the family members' lives, mastering treatment regimens, adapting the family routine and budget to the demands of the illness, creating a normal life for the child in spite of the illness, and negotiating with health care

and school professionals are the most common challenges cited in the literature. Ray (1997) defined special needs parenting as the work required to raise a child with a chronic illness or disability that is above and beyond that of raising a typical child. This work included additional care that the child needs such as medical care, parenting plus, and working the system as well as struggling to balance the rest of family life. Olson (1993) noted that family systems often change in response to the challenges of a child's chronic illness (i.e., from connected to enmeshed). Perhaps due to these changes, adolescents have used other coping strategies such as investing in close friends, developing self-reliance, developing social support, engaging in demanding activities and humour and relaxation to deal with the challenges of their sibling's illness (Larocque, 1993). However, in Larocque's (1993) study, the adolescents did not always perceive these coping behaviors to be effective. As a result, these adolescents continued to experience distress.

Adolescents confronted with life stressors and challenges are often facing these challenges for the first time. Consequently, they may not necessarily have developed a full repertoire of effective coping responses (Patterson & McCubbin, 1987). According to Konopka (1980) adolescents are often at high risk because their minimal experience with new or multiple challenges may result in extreme reactions leading to potentially serious consequences such as behavioral problems (Konopka, 1980).

When parents are caring for a child who has a chronic illness, they may not be able to provide the best context for adolescents to acquire ways of coping with the challenges of their siblings' illness. That is, in part, why I have become a strong advocate for family centered care, a philosophy of care that recognizes and respects the pivotal role of the family in the lives of children with health care needs (Caty, Larocque, & Koren, 2001; Bruce et al., 2002). Within this

philosophical perspective, siblings' needs are acknowledged and met. However, to meet the adolescent siblings' needs, we must understand what they perceive to be helpful and unhelpful in meeting the illness challenges as well as how family and contacts outside the family have influenced their interpretations. This understanding is important for designing appropriately targeted interventions, such as helping parents help their adolescents, because the coping style that emerges from the adolescents' efforts may have long-term consequences and may shape their coping styles as adults (Valliant, 1977).

CF Versus Another or Many Chronic Illnesses

CF is the illness of choice for my dissertation because of my nursing experience with this population. Furthermore, it has not yet been studied as often as other chronic illnesses such as cancer or disabilities. Yet, the complex nature of CF may affect the way siblings experience the illness. CF is genetically inherited with no cure (although the gene that causes CF has been identified) and has a poor prognosis. The illness symptoms may be invisible to others for many years; but as the illness progresses, it often becomes visible to others due to the increased hospitalizations as well as the constant coughing, the delayed physical maturation, the clubbing of fingers and the development of a barrel chest. These symptoms result from the exocrine glands' abnormal secretions, which affect the gastrointestinal, respiratory, hepatic and reproductive systems (Wong, 1999).

Treatment of CF is essentially palliative and based on the degree of disease involvement and disease severity. Thus, family life usually involves a constant daily round of: percussion and postural drainage to help loosen the mucus clogging the lungs, pancreatic enzymes taken with all meals to aid digestion, nutritional supplements and vitamins to promote good nutritional status, inhalation of aerosol medications to alleviate congestion and combat lung infection, and exercise.

An increasing number of children with CF are now living to adulthood as a result of early diagnosis and intensive treatment (Loutzenhiser & Clark, 1993), but the prognosis, the treatment and the work involved in caring for a child who has this illness constantly challenge the management resources of family members.

Studies with siblings of children with a chronic condition have frequently included many different illnesses and disabilities when trying to understand the responses of families and siblings. This approach is referred to as the non-categorical approach (Pless & Pinkerton, 1975; Stein & Jessop, 1989) and assumes that although the characteristics of the illness or disability create needs specific to the condition, various pediatric chronic illnesses and disability generate common issues including the long-term caregiving demands which produce strain on the family's physical, financial and emotional resources (Stein, 1989). However, after completing a review of the literature on the adjustment of siblings of children with a disability, Cuskelly (1999) recommended the use of single diagnostic group because "research which uses multidiagnostic groups and does not differentiate between diagnostic categories continues to perpetuate the assumption that all disabilities will have the same impact on families" (p. 113).

The choice between a diagnosis-based or noncategorical approach should be driven by the research question. For this study, diagnosis-based approach was selected because CF is characterized by particular features that are salient to adolescent siblings' interpretation. These features, as previously described, include: a progressive trajectory and fatal prognosis, relative invisibility of the condition that allows the child a reasonable probability of fitting in with peers, a demanding home care regimen, and intermittent and unpredictable exacerbations. Such illness features have been reported as significant in influencing sibling adjustment (Cadman, Boyle & Offord, 1988; Cohen Freidrich, Jaworski, Copeland & Pendergrass, 1995; Williams, Lorenzo &

Borja, 1993). By focusing on one diagnosis, a sibling's experience with a singular set of illness features could be examined in depth.

In seeking to understand the experience of adolescent siblings of children with CF, I do not attempt to predict a particular response to the ill child's condition or to solve the siblings' adjustment problems in the matter of the deductive approaches of the natural sciences. Instead, I take a hermeneutic approach in which I seek to understand "What is it like for adolescents to live with a sibling who has CF?" Subquestions include: "What are some of their feelings, concerns and struggles?" "What are some of their joys, hopes and rewards?" "What have they found helpful and unhelpful in dealing with the challenges of their siblings' illness?" "What perceived impact has the illness had on their family?" and "How have family and contacts outside the family influenced the adolescents' interpretations?" This present study is not meant to be a definitive work on this topic, but is intended to open a conversation, to pose meanings that are shared (Gadamer, 1989), and to evoke in the reader a new way of understanding adolescents and the lives they are living (Jardine, 1998).

CHAPTER THREE

PHILOSOPHY AND METHODS

Philosophical Hermeneutic Perspective

The philosophical perspective that informed this study is hermeneutics. Since the 1980s, interest in hermeneutics has grown steadily in North America, and now, hermeneutic philosophy is cited as an important philosophical alternative to empiricist and historicist accounts of science (Hekman, 1986). This approach has enabled nurses to explore and to understand more completely the often elusive but fundamental elements of nursing practice. Jardine (2000) creatively demonstrated the connection between the art of nursing and interpretive inquiry informed by philosophical hermeneutics: "As an expression and understanding of this practice of loving [the ill and their families], nursing has a innate affinity between its own tradition and philosophy of care which resonates strongly with the traditions and practices of interpretive inquiry..." (p. 193). According to Van der Zalm and Bergum (2000), the more that is known about human experience, the more sensitive nurses can be to the needs of patients and families and to each other.

My hermeneutic understanding is based on the philosophic hermeneutics of Hans George Gadamer (Gadamer, 1975; Hekman, 1986; Thompson, 1990), which provided the interpretive lens for this study. The work of this German philosopher has been recognized as central to the evolution of contemporary hermeneutics. I will describe the major hermeneutic philosophical tenets as well as their methodological implications for studying the experience of adolescent siblings of children who have CF.

Social and Historical Context

Within this hermeneutic tradition, a person's understanding of his or her situation stems from social and historical context. According to Gadamer (1989), we are historical beings, in that "history does not belong to us; we belong to it" (p. 276). Therefore, in order to understand a person's experience, one has to study the person in context, as it is only then that what an individual values and finds significant becomes visible (Pascoe, 1996). A study of the experience of adolescent siblings should account for the historical and social context because the context will pre-figure and define the range of the adolescents' interpretation of living with a sibling who has CF. Context for the adolescents would include family, friends, school, the medical community, culture, society and politics. From a hermeneutic perspective family is an assumed part of the context; in the family research tradition this is consistent with studying the individual within the context of the family (Hayes, 1993; Feetham, 1991). Furthermore, the cognitive development of adolescents and the prior meanings in their everyday lives provide both the conditions and the limits of their understanding (Wachterhauser, 1986). The adolescents are at a developmental stage in which they are forming early notions of how the broader culture and society affect their lives.

Understanding and Language

Adolescents' understanding will be expressed through language. According to Gadamer (Hekman, 1986), language carries everything with it:

> not only "culture" but everything (in the world and out of it) is included in the realm of "understanding" and understandability in which we move. . . . We become acquainted with the world and even ourselves through language because language is the universal

> mode of being and knowledge . . . [I]t is more correct to say that language speaks us rather than we speak it. (p. 110-111)

We grow up in a linguistic community, and in the process of learning our native language, we inherit the traditions that have shaped the linguistic meanings. For this reason, language is the reservoir of tradition and the medium in and through which we exist and perceive our world (Gadamer, 1986).

Gadamer does not see language as a tool that individuals use to convey pre-determined meanings. Rather, language precedes any reflective understanding and shapes our understanding of the subject matter; language and the understanding of expressed meanings are parts of the same process (Smith, 1993; Wachterhauser, 1986). When we invite the adolescents to tell their stories rather than interpret stories of parents or health professionals, we better understand what it is like for adolescents to live with a sibling who has a chronic illness.

According to Gadamer (1982), "language, in the process of question and answer, giving and taking, talking at cross purposes and seeing each other's point, performs that communication of meaning which, with respect to the written tradition, is the task of hermeneutics" (p. 331). When engaging in a conversation with these adolescents, we must attempt not to interrogate nor passively surrender to their stories (Smith, 1993). Rather, we must attempt to have a conversation with the adolescents, to evoke their experiences, seeking shared understanding as well as a willingness to learn. As Weber (1986) noted, "the interview has its best moments when the interviewer and the participant are both caught up in the phenomenon being discussed, when both are trying and wanting to understand"(p. 69).

Language and Children/Adolescents

Openness to meaning is essential to understanding the phenomenon being explored (Gadamer, 1989). Since interviewing is an especially important means of obtaining information from children/adolescents on a wide range of topics (Kotzer, 1990), researchers have sought ways to conduct interviews that best enable children/adolescents to convey their experiences (Baker-Ward, Gordon, Ornstein, Larus & Clubb, 1993). According to Eder and Fingerson (2002), interviewing children and adolescents allows "them to give voice to their own interpretations and thoughts rather than rely solely on our adult interpretations of their lives" (p. 181). Based on years of experience with interviewing children and adolescents, researchers have concluded that most children/adolescents clearly enjoy the attention of the interview (Ellis, 1998a; Kortesluoma, Hentinen & Nikkonen, 2003).

According to Weinsheimer (1985), "the object of the conversation is what both want to understand, and it is by reference to this object that they reach a mutual understanding. This joint object, not the partners, conducts the conversation" (p. 209). Thus, unstructured interviews which are conversational in nature, as opposed to receiving responses to questions posed from an adult's perspective, are more likely to provide an understanding of the object of inquiry (Engel, 1995); that is, what it's like for adolescents to have a sibling who is living with CF.

However, according to Docherty and Sandelowski (1999), the type of event of interest to the researcher may affect how children/adolescents are able to remember and communicate that event. For example, children/adolescents may withhold information about unpleasant experiences because they do not want to elicit a negative response from the interviewer or others who might overhear what they say. This concern is relevant for siblings of children with a chronic illness because many have an overwhelming need to protect the ill child and their parents

(Bluebond-Langner, 1996). However, based on my experience as a pediatric nurse, I have found that frequently children and adolescents are willing to discuss their concerns with an adult outside the family and often welcome the opportunity to interact with a health care professional. Eder and Fingerson (2002) also concluded that given the difficulty adolescents have in talking with the adults to whom they are closest, it is not surprising that adolescents are often eager to be listened to in a nonjudgmental and accepting manner. Thus, as researchers, we must convey a genuine interest and acceptance during the interview (Ellis, 1998a; Weber, 1986).

Pre-understandings

Gadamer's account of language also suggests that within any given historical and social context, scholars come to their work with an already established background of pre-understanding conveyed through language. Gadamer uses the term "prejudice" when referring to this background of linguistically mediated pre-understandings. It is a "forestructure" or a necessary condition of knowledge in that it determines what we may find intelligible in any given situation (Thompson, 1990). Some researchers argue that in order to gain knowledge, we must "bracket" or put aside this prejudice. Gadamer disagrees with this stance, pointing out that scientific neutrality is always problematic because it arises from a hyper-objectivity premised on the belief that scientific knowledge is free from social construction (value-free). From a Gadamerian perspective, understanding stems from social and historical roots and cannot be separated from one's interests, culture, history or ethical perspectives. As Smith (1993) noted, "it is only in the presence of our prejudices that we are open to our own experiences and allow these experiences to make a claim on us" (p. 136).

Using this interpretive approach means that as a sibling of two chronically ill brothers, a mother of two sons who have chronic illnesses, a pediatric-family nurse and educator, a

researcher, and someone with a unique set of social and historical life circumstances, I, my pre-understandings, perceptions, and prejudices, and my "horizon" are intricately a part of this work. For Gadamer (1975), a "horizon is the range of vision that includes everything that can be seen from a particular vantage point" (p. 269). Although our prejudices determine our vantage points (horizons), they do not shut us off from the horizons of others (Smith, 1993). The obligation to reflect on pre-understandings does not mean reflection occurs only once in the research process; rather, this obligation requires that pre-understandings be reviewed through continued reading, writing and interpretation to determine how they have originated and how they may develop.

Accordingly, reflection is an ongoing process in which interpreters/researchers take account of old and new pre-understandings and their influence on the research (Geanellos, 1998). Hermeneutically speaking, pre-understandings need to be seen as an initial perspective for attaining new meanings. Because we are always interpreting in light of our anticipatory pre-judgments and prejudices, which are themselves always changing in the course of our personal histories, our understanding of the meanings given to situations and events is always evolving and changing (Ellis, 1998a; Pascoe, 1996). Thus, this work will take into account the changes in my own understanding of the topic.

Hermeneutic Circle

The circularity of understanding means that we understand in terms of what we already know (Packer & Addison, 1989). According to Ellis (1998b), in the forward arc of the hermeneutic circle, "one uses [this] 'forestructure' to make some initial sense of the research text or data" (p. 26). In the backward arc of the hermeneutic circle, "we gain an increased appreciation of what the forestructure involves, and where it might best be changed (Packer & Addison, 1989). That is to say, interpretation "makes the novel [our subject of inquiry] seem

familiar by relating it to prior knowledge, [and] makes the familiar [what we have already understood of the experience of siblings to mean] seem strange by viewing it from a new perspective" (Gick & Holyoak, 1983, p. 1-2). Meaning, according to Gadamer, is achieved through a process of moving dialectically between a background of shared meaning (the whole) and a more finite focused experience within it (the part). This process is what Gadamer (1979; 1989) refers to as the hermeneutic circle.

Fusion of Horizons

Understanding, according to Gadamer (1989), "is always the fusion of horizons supposedly existing by themselves" (p. 306). A fusion of horizons occurs when there is a conscious act of fusing two or more horizons which creates historical consciousness (Turner, 2003). Thus, our fusion of horizons will allow us to broaden our own horizon through a dialogical encounter of questions and answers. During this continuous widening of our horizon about a phenomenon, our understanding of it changes. The goal of a hermeneutic conversation is to understand not better but differently: "A deep experience teaches us not to understand better what is already partially understood so much as that we were understanding wrongly" (Palmer, 1969, p. 233).

Methods

A fundamental tenet throughout Gadamer's work is that hermeneutic philosophy does not correspond directly to a particular method. For Gadamer, understanding happens when the scholar's horizons intersect or fuse with the horizon, context, or standpoint of the object of inquiry. As Smith (1991) noted, "Understanding between persons is possible only to the degree that people can initiate a conversation between themselves and bring about a 'fusion' of their different horizons into a new understanding which they then hold in common" (p. 193).

Although, according to Hekman (1986), Gadamer is not offering a methodology in his work, Gadamer's philosophical position emphasizing the fusion of horizons and dialogue as metaphors has profound implications for interpretive work. These hermeneutic tenets which incorporate the centrality of social and historical context, understanding language, pre-understandings, circularity of understanding and the fusion of horizons will be incorporated within the sections of the study's method.

Understanding Context

In order to begin to understand the medical context of families who have a child with CF, which largely involves the medical regime families take up, I spent one afternoon a week for a period of four months observing families at a CF clinic. I was also interested in seeing who accompanied the children to their CF appointments, the parental work involved as a caregiving role and the type (quantity and quality) of interaction between health care professionals and the siblings.

Understanding Adolescents' Communicative Norms

To reacquaint the communicative norms of adolescents (Eder & Fingerson, 2002), I informally interviewed two adolescents, a 14-year-old male and a 15-year-old female, prior to interviewing the participants of the study. I used an interview schedule developed by Ellis (1998c) with open-ended questions, which was intended to evoke a variety of memories, feelings and categories. This type of memory seeking interview was similar to the one I proposed for my study. The experience was positive as the adolescents proved to be good informants, and the linguistic community of adolescents was not as different as I had anticipated. I also listened to the tape recording of the practice interviews so that I could attend to aspects of my interviewing style that I wanted to modify. This experience also helped me when it came time to formulate

questions for my interview guide in that I was better able to make the questions compatible with the linguistic and cognitive stage (Kortesluoma et al., 2003) of the adolescents.

Acknowledging My Pre-Understandings

Bearing in mind Gadamer's (1979; 1989) assertion that to understand one another we must first understand ourselves, I agreed to be interviewed by a doctoral student experienced in qualitative interviews about my own experience of living with two chronically ill brothers. I transcribed my interview, entered into a dialogue with the text and reflected on my experience by journaling. The following is an excerpt from my journal:

> *After reading my own account of having two chronically ill brothers, I recognized my experience was (and is) a very difficult one. The difficulties were experienced with greater intensity during adolescence and resided in seeing my brothers and parents suffer. At times, we had little control over the situation, lack of social support (which forced my parents to institutionalize my brothers) and we lacked opportunities to convey our feelings and meanings within the family. I recognize that my experience was both negative (anger and guilt) and positive (family unity, personal and family strength). I had chosen a variety of strategies to deal with the challenges of living with chronically ill brothers such as bargaining, acceptance and keeping a positive attitude. My parents also played a major role in my ability to cope by maintaining family unity and by recognizing the unique strengths of their children and building on those strengths. My parents also attempted to "normalize" the situation by treating each child equally and by including my chronically ill brothers as much as possible in everyday life despite the many illness and institutional challenges. I only wished that we had been able to speak*

more openly about our feelings and had received professional, emotional and informational support.

I then made the following list of my pre-understandings of what it's like for adolescents to live with a child who has a chronic illness based on my personal experience of having two chronically ill brothers, my experience of having two children with asthma, my experience as pediatric-family nurse and educator, my experience as a researcher, my knowledge of the literature, and my life as someone with a unique set of social and historical life circumstances. This list of pre-understandings includes:

1) The adolescents' social and historical context will influence their interpretation of living with chronically ill sibling;
2) Adolescents may have difficulty dealing with the challenges of their sibling's illness due to their many developmental challenges;
3) Adolescents may experience a combination of negative and positive feelings about having a chronically ill sibling;
4) The illness challenges and the prognosis of CF may influence the adolescent's interpretation;
5) Every person may experience living with a chronically ill child differently; however, there can be commonalities in meanings;
6) A variety of strategies may be used by adolescents to manage the illness challenges;
7) Although the adolescent's strategies to manage the illness challenges may be influenced by internal factors (i.e. developmental stages), family as an external factor will be a major contributor;

8) Talking about the experience of having a brother/sister with a chronic illness may be difficult, but can also be very helpful;
9) Nurses should play an important role in the informational and emotional support of the adolescents.

Recruiting Adolescent Siblings

The adolescents were recruited through a CF outpatient clinic. As an outsider to the CF outpatient clinic, the time spent there observing families gave me the opportunity to also gain the trust of the CF team. As a result, the physician and the clinical nurse specialists supported this study and were eager for it to commence, because they felt more valuable information was needed to help develop programs for siblings. The clinical nurse specialist assisted in recruiting the adolescents. A list of inclusion criteria was generated and given to the clinical nurse specialist (CNS) and the criteria specified: adolescents who were between 13 and 18 years of age, who did not have CF themselves, who had diverse experiences (e.g., different timing in illness progression), who represented diverse experiential contexts, who were likely to commit time to be interviewed, who were articulate, who were likely to share their experiences, and who lived within a maximum driving distance of four hours from Edmonton. However, the clinical nurse specialist did not know every adolescent sibling well enough to determine if the adolescent would be likely to share his or her experiences. Therefore, she attempted to identify every family she believed had a well adolescent.

The CF clinic requested that a letter from the CF clinic inviting the adolescents to participate (see Appendix A) accompany the parent's information letter describing the study (see Appendix B). These letters were mailed by the CF clinic secretary to thirty-nine of the families identified by the CNS as having an adolescent. A similar letter was mailed to the other families

(approximately 180 families) who attended the CF clinic to inform them of the study (see Appendix C). Families who had adolescents but who had not been initially identified as having adolescents were invited to call the CF clinic for more information.

Since only two families from the thirty-nine families identified as having adolescents called to give the CF clinic permission to release their names and phone number to the investigator, the secretary at the CF clinic made follow-up telephone calls to confirm that the adolescents had received the information about the study, to determine whether they had any concerns or questions regarding the study and to ask if their names and phone numbers could be released to the investigator. A guide was developed to assist the secretary with the recruitment of adolescents via telephone (see Appendix D). This recruitment guide not only provided consistency, but also ensured that the families understood that agreeing to release their names to the investigator did not mean they had agreed to participate in the study. After the follow-up telephone calls were completed, the secretary gave me the names and phone numbers of nine parents who were interested in the study.

I telephoned each parent on the list to explain the study in more detail and to answer any questions. Eight parents continued to feel that their adolescent would be interested in participating in the study. One of the parents stated that she had two adolescents who may be interested in participating in the study. I asked to talk to the adolescents to explain the study in more detail, to answer any questions and to set up a date and time for the interview. Initially, nine of the adolescents to whom I spoke to on the telephone were interested in participating in the study. When one of the adolescents failed to show up for our first scheduled interview, his mother not only rescheduled the interview but also mentioned that she had another adolescent who may want to participate in the study. After spending time explaining the study to the

adolescent and answering her questions and concerns, she agreed to participate. Thus, a total of 10 adolescents from eight different families participated in the study.

Thirty-one of the 39 families (79%) did not participate in the study for various reasons: the adolescent did not meet the inclusion criteria (i.e.; too old or too young, the adolescents lacked commitment or willingness to talk, the travel distance exceeded the limit) (14), the adolescent was no longer living with the family (2), the secretary was unable to contact the family (7), the parents were not interested or were too busy (7), and one mother explained that she had not asked her adolescent because she had not yet told her about the ill sibling's condition.

The convenience sample (Coyne, 1997b; Morse, 1991) consisted of 10 adolescents between the ages of 12 and 21 years who had a sibling who has CF. The target age range had been set at between 13 and 18; however, younger and older adolescents voiced an interest in participating in the study and were invited to do so. After reading their interviews, it was evident that the stories of the younger and older siblings were developmentally similar to those between the ages of 13 and 18. For this reason, the age range was expanded to include the younger and older siblings. I continue to refer to the group of participants as "the adolescents," because early adolescence starts at 11 and late adolescence ends at approximately 20 (Hockenberry, Wilson, Winkelstein & Kline, 2003).

I anticipated, based on previous research using hermeneutics (Gallison, 1992; Monsen, 1999; Turner, 2003), that 10 informants would be adequate to obtain comprehensive descriptions. Designation of sample size in hermeneutic inquiry is a heuristic process, since each adolescent sibling of a child with CF has shared cultural meanings about that experience. I encouraged the CNS to seek for participants from diverse experiential contexts: from two parent

as well as single-parent families, older siblings as well as younger ones, males as well as females, a range of illness severity. However, the range of participants may have been limited because of her reluctance to approach complex families such as those with a dying child and a noted difficulty in accessing certain cultural/religious and linguistic groups.

Despite the influence that the nurse's pre-understandings may have had on the recruitment, sample diversity was achieved at many levels. For example, six male adolescents and four female adolescents participated in the study. Four of the adolescents were younger than their sibling who had CF and six were older. According to the adolescents, every one of their ill siblings had experienced episodes of acute sickness which required hospitalization or home intravenous treatment from which they subsequently recovered. However, the number of exacerbations varied. None of the ill siblings were experiencing exacerbations during the interview process. Only one of the adolescents came from a one-parent family. There were two adolescent brothers who came from the same family and an adolescent brother and sister who came from another family. Although these two pairs of adolescents came from the same families, their experiences were remarkably different. Indeed, when reading the adolescents' stories, it is almost impossible to determine which adolescents came from the same families. All other adolescents came from different families. The total number of children per family varied from two to five.

Conducting the Interviews

I explained to the parents and to the adolescents who agreed to participate in the study that the interviews would be conducted face-to-face at a time and a place that was best for the adolescents. Seven of the first interviews were done at the adolescents' home as per their request. One of the adolescents preferred to be interviewed at the University. Two of the first

interviews were conducted over the telephone in order to save time and travel expenses. According to Shuy (2002), the thoughtfulness of responses during telephone interviews is similar to those of face-to-face interviews. Furthermore, the same author concluded that there is no difference in completion time for both interview methods but that telephone interviews are less expensive than face-to-face interviews. Although I decided to do the first interviews by telephone, due to the interactive and visual nature of the second interviews, face-to-face method was more appropriate. Thus, the second interviews with these two adolescents were conducted face-to-face. When comparing the adolescents' telephone interviews with their face-to-face interviews, no systematic differences were noted in the way the adolescents responded to the questions. A total of three second interviews were conducted at the University, one at an agreed upon location two hours from the University and the others were conducted in the adolescents' homes.

I also specified the approximate time needed for the interview and the importance of eliminating all potential interruptions (e.g., they should tell their friends not to call and should not plan any major events for a few hours to allow enough time to have a meaningful conversation). Although one interview lasted two and a half hours, all other interviews, including the telephone interviews, were on average one and a half hours long. The adolescents respected my request to eliminate potential interruptions, thus only a few of the interviews were unexpectedly interrupted (i.e., child with CF would enter the room where the interview was being conducted).

Ethical Considerations

Ethical approval for this study was obtained from the Health Research Ethics Board: Panel B, University of Alberta (see Appendix E). Prior to commencing each interview, a written

and verbal explanation of the study was given to the participating adolescent siblings (see Appendix F) and their parents (see Appendix B). When the adolescent was less than 18 years of age, written assent from adolescents (see Appendix G) was obtained as well as written consent from parents. The adolescent's assent was the final determining factor for participating in the study. This factor was explained to the parents before seeking assent from the adolescent. When the adolescents were 18 years of age, parental consent was not required, thus written consent was obtained from adolescents only. For the two adolescents who did an initial telephone interview, the consent forms were mailed to the adolescents and their parents; they signed and returned the consent forms prior to doing the interview.

The adolescents and the parents were informed that they were not required to participate in the study. Because parents' presence during interviews may have influenced the study's integrity, parents were asked not to be present during the interview except to sign the consent. I explained to parents that the interview process was designed for adolescents and that the child's responses were needed and would be most beneficial for nurses caring for siblings of children with a chronic illness. I reassured both adolescents and the parents that their adolescents could stop the interview at any time and they could refuse to answer any questions. They were given a copy of the information sheet and the consent form, which included a statement of their rights as participants, my name and phone number as well as those of my supervisors and the recruiting hospital's Patient Concerns Office should any questions or concerns arise.

The adolescents and their families were assured of anonymity, and although some of the information they provided would be published, their names would not be included in the publication. Morse (1998) recommended that to reduce the risk of identification, participants' identifiers should be grouped together, and participants should be described using aggregate

characteristic. Instead of replacing their names by a number or a letter, I asked the adolescents if they would like to choose a pseudonym that would appear in publications. The adolescents enjoyed choosing a pseudonym for themselves. I made up a pseudonym for the two adolescents who could not think of one. The pseudonyms were: Romeo, Michelle, Ayla, Dave, Arliss, Gabrielle, Robbie, Krys, Serge and Pamela.

Because many well siblings have an overwhelming need to protect the ill child and their parents, researchers have an ethical responsibility to consider the consequences of the information regarding family members that will be published (Kvale, 1996). I have recently begun writing about my own experience as a sibling of two chronically ill brothers and often found myself hesitating because although I want my story to be a "true" reflection of my experience, I simultaneously carefully craft my sentences so that reading my story could not harm my parents. In reporting the findings of this study, I attempted to create a true-to-life and meaningful portrait of adolescents' experience (Sandelowski, 1993) by integrating their quotes in my interpretation while considering the potential harmful consequences to family members from how the stories are told. I believe that my preunderstanding of the issue of protection provides both the conditions and the limits of my understanding and reporting of the siblings' experiences (Wachterhauser, 1986). Therefore, I reflected on how these pre-understandings influenced my interpretation and writing of the siblings' experiences.

Confidentiality of the information shared during interviews with adolescents was maintained. I explained to the parents, prior to consent, that although permission from them was necessary for the study to proceed, a researcher's role is not one of informant unless required by law (e.g., in cases of child abuse) or for the protection of health and safety of others (Report of the Tri-Council Working Group, 1997, Section I, p. 12). One parent needed to be reminded of

the importance of confidentiality when she called for information about her adolescent. All other parents respected the confidentiality of the interview process.

The audiotapes of the interviews were kept in a locked cabinet to which only I had access. All identifying information was removed from the tapes during the transcription process. All transcripts were given pseudonyms, and informed consent forms were stored separately from the data. Transcripts and consent forms will be stored for seven years after completion of the study.

I explained to both adolescents and parents that there was no apparent risk by participating in this study. However, the experience of living with a sibling's chronic illness for some adolescents may bring strong emotions to the surface. For this reason, mechanisms were in place to deal with potential distress through referral to a professional counselor. Furthermore, the adolescents and the parents were notified that the study was not intended to benefit the adolescents participating in the study, but rather to help health professionals caring for families living with a childhood chronic illness learn more about the siblings' experiences. The adolescents in this study claimed that talking about what it is like to live with a sibling who has a chronic illness was a very positive and rewarding experience. They also welcomed the opportunity to tell their stories and to be listened to seriously. With parents' permission and preference, a gift certificate to a popular music store or the equivalent in cash ($25.00) was given to each adolescent in appreciation of his or her participation, regardless of how many interviews they participated in. A summary of the findings was also provided to participants who wished to have one, as well as to the CF Clinic.

Interviewing the Adolescents

After reviewing the information sheet with the parents and the adolescents, and obtaining informed consent from the parents and written assent or consent from the adolescents, an internal and external structural assessment of the family was completed for each adolescent with the help of a genogram and an ecomap. The genogram is a diagram of the family constellation, and the ecomap is a diagram of the adolescent's (and the family's) contact with others outside the family (Wright & Leahey, 1994). The diagrams were helpful when seeking information on which family members and other contacts outside the family have influenced the adolescent's interpretations.

First Interviews

In-depth interviews/conversations were conducted with 10 adolescents. I attempted neither to interrogate nor to surrender passively to their stories (Smith, 1993). Furthermore, I conveyed a genuine interest and acceptance during the interview so that siblings perceived that I was genuinely present, committed, and open to their stories (Ellis, 1998a; Weber, 1986). For example, in order to engage in a conversation with the adolescent siblings, I invited them to respond to the following question: "As you know, I am here to find out what it's like to grow up with a brother or sister who has cystic fibrosis. So, tell me what it's like to live in your family." Such a question invites an in-depth description of the experience while attempting to negate any expected negative (or positive) outcomes identified in the literature.

Other questions were formulated in order to elicit some of the feelings, concerns, struggles, joys, hopes and rewards and what they have found helpful as well as unhelpful in meeting the challenges of the illness (see Appendix H). Although questions were formulated, the interview approach was intended to be conversational in nature.

Gadamer (1989) maintains that dialogue and genuine questions contain an element of negativity. This creative negativity of true questioning, which is essentially the negativity in experience that teaches and transforms, is at the heart of the hermeneutical experience. For Gadamer (1989), negativity "is not simply that we see through a deception and hence make a correction, but we acquire a comprehensive knowledge" (p. 353). The following excerpt from one of the adolescent's interview provides an example of this hermeneutic dialogue process. After asking the adolescent to tell me what it's like to live in her family, he responded, *Pretty good I'd say. It's not that different from any other family.* Arliss

According to Gadamer (1975), in a true conversation, each person "opens himself to the other person, truly accepts his point of view as worthy of consideration and gets inside the other to such an extent that he understands not a particular individual, but what he says" (p. 347). At first glance (and influenced by my pre-understandings), I could not understand why the adolescent was not viewing his family as different. Had my knowledge of what it's like to live with chronically ill siblings deceived me? According to Smith (1991), in order to be transformed in the face of the adolescent's lived reality, I must engage in "what meets me as new" (p. 193) and engage in it creatively in an effort to create a new and shared reality. As a result, the interview is shaped by both people, "becoming, for the moment, their shared abode" (Weber, 1986). Thus, not understanding the adolescent's interpretation of "not different," I asked him to explain what he meant.

Researcher: Can you tell what you mean by "not different from any other family"?

Adolescent: *Ah, well hearing him cough a lot. Wondering what it is that's making him cough so much. Watching him take all of his medicine. I guess that would be different from any other families. They wouldn't have to deal with that...but besides that it's the same.* Arliss

The insistence on lack of differentiation from other families described by the adolescent was not expected. According to Ellis (1998b), "in hermeneutic terms, these unexpected dimensions are called *uncoverings*" (p. 22) and should be used for reframing questions in the next interview.

An initial schema of uncoverings emerged from the first interviews which invited new questioning. However, when I re-read the transcribed interviews, although informative, they were not as swift flowing and lacked depth. I recalled leaving the first interviews feeling extremely exhausted and unsatisfied, and later realizing that I was constantly attempting to prompt more story telling from the adolescents and found myself talking more than I should have in an attempt to increase the flow and depth of the conversation. Other interviewers have found that the standard unstructured qualitative interview is not easily met when interviewing children (Irwin & Johnson, 2005). I needed to modify my interviewing style to invite a more in-depth description of the adolescents' experience. I also needed to clarify, verify and expand on the initial uncoverings. Thus, I invited the adolescents to choose their own projective props (e.g., family pictures, scrap books, music and poems) to elicit their "...beliefs, attitudes, and [shared] meanings" (Prosser & Schwartz, 1998, p. 124) about the experience of living with a sibling who has a chronic illness. According to Prosser and Schwartz (1998), prop elicitation takes many differing forms and can be used during interviews with individuals, with groups, with children, and those who respond more easily to visual and other senses, than to verbal prompts. Researchers have found external cues such as props effective in eliciting children's and adolescents' memories during interviews (Davies, 1991; Price & Goodman, 1990).

Second Interviews

Eight adolescents agreed to participate in the second interview. Two adolescent siblings refused to be interviewed a second time. One adolescent stated that he felt that he had shared

everything that he wanted to share, and the second adolescent had initially agreed but declined when I attempted to set up a second interview, stating she could not fit it into her schedule. These two adolescents were siblings from the same family, thus the refusal of one may have influenced the decision of the other. Eight of the ten adolescents (Romeo, Michelle, Ayla, Dave, Arliss, Gabrielle, Robbie and Serge) participated in the second interviews. The age of these eight adolescents ranged from 12 to 21. Three interactive activities were created in order to encourage a more in-depth description of the adolescents' experiences of having a sibling who has CF. A photographic activity, a think cloud activity, as well as a card sort activity were all part of the second interview.

Photographic activity. A pilot exercise of the photographic activity was done with two male adolescents, 12 and 15 years of age, prior to conducting the activity with the participants of this study in order to evaluate the process (see Appendix I, # 1). Before meeting with the two adolescents, I asked them to choose pictures from photo albums that would illustrate what it is like to live in their family. I completed the activity with the adolescents and asked them to evaluate it. Both adolescents stated that they enjoyed talking about their chosen pictures because it was a good way to "connect with your memories" $_{\text{Pilot 2}}$ and because "you can show what you mean" $_{\text{Pilot 1}}$. They did not recommend any changes to the activity. As a result of the adolescents' positive evaluation, no changes were made to the photographic activity.

Every adolescent in the study who chose to participate in the second interview voiced an interest in using pictures to illustrate what it's like to live with a sibling who has CF. Four adolescents were given a disposable camera and created their own pictures. Three other adolescents decided to choose pictures from photo albums. One adolescent did not have access to pictures and was living outside the home due to schooling, thus he decided that he could not

participate in this particular activity. Questions were formulated in order to encourage adolescents to talk about their pictures (see Appendix J). For example, adolescents were asked to describe the picture and to tell me what they hoped the picture would show me about their family. Although questions were formulated, they were rarely referred to because as soon as I entered their homes or designated interview location, the adolescents had their pictures in hand and were excited to share the stories behind them.

Many researchers have used children's photography as an effective research method (Dell Clark, 1999; Orellana, 1999; Rich & Chalfen, 1999). According to Collier (1967) and Turner (2003), photographs have the capacity to create passionate and lively discussion. Collier claims that a photographer enters into a period of excitement, in which there is an anticipation of feedback, as well as the excitement of seeing the images that were taken and sharing them with others. I certainly found this to be true; the adolescents' experiences of living in families who have a chronically ill child came alive as they explained why they had taken or had chosen to show me a particular picture. Thus, this activity helped them express with more depth their interpretation of their lived experience.

A few of the adolescents who took pictures were reluctant to participate in the activity if I would have kept a copy of the pictures because their ill siblings had forbidden them to do so and had stated they would limit the type of pictures they would allow their well sibling to take ensuring that no evidence of CF was visible in the photographs. Therefore, I decided not to keep any copies of the pictures because I was interested in the stories behind the pictures. That is, I was utilizing the pictures as props to elicit conversation. Once I told the adolescents that I would not be keeping a copy of their pictures, they were relieved and stated that it would allow them to take any type of picture. I did keep notes on what the pictures were and what meaning the

adolescents gave them (see Appendix J). As soon as the interviews were transcribed, I noted what picture (i.e. picture 1) the adolescent was referring to in the text. Thus, when I was reading the story about a particular picture, I could return to my table for a description of that picture. Because the adolescents' pictures were very powerful visual representations of what it is like for them to live in their family, I decided to use a few pictures of my own family and extended family, similar in structure and context to those chosen by the adolescents, in my interpretative account to illustrate the type of photos that were shared by the adolescents. Written permission was obtained from every member of my family whose pictures were utilized (see Appendix K).

Think cloud activity. Based on the adolescents' stories during the first interviews and inspired by the Shifting Perspective Model (Paterson, 2001), I created a cartoon "think cloud" to have adolescents talk about things they can't stop thinking about in order to determine if one of these preoccupations was their sibling's illness (see Appendix L). According to the Shifting Perspective Model, the illness-in-the-foreground perspective is characterized by focusing on the illness, which thus represents being pre-occupied by the illness. In the illness-in-the-background perspective, the self becomes the source of identity. According to Paterson (2001), people living with a chronic illness will often shift back and forth between the two different perspectives. When I first interviewed the adolescents, their siblings' illness seemed to be in the background of their thoughts. That is, the adolescents did not seem to have their siblings' illness on their minds; it did not seem to be important or a big deal. Thus, this second activity was created in order to elicit conversation with the adolescents and to test this particular uncovering.

The adolescents were given instructions about the activity (see Appendix M). For example, the adolescents were asked to note the things they couldn't stop thinking about (preoccupations) on individual "post-it" notes. They were asked to place the things they think

about the most in the front of the think cloud or in the "foreground" and those they think the least about in the back of the think cloud or "background" (see Appendix L). They were then asked to explain each preoccupation and why they had placed it in the front of the think cloud (foreground) or in the back of the think cloud (background). I made a list of foreground and background preoccupations for every adolescent to facilitate future comparison.

A pilot exercise of the "think cloud" activity was done prior to introducing it to the participants of this study with the two same adolescents who participated in the pilot exercise for the photographic activity. I completed the activity with the adolescents and asked them to evaluate it (see Appendix I, #2). Both adolescents stated that they enjoyed the activity and had no difficulty understanding it. One of the adolescents appeared a little frustrated during the exercise because he wanted to place the "post-it" notes on top of each other because he felt that they were all things that were equally preoccupying him. Once I told him to feel free to do so, he had no problem completing the activity. Although no changes were made based on the two adolescents' comments, two series of questions (questions 5 and 6 on Appendix M) were added to the original four in order to probe the adolescents on choosing or not choosing to place their siblings' illness as one of the things that preoccupied them.

Card sort activity. A third activity, a card sort exercise, was also developed for the second interview. Card sort is a data collection technique that enables researchers to gain information about the conceptual dimensions participants use to interpret their social experience (Nastasi & Berg, 1999; Spradley, 1979). Because it is a concrete task, card sorts are also appropriate for use with children and adolescents (Roos, 1998). Statements were extracted from the first interviews and transcribed on individual cards. These statements were ones that I did not expect and/or were often expressed by the adolescents. The purpose of this exercise was to

encourage a more in-depth dialogue about these different uncoverings. The adolescents were asked to determine for each statement if they felt that the statement was "always like me," "sometimes like me," or "never like me" by placing the statements on the different piles identified by separate cartoon characters (see Appendix N). Instructions were given to the adolescents to help them complete the activity (see Appendix O).

Originally, fifteen statements were extracted from the first interviews. A pilot exercise was done prior to conducting the activity with the participants of the present study. The two adolescents who piloted the previous exercises were asked to evaluate the structure and clarity of the sentences (see Appendix J, # 3). As the adolescents were commenting on the clarity of the statements, I wrote comments directly on the cards. Changes were made to the statements which seemed to pose a problem for the adolescents. For example, the statement "Our family is normal" was changed to "My family is normal." Another statement clarification was performed after one adolescent read, "I feel that people should care more about how I'm feeling" and wanted to know what people I was referring to. Thus, the statement was changed to "I think that health care professionals should care more about how I'm feeling." Another reading of the transcribed interviews was done after the pilot exercise, and two more uncoverings were made and turned into statements. The following seventeen statements were used in the card sort activity with the participants: 1) My family is normal; 2) My sister/brother is a normal kid; 3) My relationship with my sister/brother hasn't changed because she's/he's got CF; 4) My parents treat my sister/brother differently because she's/he's got CF; 5) I do extra stuff to help out; 6) I worry about my sister/brother; 7) I worry about my parents; 8) I try to make sense of the things that happen because of my sister's/brother's illness; 9) I want to hear how other people with CF are doing; 10) I try not to think about my sister's/brother's illness; 11) I don't think my

sister's/brother's illness is that big of a thing; 12) I wish I could be more involved in my sister's/brother's care; 13) I feel that I should be getting more attention then I'm getting right now; 14) I don't talk to my parents about the illness or my feelings; 15) I think health care professionals should care more about how I'm feeling; 16) I wish I had more information about my sister's/brother's illness; and, 17) I feel that people don't understand what it's like to have CF.

I laminated the three cartoon characters "always like me," "sometimes like me," and "never like me" on 4- by 8-inch cards to facilitate the manipulation of the cards. The statements were written on individual cards using a 28 Font for easy reading. Prompts were also developed to encourage the adolescents to talk more in depth about each one of the statements and to explain why they chose to place a particular statement in the "always like me" or "sometimes like me" pile. Examples of prompts for the "My family is normal" statement included the following:

1) Why have you chosen this sentence as being part of what it's been like for you/or what it's sometimes like for you? 2) What does a normal family look like?...act like?...do? 3) What makes your family "normal"? 4) How do you think others perceive your family? 5) Let's say someone comes up to you and says, "I don't think your family is normal," what would you say to this person to convince them that you were? 6) Why is it important for you to be part of a normal family? As Weber (1986) stated, "Through me, the ideas of participants [were] exchanged, challenged, tested" (p. 69). I then recorded the choices for each statement.

The three pilot exercises were done during the same visit to ensure that the three exercises would be manageable during a second interview. The three pilot exercises took one hour to complete, thus I concluded that it would be feasible for the participants to complete.

Indeed, the second interviews were, with the exception of one, no longer than 1½-hours. The adolescents enjoyed the interaction involved in the activities and spoke with ease and depth about their experience of living with a sibling who has CF.

Interpretation

To prepare the first interviews for interpretation, they were turned into text through transcription. After the interviews/conversations were transcribed, I reviewed every transcription while listening to the taped conversation. I then entered into a dialogue with the text and became a mediator between it and all it implies. In other words, I sought to understand the content of the text rather than the adolescents' meanings.

Hermeneutic interpretation entails a systematic analysis of the whole text, a systematic analysis of parts of the text, and a comparison of the two interpretations for conflicts and for understanding the whole in relation to the parts and vice versa (Allen, 1995). Thus, I read through the first interviews several times, writing recursive thoughts that were being expressed, as well as singular or unique ideas that I did not expect (uncoverings). NVivo™ software was used for data management.

A list of thoughts and uncoverings was created for each adolescent. I then conceptually partitioned the thoughts and uncoverings from the first 10 interviews and used the list to facilitate interpretation. Once all the interviews were interpreted, a "profile set's coding" was created using N-Vivo to determine which thoughts were being mentioned more frequently by the adolescents. For example, "increased responsibilities" was mentioned often by the adolescents, thus the statement "I do extra stuff to help out" was included in the card sort exercise.

Although I attempted to put my prejudices aside, I recognized that the major conceptual partitions not only reflected the questions I had asked the adolescents during the first interview

but were strongly influenced by my prejudices that living with a chronically ill sibling is difficult, thus one needs to deal with challenges. I decided to re-read the interviews and to ask myself the following questions, "What is the adolescent experiencing? How is the experience described? Why is it described in this way?" and wrote in my journal a summary for each adolescent. In the backward arc of the hermeneutic circle of interpretation, I attempted to see what was previously invisible. This reexamination of the data is a search for new themes, new issues, and new questions. Interpretation involves "making the object and all its possibilities fluid" (Gadamer, 1989, p. 367).

I looked for commonalities in meanings and situations. For example, using the previous excerpts, I attempted, when reviewing the transcribed interviews, to discern if the dichotomy between viewing one's family as similar to other families, yet also different due to illness challenges was a shared meaning between the adolescents. I also kept a journal which acted as a reservoir for my reactions to different aspects of the conversations with the adolescents and the context, for how my pre-understandings were being transformed by each adolescent's story, and as a medium for articulating questions about these aspects. These questionings as well as the interpreted commonalities in meanings were helpful in creating the three different activities which were used during the second interviews.

Once the second interviews were transcribed and reviewed, I read them several times to identify recurring thoughts as well as uncoverings. I then conceptually partitioned the thoughts and uncoverings from the second interviews only and used the list to interpret the second interviews as well as the first interviews. This second interpretation of the first interviews allowed me to view the familiar with new lenses. It also gave me the opportunity to compare first interviews with second interviews, as well as whole cases with other whole cases.

I then considered the horizons of meaning in the adolescents' text, in the literature and in my own preunderstandings thereby seeking to offer the reader a new perspective of what it is like for adolescents to live with a sibling who has CF. In the interpretive dialogue between the text and interpreter there is fusion of the horizon of the text with that of the interpreter (Hekman, 1986; Smith, 1993). According to Ellis (1998b), "the task at the end is to articulate the most coherent and comprehensive account of what one can learn from the sum of the inquiries" (p. 26). My interpretive account centers on four significant meanings: 1) We are normal; 2) Acknowledging the condition; 3) Not always on my mind, and 4) Wanting to know more. The adolescents' interpretation of having a sibling living with CF did not seem to be influenced by their age, if they were older or younger than their ill sibling, their gender or socioeconomic status, thus no differences have been attributed to these factors.

Self-Evaluation of the Interpretive Account

All that an interpreter brings to the text, including pre-understandings, influences the interpreter's horizon. As a result, pre-understandings influence the fusion of horizons between the text and the interpreter. Thus, different interpreters will produce different interpretations of a text. There is no single correct interpretation possible since "perception is interpretation and each person perceives from a different vantage point and history" (Ellis, 1998c, p. 8). A "good" interpretation "then is not definitive and final, but is one that keeps open the possibility and the responsibility of returning, for the very next instance might demand of us that we understand anew" (Jardine, 1998, p. 43).

I entered the hermeneutic circle with humility, a willingness to learn and a caring concern about the adolescents' experiences. This type of "inquisitiveness [that] includes a kind of caring concern that accommodates a perspective...which might otherwise be impossible to achieve"

(Ellis, 1998b, p. 29). According to Packer and Addison (1989), circularity of understanding is essential, and the real test of an interpretation is whether the concern that motivated the inquiry has been advanced.

Ellis' (1998b) questions were considered when judging whether the concern motivating the inquiry has been uncovered by the interpretive account: "1) Is it plausible, convincing? 2) Does it fit with other material we know? 3) Does it have the power to change practice? 4) Has the researcher's understanding been transformed? 5) Has a solution been uncovered? 6) Have new possibilities been opened up for the researcher, research participants, and the structure of the context?" (pp. 30-31). Throughout my interpretive account, I have attempted to convince the reader with the use of direct quotations from the text; I have supported the interpretation within our known body of literature; I indicated how my understandings have been transformed and will offer new horizons to inform theory and research, practice as well as education.

Thus, self-evaluation of the interpretive account was accomplished by examining its relationship to external evidence (Packer & Addison, 1989) and by using the text and pre-understandings to attain new meaning. My journal was instrumental in monitoring the fusion of horizons, or how my horizon and interpretation had been fused. In the journal, I documented personal reactions, noticing how my own horizon was changing or transforming in the way interpretations were made, and documenting differences in the way I analyzed events compared to the meaning those events had in their natural context (Thompson, 1990). According to Smith (1991), "any study carried on in the name of hermeneutics should provide a report of the researcher's own transformations undergone in the process of the inquiry" (p. 199).

During self-evaluation, I also attempted to understand the adolescents' recursive thoughts as well as the uncoverings following my interpretation of the first interviews, with the help of the

think cloud and card sort activities conducted with the adolescents during the second interviews. I also sought a shared horizon of meaning (consensus) between me and my dissertation supervisor (Packer & Addison, 1989) for a subset of the data in order to guard against the ascription of meanings not actually supported by the text. Thus, my supervisor who is experienced in hermeneutic interpretation was involved in the analysis of the initial interviews until I was perceived to be respecting this mode of interpretation. The assumption is that the interpretations offered by my thesis supervisor are based on shared professional cultural meanings and are therefore recognizable by other readers who share a similar culture.

Limitations

According to Wachterhauser (1986), prejudice when defined as prior socialization and history provides both the conditions and the limits of understanding. Thus, my individual, social, and historical life circumstances as well as my pre-understandings, perceptions, and prejudices of the topic limit my understanding of the adolescents' experience of living with a sibling who has CF. For example, my experience of having two chronically ill brothers may make me more sensitive to some and less sensitive to other aspects of the adolescents' experiences. This inquiry is also limited by my ability to interpret the experience of living with a sibling who has CF from the conversations I have had and from the chosen sources that I have used.

Although my inclusion criteria were originally generated to obtain a purposeful sample, the actual recruiting method was one of convenience. Families who had a healthy adolescent were identified for the study in an attempt to protect families who were experiencing a family crisis such as the death of the child with CF or family conflicts. The recruitment clinician's desire to screen and protect families, which resulted in the use of a convenience sample as opposed to a purposeful sample, may have influenced the diversity of the sample by limiting the interpretation

to a specific group of adolescents. The study was not able to capture the real-time experiences of siblings when the family was facing illness exacerbations or the potential death of the child with CF. Siblings' interpretations during those events may have been different from those during the relatively stable circumstances in this study.

Limiting the recruitment of adolescents to one CF clinic may have influenced the adolescents' experience to that environmental context, thus reflecting the philosophy and approach of a unique CF program.

CHAPTER FOUR

WE ARE NORMAL

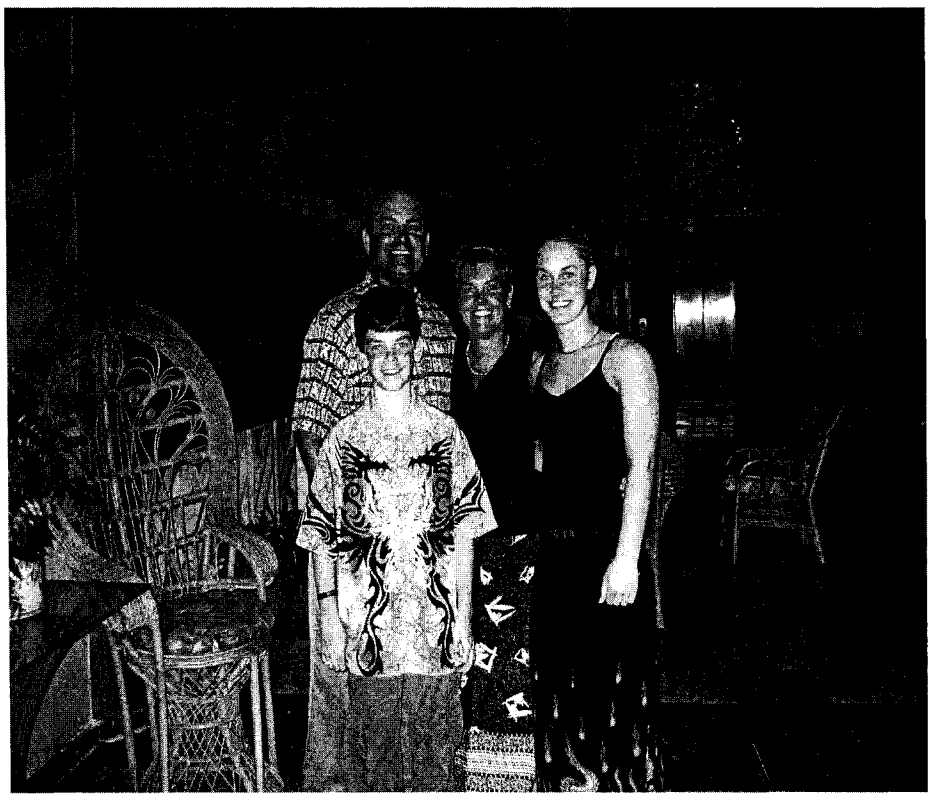
Different lenses may be worn in one's interpretation of the experience of living with a family member who has a chronic illness. The adolescents in this study had adopted a normalcy lens and thus told normalcy stories when describing their families, their siblings, and their sibling relationships. When adopting a normalcy lens, attention is paid to those aspects of family life that remain the same despite illness (Robinson, 1993). The following sections first illustrate how the adolescents described their families, their siblings, and their sibling relationships as normal despite the presence of their sibling's chronic illness. Secondly, the adolescents' interpretations of the factors that have enabled them to define their family as normal are presented. Lastly, a transformation of my horizon is shared.

My Family Is Normal

When asked what it was like to live in their family, all ten adolescents described their family as "normal." A common answer to my opening question was: "It's fairly normal." Michelle The card sort exercise in the second interview further confirmed this view of their family as normal with three out of the eight adolescents placing the card statement "My family is normal" in the "Always like me" pile. Adolescents placed the statement in other piles for reasons not related to their sibling's illness. For instance, "sometimes my brother he acts like a retard" Robbie or "me and my dad fight a lot." Gabrielle When attempting to describe their interpretation of a "normal family", the adolescents based their interpretation on family composition, family closeness, and family activities. The adolescents used other families as frames of comparison in their description of a normal family. Accomplishing typical tasks of families who have adolescents (Wright & Leahey, 2000) was also indicative of normal family life.

Family Composition

When describing her "normal family," Ayla responded: "I mean you've got two kids, two parents, um and a house and a cat." This conceptualization of the nuclear family was common amongst the adolescents. The genograms confirmed that nine of the ten adolescents were living as part of a nuclear family. All of the adolescents chose pictures to give a visual representation of their family composition. The following picture of members of my extended family illustrates the type of pictures chosen by the adolescents.



Note: Permission granted by all members of my brother's family

When describing the pictures, the adolescents pointed to different family members: "There's me, that's [John], and then there's [Sam]...and that's my dad." Dave

I asked Robbie why he had chosen to show me a picture of his sister, he responded "Just to show you that she's my sister." The same adolescent attempted to stress the importance of

family composition; when asked why he had chosen to show me a picture of his mother, he said "...so I could get a picture of EVERYONE in my family."

While visually representing their family composition, a few adolescents pointed out the positive qualities of the pictures as well as the emotions they felt when looking at them. An adolescent expressed how "nice" a picture was because "it's got, like more of my family and stuff with my Dad in it and everybody really happy and excited and, it's just a nice picture I think." Michelle Ayla, while showing a picture of her and her sibling at a very young age, explained how "everybody in the family has it [picture]...because it's so cute...It's just a nice picture, just so happy."

Adolescents' representation of family composition consisted of immediate family, as well as pets and extended family based on the significance of their relationships. One adolescent had taken pictures of her brother and his dog because "they're so close. They're so funny...He's got this unique relationship with them [animals]."Ayla Dave shared many pictures of his dogs and cats, as well as those of other family members because "I just love them. I love cats and dogs." Dave also explained with the help of his family pictures the relationship he has with his extended family which included his grandparents, aunts, uncles and cousins: "This is more of my Mom's life, just that she's with Grandpa and Grandma...and mother's taking care of her because now she's [ill]...and we always come and visit her."

Family Closeness

In order to explain how their families are normal, the adolescents described the closeness of their families. For example, Ayla explained "We get along really well...we talk...we have fun. Get along, spend all the holidays together, see each other on a regular basis. I think that's my normal [family]." Serge showed pictures of family members hugging and explained,

> We're a very close family. We've always been close. We're all so close, I mean when we gather around a table and we're all open, you know, like, how's your day? And go into a half an hour description of our day and get into different subjects over dinner... it's something that's always been important for our family, just so we know what's going on with our parents, and as brothers and sisters, and it's just to keep an open communication of it. It's really important for families. Just to always be able to, if one of us is down then we know what's been going on so we kind of know what they're upset about so we can help them out you know and kind of say it's okay.

Another adolescent described how decisions are made in his family based on family closeness and similarities: "I'll always go and try to seek out advice from him [sibling with CF], before anyone else actually, before my parents or anyone...It's the type of family where, my Dad can come and ask me for advice or Mom usually went to [John, sibling with CF] because they're so much alike. Whereas my Dad and I are so much alike..." Arliss

The family pictures were often chosen by the adolescents to describe a close relationship with a family member as Gabrielle explained: "I took this picture because I love my mom...my mom is really supportive." Not wanting to show a certain family member was also very significant in expressing a lack of family closeness. For example, when I shared my observation with Gabrielle that she had a picture of every member of her family except her father, Gabrielle explained "because my Dad acts sort of like sometimes he doesn't care..."

Family Activities

Other adolescents said that their families are normal because they participate in activities together. For example, Michelle stated "We've gone on family holidays every summer, usually out to the west coast, to visit my mom's family...." Dave showed many pictures of him and his

brothers, father, uncles and cousins hunting or on family holidays. Ayla explained that the reason she picked a particular picture "is because we used to go there every spring break with the family... " Ayla showed several pictures of family and friends at this usual holiday location, attempting to illustrate how much fun they had as children during their family holidays as well as growing up. In an attempt to sort her piles of pictures, she explained that she had created a category "doing normal family things." These examples of family activities illustrated the efforts that parents took to maintain family unity. This is congruent with literature that emphasizes the importance of engaging in family activities as a family unit in order to create or to sustain normal family life (Bossert, Holaday, Harkins, & Turner-Henson, 1990; Callery, 2001).

Other Families as Frames of Comparison

A common mechanism that was used by the adolescents for portraying a normalcy lens was through the comparison to an external standard. The ability to use objectivity and relativity during the cognitive development stage of formal operations enables adolescents to discern similarities and differences in situations (Hunsberger, & Wright, 1994; Piaget & Inhelder, 1958). Furthermore, an adolescent will take into account another's perspective or experience and is able to compare it to his own experience. Indeed, nine of the ten adolescents used other families as their frame of comparison to argue that their family is normal. As a result, another common answer to my opening question of what it was like for them to live in their family was "It's not that different from any other family" $_{\text{Dave}}$ or "it's been nothing, like weird." $_{\text{Krys}}$ Other adolescents explained that although their sibling has CF "[they] still do the things that every other family does" $_{\text{Michelle}}$, "[they] still communicate like a family does so [the] disease hasn't imposed on [the family] to make [them] not normal or dysfunctional or anything other than

average." Ayla Ayla further explained "...every family has something different. Every family does things that are different...I don't think we would be any less close, or I don't think we would be any different. It's not the disease that really makes or breaks us or, you know, makes us different."

Romeo also compared his family to other families when I asked him what a normal family looks like, but acknowledged the presence of illness. He answered "Well, could be us just without her having cystic fibrosis...it's not a horrible difference, but so she has it, and most families don't you know." He was the only adolescent who placed the "My family is normal" statement in the "Never like me" pile during the card sort exercise and based his choice on his sister's illness. He stated "...She has her cystic fibrosis so of course we're not normal in any means, you know. She has to have a lot of extra things around the house done. And then she goes to the hospital way more than most people do. And, if you go on a trip, you know, all the stuff has to come with you so, we're always constantly carrying all that, so...."

The adolescents' interpretation of a "normal" family included who was part of their family, the importance of strong emotional ties or family closeness as well as a passion for being involved in one another's lives. These factors are similar to those found in Wright, Watson, and Bell's (1996) definition of family. Family and parental involvement and support, as described in the adolescents' interpretation of their family life, are important foundations for children and adolescent development (Peterson & Leigh, 1990).

Accomplishing Typical Family Tasks

According to Wright and Leahey (2000), a task facing families with adolescents is a shift in the parent-child relationships to permit adolescents to move in or out of the system. In collaboration with the adolescents, I drew their ecomaps. The lines drawn between the family

members and the outer circles indicate the nature of the connections that exist: "Straight lines indicate strong connections, dotted lines indicate tenuous connections, and slashed lines indicate stressful relations" (Wright & Leahey, 2000, p. 95). The more lines indicate a stronger tie. The following fictional ecomap is an illustration of the reality of the interactions with external systems of the families of the adolescents in this study.

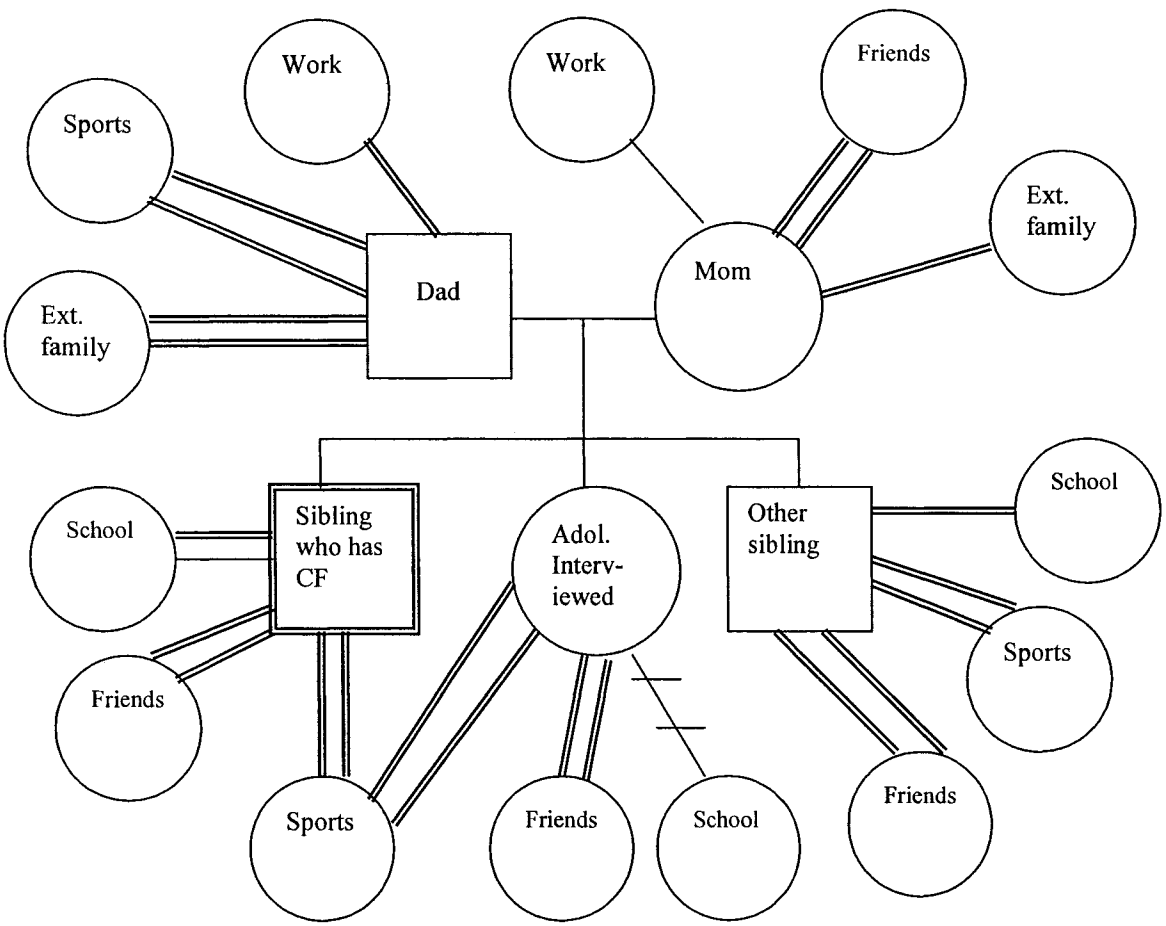


Figure 1: Fictional example of an ecomap.

The adolescents' ecomaps, as illustrated by the above fictional ecomap, made evident the many contacts and activities the adolescents had with larger systems, as well as the strong

connections with their friends. Thus, the ecomaps indicate the adolescents' increasing independence from their parents, an expected outcome during adolescence. Several studies found that activities outside the family unit are not altered by the presence of a childhood chronic illness. For example, in a study by Gallo, Breitmayer, Knafl and Zoeller (1991), siblings of children with a variety of chronic illnesses reported having no major changes in their daily lives. Pit-Ten Cate and Loots (2000) also found that there were no indications of complications in peer relationships associated with having a sibling with a disability.

The ecomaps, and the adolescents' explanations of them, were also congruent with their interpretation of accomplishing "typical" nuclear family tasks. That is, parents were not only allowing their adolescents to move in and out of the family system (i.e., participating in sports), but they were also attempting to maintain balance in their lives as adults (i.e., work, friends,...) as well as being resources for older generations (i.e., taking care of their aging parents) (Wright & Leahey, 2000).

The involvement with larger systems experienced by the adolescents was also apparent for the other children in the families including the child who had CF. According to the Canadian Cystic Fibrosis Foundation (2003); "most individuals with cystic fibrosis lead normal lives, for many years, in terms of education, physical activity, and social relationships" (p. 3). The adolescents used this apparent involvement in activities when explaining why they felt their sibling was a normal kid.

My Sibling Is a Normal kid

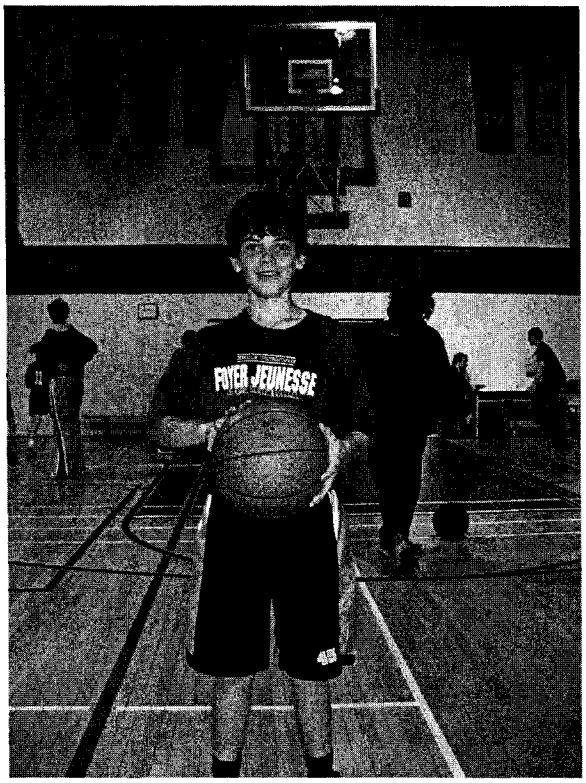
According to Ayla, "I just see him as a normal kid." This was how adolescents described the sibling who had CF. During the card sort exercise, three of the adolescents placed the statement "My sister/brother is a normal kid" in the "Always like me" pile, while the others

placed the card in the "Sometimes like me" pile. The latter choice was because they felt their siblings were not normal at times, but the abnormal characteristics or behaviors were not always related to the illness. For example, Dave stated, "Sometimes he's a goofball, and sometimes he's a pain, and sometimes he is normal." Two adolescents considered their sibling normal but were also reminded of the presence of an illness. For example, Arliss responded: "I'll forget that he has CF and just like 'oh well, he's just like every other normal kid' and then, whoops, you know. Because yeah, he'll be coughing a lung up and, you know that's not normal."

However, even the adolescents who acknowledged the presence of the illness felt that their sibling was a normal kid because: a) they grew up thinking it was normal for their sibling to have CF, b) the ill child had a unique personality or characteristics, and c) the ill child was not that different from themselves or other children their age.

Growing Up "Normal"

Ayla explained that she had never thought of her brother as "not normal" or ill because "I've grown up with him and he's always had it and it's always been normal. There hasn't been a moment of realization that he's got a disease. I've always seen him as a normal kid, with normal insecurities." The daily medical routine that is expected from children who have CF became part of everyday life for most adolescents, thus they viewed their sibling as normal. As Serge showed a picture of his sister, he stated: "That's my sister taking pills again...part of her day." He further explained, "I know she has CF, but it doesn't click up here (pointing to his head), and she's a normal person that you can have a relationship with..." The pictures they shared of their sibling, as illustrated by the following picture of my nephew, and the way they described their personality or characteristics was also a way of demonstrating how they had viewed and continue to view their siblings as normal kids.



Note: Permission granted by my nephew

Siblings' Personalities or Characteristics

When I asked Robbie what he saw when he looked at his brother, he responded "A scar face. He has a cut here and a cut there." Many of the adolescents would describe the personality or certain characteristics of their sibling when showing pictures of them in an attempt to show how "normal" they are. For example, when Michelle was showing a picture of her sister she had chosen from a family album, she stated,

> [My sister] was really cute. She fell and cut her eye on the coffee table one time, and that's what that's from (pointing out a scar). And, then, this one here on her forehead is from falling down the stairs in her walker, and, I mean, things that happen to all kids, but

she was just always a wreck (laughs). Just always into everything. I mean she's still like that now too. It's just her personality.

While sorting her pictures in piles of similar themes, Ayla explained "I put these three [pictures] together because these are distinct characteristics of him. When he was little, he was hyperactive, loved watching TV, and he was always on the phone and likes Pamela Anderson." Serge took pictures of his sister sleeping, eating, reading, smiling.... When I asked him what he was hoping to show me with these pictures, he answered: "Her personality, and that she's just a regular sister." Similarly, Bluebond-Langner (1996) found that well siblings do not list CF as one of their ill sibling's primary characteristics in their description of their ill brothers and sisters. Many adolescents also compared their sibling to themselves or to other children their age to demonstrate how "normal" there siblings were.

Like Me and Other Kids

Serge described his sister as "...a normal person like everybody else." Romeo compared his sister to himself when explaining "We both have friends, we both go out, we party and stuff like that. So, in that way, we're both similar." Pamela explained that her sister was able to do the same things as her other sister who was very close in age, "they have pretty much the same friends and they're all in the same sports and everything." When asked why she considers her sister a "normal kid," Michelle also made reference to other adolescents her sister's age and responded "Well I mean she's 15 now, so, I mean, she's going to the mall shopping all the time, going to movies, she plays outside all the time, goes skating, tobogganing or swimming in the summer, and...goes for sleep-overs at her friend's house, and has stayovers at our house." Similar findings were reported in a study with adolescents between the ages of 16 and 25 who have CF. The adolescents felt that as children, they defined themselves "as basically ordinary,

active children..." (Admi, 1996, p.167). Bluebond-Langner (1996) also found that healthy siblings viewed the child with CF as essentially like other children.

Only when asked why it was important for their sibling to be normal and active did the adolescents make the connection with the illness. For example, Gabrielle responded to the question: "Because he has to, in some ways he's different not like a normal kid because he HAS to be active to be healthy." Serge also acknowledged the importance of physical activity for his sister's health. He stated: "because she likes it [dancing], and it's fun...and because the physical activity helps with the mucus...It's like the physio activity, and so it's good for her lungs."

Our Sibling Relationship Is Normal

The adolescents in this study interpreted their sibling relationship as "typical" or "normal." They based their interpretation of a normal relationship on the following factors: 1) they had grown up in the relationship knowing that their sibling had CF, 2) they did activities together, and c) they felt that they had a similar relationship with their sibling as their friends had with their siblings.

Growing up in a CF Relationship

Two adolescents clearly articulated that their sibling relationship was not affected by the illness, that it had been created by the fact that they had grown up together. Ayla explained that it is impossible for her to imagine that her relationship with her brother would be different or had changed because of the fact that he had CF. She said, "I don't think there has been a relationship before he had CF because he's always had CF since he was born pretty much...When you're a kid, you don't really understand he's got CF. You treat him like somebody you know you have to live with and you fight with sometimes and sometimes you watch over, but you treat him like

that because he's your brother....As you get older you can't help but look at him in the same way."

Arliss also made reference to the fact that the relationship with his sibling was based on other factors because his brother had always had CF. He explained, "The thing is with CF you're born with it. It's not like you get it later on in life. So you're pretty much raised with that being the normal thing." Arliss explained that his brother with CF has become his best friend because they have similar philosophical views. He further stated, "take away the CF, I'd try and hang out with him as much as I do now."

Doing Activities Together

Dave explained that his sibling relationship was normal because he engaged in activities with his brother who has CF; they "build armour type stuff and swords and snowboarding and stuff like that." Arliss explained that his brother and he spent a lot of time together because "we always had the same friends, we always did the same things together." Gabrielle also highlighted the sports she did with her brother. Serge believed he had a closer relationship with his sister than most adolescents. He did not believe it was due to the illness; "It's who we are." He described all the things they did together as siblings: "We play around with each other, running, chasing each other around. We play playstation together, watch TV, all sorts of stuff like that."

Like Other Sibling Relationships

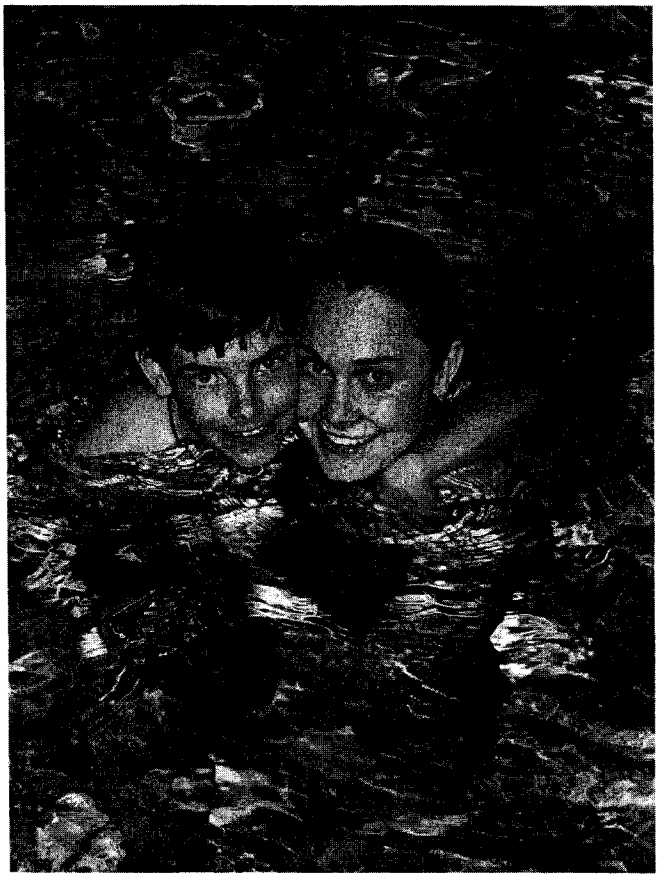
Michelle believed that her relationship with her sister was typical. She stated, "She and me fight just like every other brother and sister. I think it's just the age right now that she's at, just trying to break away and do her own thing that any little comment you make she sends back but that's just her age. So, yeah, it's just a normal relationship..." This wide range of emotional

responses that can quickly move from warm to hostile and back often characterizes a typical sibling relationship (Dunn & Kendrick, 1982). Michelle did not believe that her relationship would be different if her sister did not have CF; she explained "I think it'd be the same. If anything it should have made us closer but I mean we're not super close anyway so. I mean she still bugs me as much as any other kid would (laughs)."

Ayla also described her relationship as being typical; "He drives me crazy. He's always driven me crazy. Isn't that a normal brother? (laughs)...When I look at our relationship I don't see anything different from any other brother and sister relationship....Sometimes I worry about him not because he's got CF, just because he's a boy, and he's [a teen], and they do stupid things."

Dave also explained that his relationship with his brother was like that of other siblings because "we fight like other brothers probably do, but we do get along. If any of us are having problems, one of us will help. I worry about him. Like I hope he's always in good health, but I also worry about my other [healthy] brother for different reasons. I really do treat him like any other brother would. Even if he didn't have CF, I'd still treat him the way I do." These adolescents did not believe that their sibling's illness had changed their relationship.

During the card sort exercise, five of the eight adolescents placed the statement "My relationship with my sister/brother hasn't changed because she's/he's got CF" in the "Always like me pile. The pictures of themselves with their siblings who have CF offered no evidence of the illness; they were visual representations of "typical" sibling relationships.



Note: Permission granted by my niece and nephew

Despite the unique characteristics of the following diagnostic groups, the perception of no significant difference between the sibling relationships among chronically ill children and their siblings and those among healthy children was found to be similar to the finding of this study. For example, a study by Weiss, Schiaffino and Ilowite (2001), based on the perspectives of 20 children with juvenile chronic arthritis and their siblings, involving 20 comparison sibling pairs ranging from seven to twenty-one years, as well as their parents, concluded that sibling relationships in which one child has juvenile chronic arthritis did not differ significantly from those of healthy sibling pairs in terms of perceived levels of positive feelings, conflict and authority over each other. In another study of sibling relationships among Japanese children

with diabetes, Minagawa (1997) also concluded that sibling relationships were similar to those of healthy children.

Similar findings were found in the recent disability literature such as a study based on the perception of parents and well siblings ranging in age from 10 to 19 who were living with children who had a learning disability. The study examined the sibling relationship and found that families with a sibling with learning disabilities experienced both the positive and negative dynamics found in all sibling relationship (Lardieri, Blacher, & Swanson, 2000). Although based on the unique perspective of parents, Bat-Chava and Martin (2002) also found that current relationships between the siblings of deaf children were largely satisfying.

Although the adolescents used pictures that visually represented their sibling relationship as "typical", three adolescents in this study placed the statement "My relationship with my sister/brother hasn't changed because she's/he's got CF" in the "Sometime like me pile." Romeo explained, "Sometimes it's just because I have to do her physio, so it's the only real thing. I don't think her attitude towards me or me towards her would change if she didn't have it (referring to CF). I'm pretty sure she'd be the same person. She'd still be a mean person. It's just her personality." Robbie also noted changes in his relationship with his brother when play time had to be interrupted for CF treatment; "The only thing that's changed is like when we're in the middle of like floor hockey or something; he has to like stop sometimes... to do his physio or Ventolin." Gabrielle described an element of difference in her relationship with her brother due to the responsibilities she had in caring for him, and due to the parental differential treatment she perceived, which made her feel "annoyed" and "jealous."

Although the three adolescents in the present study felt that the illness demands affected, in varying degrees, their relationships with their sibling they continued to describe their sibling

relationship as typical or normal. The adolescents identified many factors that had influenced their ability to view their situation as normal.

Factors Influencing Adolescents' Interpretation

The adolescents in this study attributed their ability to view their family as normal, their sibling as normal and their sibling relationship as normal to the invisibility of the illness. The invisibility of the illness had been influenced by the ill siblings' actions, by management advancement and by the stability of the illness. The invisibility and stability of the illness had facilitated the family members' ability to adopt normalization as an approach to living with a child who has CF.

Invisibility of the Illness

According to the adolescents, the fact that individuals outside the family could not see visual cues indicative of illness facilitated their ability to view their siblings as normal. For many of the adolescents, the CF in their lives was not apparent. Romeo and many other adolescents explained: "It's not even like she has it." According to Pamela, "Somebody who doesn't really know her would come, and they wouldn't think anything's wrong. Like, if they just met her in a playground or something. Because, she looks like a normal kid except she coughs a lot." The adolescents compared their sibling's illness to other conditions in an attempt to illustrate its invisibility. For example, Arliss stated, "Because with cancer patients they lose their hair from their care or whatever. With a CF person, you can't tell, other than he's coughing his lungs out every day. But, otherwise, you can't tell." The adolescents recognized that the invisibility of the illness went beyond the visual inability to perceive symptoms of illness; at times the illness could be made "visible" by the auditory cues of the distinctive CF cough or chest percussion. However, despite these cues, the adolescents continued to interpret the illness

as invisible. They attributed the invisibility of the illness to the ill sibling's actions, the management advancement and the stability of the illness.

Ill Siblings' Actions

Many of the adolescents reported that their siblings would refrain from talking about their illness in an effort to be perceived as normal kids. Ayla explained that her brother does not mention that he has CF "because he sees himself as normal,..." There were no visual signs of her brother's illness in any of Ayla's pictures. According to Ayla, "we don't take pictures of him that show he has CF...these types of pictures ["normal" pictures] are just the kind of picture he allows us to take."

The fact that their siblings did not complain about their illness and tried to maintain good health by physical activity, for instance, seemed to have enhanced the invisibility of the illness and helped the adolescents to view their siblings as normal. For example, Pamela explained,

> She doesn't complain about it. Like, she'll cough, but she's really active, and she doesn't just sit there. When she gets colds and she does all this coughing and sneezing and stuff, she doesn't complain about the CF, and she doesn't really bring it up. Like, she just carries her pills around, and she'll take her pills, and she's really good about it. So, that's a good thing.

Management Advancements

According to the adolescents, the invisibility of the illness had also been made possible by management advancements. Management of CF typically consists of antibiotic therapy and physiotherapy to remove secretions from the chest and to minimize infections, good nutrition combined with nutritional supplements and pancreatic enzyme replacements to counter the problems of malabsorption and malnutrition, and frequent outpatient visits and hospitalization

(Hodgkinson & Lester, 2002). The daily management of illness is carried out predominantly by the parents, with the ill children taking on more and more responsibility for self-management of treatment as they age (Goldbeck & Babka, 2001).

New approaches to clinical management are continually being developed to facilitate parental and self-management and to decrease the number of hospitalizations. As Michelle explained, her sister used to be admitted to hospital for intravenous antibiotics: "But that was a long time ago; we've been doing home IVs since then. Other than that, it's [family life] been pretty normal because now that she doesn't have to go to the hospital, it doesn't interrupt our lives so much and so things just go along more smoothly as they would any other day."

Ayla was excited when she explained that her brother "just got a new vibrating vest pounder thing." She complained about how loud the apparatus was, but recognized the advantages of the vest: "He loves it. He thinks it is great because he can do whatever he wants. Watch TV, he can do it whenever he wants. He doesn't have to wait for mom anymore."

Although these new approaches can increase the possibility of normal family functioning and adolescent independence, intravenous antibiotics and chest vibrations are not always financially accessible to all families. Serge explained that his mother had been learning how to administer intravenous medication to his sister in order to get early discharge from the hospital: "But it would've been too expensive. We had to decide if she would stay another week in the hospital or come home. But we would've had to pay hundreds of dollars [for the intravenous medication], so she stayed in the hospital for another week." For some families, certain medical expenses (e.g., medications) were not covered by health insurance plans or were not easily accessible (e.g., vibrating vest was not available in Canada). Thus, only those families who could afford to pay privately for treatments had access to them.

Improvements in early diagnosis and management of CF have resulted in increasing longevity and declining death rates in CF. In 1960, a child born with CF rarely lived four years. Today, in Canada, persons with CF are living into their mid-thirties and beyond (Canadian Cystic Fibrosis Foundation, 2003). Management improvement has also helped stabilize the illness, often making the illness invisible and family life appear normal. In fact, the adolescents noted that the stability of the illness played an important role in allowing them to view their sibling as "normal."

Stability of the Illness

According to Krys, his sister's illness "is neither here nor there" because "she's young right now, and she's doing like really fine right now." Even when hospitalized, the siblings perceived their sibling as stable, as not needing any special attention. Ayla explained, "I've seen him a few times in a hospital, but he never has looked really sick. Like if I saw him, and he looked really sick, I might be a little more shocked or a little more feeling like I need to protect him, or something. But, as far as it goes now, I don't really have that urge." The adolescents seemed to be aware that illness stability and invisibility was not something that would always be present but acknowledged that these characteristics allowed them to perceive their sibling as normal.

Adopting a Normalization Approach

The adolescents described how their families were able to adopt a normalization approach to living with a child who has CF. The stability of the illness had enabled families to normalize their experience making the illness and its treatment part of everyday life...routine. As Arliss explained, "he takes all his pills...routine. I've gotten used to it. He does his physio, and it's just become part of life, you know." A few adolescents relied on this type of routine to

organize their own lives. Dave explained, "When [my brother] used to live here, I'd wake up, and I could hear him and my dad doing his Ventolin and his physio, and I'd know what time it was because I'd get a routine of when [my brother] started that. It was my alarm clock. Now, it's just different not hearing that." Dave could no longer hear the manmade alarm clock because his brother had temporarily moved out of the house.

Pamela's parents were giving her sister's intravenous treatment at home; her sister had "only missed two days [of school] because it was spring break." Michelle also gave an example of how giving her sister her ventolin treatment had become routine for her. She explained her parents' typical expectations of her when she babysat her sister which not only included putting on her sister's pyjamas but also administering treatments. It had become normal, routine, for Michelle; she explained "Like when you're baby sitting, that's what you do before you put them to bed. You put a kid in pyjamas and with her, you just gave her a mask and pounding before she went to bed."

According to the adolescents, many of their parents would do additional preparations in order to allow their family to enjoy family outings or vacations. When explaining the preparation her parents did prior to their family holidays, Ayla stated, "We had a little bag for him and that was for his stuff [medication, compressor,...] ..." Many studies that used normalization as an interpretive lens from which to understand family life in the context of chronic illness (Gallo & Knafl, 1998; Gravelle, 1997; Knafl, Breitmayer, Gallo, & Zoeller, 1996; Sharkey, 1995) also found that parents deliberately engaged in activities such as making the treatment regimen routine in order to create a family life that was experienced as both normal and satisfying. Bossert, Holaday, Harkins, and Turner-Henson (1990) described engaging in activities as a normal family unit as a strategy to create or sustain normal family life.

Attributes of normalization according to many researchers include not only adapting treatment regimen to minimize disruption to the child's life, but also treating children equally (Bossert, et al.,1990; Deatrick, Knafl & Walsh, 1988; Deatrick, Knafl & Murphy-Moore, 1999). According to Knafl and Gillis (2002), over time, the outcome of such strategies was the perception of living a normal family life despite a member's chronic illness. According to the majority of the adolescents, being treated equally was helpful in viewing their sibling relationship as normal. Serge explained, "My parents made a point to make sure that I don't feel left out, and we have been treated equally. I can't imagine not getting as much attention as my sister because she has CF." Studying young adolescents, Kowal and Kramer (1997) found that adolescents who rated parental differential treatment as fair also reported more positive sibling relationships.

The adolescents also spoke of the conscious efforts they made to view their sibling as normal and to treat them as they would treat any other sibling. For example, Ayla explained, "I don't associate him with weakness or with illness or something I would have to watch over." Michelle also explained how she would not let her sister get away with certain behaviors just because of her illness; "I don't say, oh well, she left a mess in the kitchen. I'm not going to let her get away with it. I'll be like...get your butt in here, and you clean this up." According to Deatrick, Knafl and Murphy-Moore (1999), adopting a normalcy lens to define the ill child is an attribute of normalization. Furthermore, comparing the ill child to a target group and emphasizing similarities have been proposed by Morse, Wilson and Penrod (2000), as normalization attributes. As previously described, this type of comparison was utilized in the adolescents' interpretation of a normal family, normal sibling and normal sibling relationship.

The ill siblings' efforts to achieve developmental milestones are also considered attributes of normalization (Morse et al.; 2000). Arliss explained how happy he was that his brother went to college: "I'm so glad that he went to college. If he would have just said, well I've got CF, I may as well stay home and mope. There's no point in me trying to get an education or anything. Like, that would have just killed him, right there. Whereas, he's getting his mind working right now and staying active." The adolescents perceived their sibling's actions as helpful in sustaining normalcy. Ayla claimed that her brother's efforts to be a normal kid had helped her the most in dealing with her brother's illness.

The invisibility of the illness helped the adolescents' view their experience through a normalcy lens and to adopt normalcy attributes. According to the adolescents, the invisibility of the illness offered both advantages and disadvantages depending on the circumstances.

Advantages of Invisibility

According to the adolescents, the most common advantage of having an invisible illness was the absence of stigmatization. Arliss explained that because his brother's illness was invisible, "he isn't stereotyped or prejudiced because of it...if he was in a wheelchair, you know, people would think different of him." The adolescents felt that, because of the invisibility of their sibling's illness, they did not have to "think about [their sibling] having CF" Arliss or to talk about the illness "all the time." Pamela People with invisible conditions and their families have the opportunity to control how, what, when, and who they tell about their condition (Goffman, 1963; Joachim & Acorn; 2000a). According to the adolescents, their siblings were able to conceal their illness by not talking about it and thus decreasing potential stigmatization. Ayla explained that her brother would not talk to his friends about his illness "because he doesn't want other

people to see him as weak or disabled, or he doesn't want people looking at him differently. He doesn't want people feeling sorry for him."

According to many adolescents, when the illness became visible due the distinctive CF cough, it was often viewed by others as another less life threatening illness. Romeo explained, "people think it's just a cold. Especially if people don't see them [children with CF] often. Everybody gets colds, so, of course, they're going to be like, Okay, she might have a cold, or it could just be asthma." When their siblings were not viewed as different or ill, the adolescents felt that their siblings were included in regular childhood activities. Pamela explained that her sister has not been "left out of the stuff her friends do...she runs a lot and does a lot of activities," things she would not be able to do if she was viewed as being different. Michelle also explained that the advantage of having an invisible illness is "HUGE.... She doesn't feel that much different from everybody else...she doesn't stand out as different."

The adolescents also mentioned that the invisibility of the illness gave them the ability to have a "typical" relationship with their sibling. Ayla explained that the invisibility of the illness allowed her to "never [think] of [her brother] as ill," which allowed her to have a "really good" relationship with her brother which included the usual sibling rivalry.

Disadvantages of Invisibility

The adolescents felt that the invisibility of their sibling's illness had lead to a lack of public awareness, the potential for disclosure conflicts and decreased family communication about the sibling's health. Several authors also identified lack of social validation and stress related to disclosure as problems particular to invisible disabilities or chronic illnesses (Falvo, Allen & Maki, 1982; Goffman, 1963; Joachim & Acorn, 2000a; Thorne, 1993).

Lack of Public Awareness

Arliss was one of the adolescents who frequently mentioned the lack of public awareness due to the invisibility of his brother's illness. He explained,

> I often wonder if people even think of it as a real disease. I watched how the CF Foundation has those ads going on where they show a guy and said "You're more likely to care about someone if you know about the disease." And, then they said, "Now you do." And, I observed my [friends] watching it [ad], and sort of tried to get their reaction, and you almost look at them and wonder like, did they even think it's a real disease or not, you know? Because this guy looks perfectly normal, but you know, here he's got this disease that will most likely kill him.

Arliss also gave examples where there was a lack of sympathy towards his brother because he appeared normal when compared to other children in their school who had, according to Arliss, a visible illnesses. He remembered "a deaf kid in school and the entire class learned sign language because you could really tell he was deaf because you'd asked him something, and he couldn't hear you. It was kind of funny that everyone was sympathetic to him, but, nobody really knew about [my brother] because he looked perfectly normal." Arliss and Dave also spoke of other children in their school who had gotten a lot of sympathy (e.g. "dances to raise money") from their classmates because they had cancer and had lost their hair. The two adolescents felt that there was "a big difference between CF and cancer" or other disease that "you can see."

Due to the invisibility of the illness, seven out of the eight adolescents who participated in the activity placed the statement "I feel that people don't understand what it's like to have CF" in the "Always like me" pile. One adolescent placed the same statement in the "Sometimes like me" pile because he felt that people who were living with the illness got "first-hand experience."

Serge The major reason given for feeling that people did not understand what it's like to have CF was the invisibility of the illness. Adolescents felt that with increased visibility came understanding of the illness; CF would not be "forgotten"Gabrielle, Arliss, there would be "more awareness of the illness"Serge, and people would no longer have "the wrong idea about the disease." Gabrielle In addition, lack of public awareness could lead to discrimination. Arliss felt that many people had the wrong idea about CF because people were probably thinking, "Well, he's probably just a smoker, or it's contagious. If he's coughing his lungs out, I betcha a lot of kids would be scared of catching cooties."

Disclosure Conflicts

According to the adolescents, disclosure conflicts were also a disadvantage of having an invisible illness. The adolescents felt that their siblings did not want to disclose their illness. For this reason, I did not keep any of the pictures the adolescents took or shared with me since some of the siblings would not allow their adolescent siblings to take them otherwise. Even if I agreed not to keep the pictures, a few adolescents admitted that the types of pictures that the adolescents took of their ill siblings were censored, that is, the siblings would tell the adolescents what type of pictures they were allowed to take. In trying to understand the experience of the adolescents, I asked Ayla "What would he have said if you'd come with a Polaroid while he was doing his mask?" She answered: "I don't want to say it on tape (laughs). There would probably be no camera left. He [brother] would have said, "What are you doing with that? Where are you going with that? Why are you doing that?" Ayla's brother had even prohibited her from participating in the study, but Ayla went against his wishes, reassuring him that she would not give me a copy of the pictures.

Most of the adolescents were less reluctant than their ill siblings to talk about CF. Most adolescents told their friends about their sibling's illness especially if their friends asked questions. For example, if a friend visited their home while the sibling was doing a treatment, the adolescent would simply tell the friend that their sibling had CF. Gallo, Breitmayer, Knafl and Zoeller (1991) found a similar pattern. In their study, fifteen (58%) of the 26 well siblings reported that they would reveal to others that the ill child had a chronic illness. The adolescents' ease in disclosing to their friends may be related to their perception that they were unlikely to experience personal discrimination if their friends knew about their sibling's condition (Joachim & Acorn, 2000a; Troster, 1997). Admi (1996) found that adolescents would consider disclosing their illness if they felt that their friends had the ability to express caring, to deal with the information and to establish social relationships on a reciprocal, symmetric basis. Perhaps the adolescents in this study felt that their friends met the criteria, thus they told them about their sibling's illness. On the other hand, the ill siblings may not have been as confident, thus opting to conceal their illness.

The ill siblings may have also perceived the risk of discrimination as higher (Joachim & Acorn, 2000a), as many of them did not tell even their closest friends that they had CF. For example, Serge explained, "especially around her friends. You know, they're always asking why she's coughing. And, she'll say she's got asthma." Other studies have found that children with invisible chronic illnesses have attempted to conceal their illness for social approval. In a qualitative study with 20 children with CF, between the age of six and 12, D'Auria, Christian and Richardson (1997) found that instead of telling others about their illness, children kept information about their illness secret to control how others viewed them. Similar protective strategies were found in a study with adolescents. Adolescents felt that "telling others about

their CF diagnosis threatened normal developmental needs to gain social approval, from friendships, and develop competence" (Christian & D'Auria, 1997, p. 6).

Some of the adolescents disagreed with their sibling's choice not to disclose their illness: "He doesn't want his friends to look at him differently, but had they known all along, they wouldn't see him differently just as I don't. If ever he gets in a serious relationship, it's going to be very hard for him to tell her." Ayla

Lack of disclosure also facilitated their sibling's actions to conceal the illness. Several adolescents felt their ill siblings did "not take it [illness] seriously as [he/she] should sometimes." Michelle According to the adolescents, their siblings, for example, "didn't take [their] enzymes in school." Ayla Non-adherence, especially during adolescence, amongst the CF population has also been identified as a major concern by several authors (Abbott, Dodd, Gee, & Webb, 2001; Esmond, 2000; Foster et al., 2001; Goldbeck & Babka, 2001; Götz & Götz, 2000; Stewart & Dearmun, 2001). According to Götz and Götz (2000), the factors that determine whether an individual will follow treatment recommendations is predominantly psychologically and socially determined. The adolescents in this study felt that their sibling's non-adherence to treatment in order to conceal their illness was unacceptable; perhaps they feared their siblings might die if they stopped taking their medication.

Sibling behaviors which went against their therapeutic regime, such as smoking, were also considered unacceptable and distressing for some adolescents. Arliss explained, "When he actually bought a pack [of cigarettes], I was really upset about that because here he is, a guy with a lung problem, doing the worst possible thing he can. Like, you know, come on [brother] I thought you were smarter than that." Confronting their siblings about these unacceptable behaviors would result in conflict between the siblings.

Not Talking About the Illness

The last disadvantage voiced by the adolescents related to having an invisible illness was not talking about the sibling's illness with parents. Three of the adolescents placed the statement "I don't talk to my parents about the illness or my feelings" in the "Always like me pile" and three others placed the same statement in the "Sometimes like me pile" during the card sort exercise. One of the many reasons for not talking to their parents about the illness was that they did not think to talk about the illness because of its invisibility. An adolescent explained,

> Like, we never talked about it really. We talked about it every once in a while if something really interested us, you know as far as talking about it all the time or whatever. Like, when someone gets cancer as an example, they probably sit down and have a big family discussion. Everybody seems to get involved because it's noticeable. Arliss

Similar findings were reported in a study by Bluebond-Langner (1996). In her study, when children viewed their siblings who had CF as "essentially like other children," they did not report talking to their parents about what it is like to have a brother or sister who has CF.
Other reasons for not talking to their parents about the illness or their feelings included worrying about their parents and questioning parents' ability to answer questions. This inability to seek informational support from parents will be discussed in detail in chapter five.

In summary, the siblings in this study interpreted their family, their sibling and their sibling relationships as normal and were able to do so because of illness invisibility. The invisibility of the illness had been influenced by ill siblings' actions, management advancements and the stability of the illness. In turn, the stability of the illness enabled the family members to

utilize a normalization approach. The adolescents' horizon of meaning offers marked contrast to mine and stimulates questions regarding differences in interpretation.

Transformation of My Horizon of Meaning

Why was my personal interpretation of living with chronically ill brothers so different than those of the adolescents in my study? In part, the context in which I experienced having chronically ill siblings has drastically changed. In contrasting early studies with more recent research, Lamorey (1999) noted that the educational, political, and medical context of disability in the 1960s and 1970s incorporated little of the advocacy, intervention efforts, normalization, and inclusion that characterize more current approaches to disability and chronic illness.

Despite my parents' efforts to keep our family intact, they needed respite from the many challenges of my brothers' illnesses. The only respite option offered was institutionalization. This forced separation from my brother had made it impossible for me to view my family as normal. In situations such as this, "the family views itself and believes others view it as not normal" (Deatrick, Knafl, & Murphy-Moore, 1999). Due to my brother's physical and mental challenges (visible illness) they were not allowed to participate in regular childhood community activities. The institutionalization and ostracizing of my brothers was very difficult for my parents. As a result, I felt a lot of anger, especially during adolescence, due to the injustice and suffering that my brothers and parents had to experience, as well as guilt for being healthy. According to Thorne (1993), having a visible difference creates the possibility for discrimination and has many frustrating and demoralizing social implications.

Contrary to the adolescents in the study, I was not able to view my brothers as similar to other children because they could not do the things other children could do. Furthermore, due to their limited communication abilities, I did not interact in the same way with my brothers who

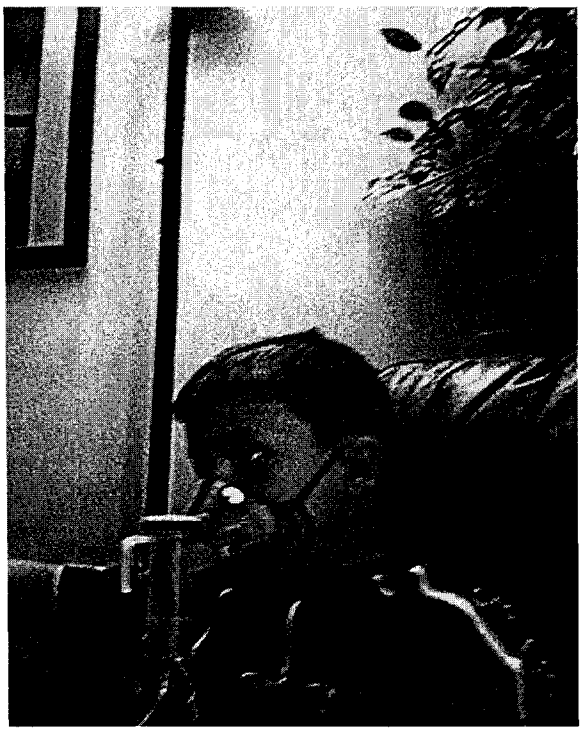
were chronically ill as I did with my healthy brother. This difference did not mean that I did not perceive my relationship with my ill brothers as positive; I loved them tremendously, but I did not experience the same sibling experience as I did with my healthy brother. I also could not view my ill brothers as normal because, contrary to the ill siblings in this study, my siblings suffered tremendously (especially Luc) from their conditions. I viewed them and my relationship with them as different from that experienced by other siblings. In an analysis of parent data from two field studies examining family experiences in raising children who were both medically fragile and developmentally delayed or disabled, Rehm and Bradley (2005) concluded that the developmental delays compounded with the effects of the children's physical chronic conditions severely affected how families organized and managed their lives making it difficult for families to adopt attributes of normalization. This research may explain why my personal experience was different than the siblings in my research.

As a health care professional, I have practiced mainly in large paediatric acute settings and the children I cared for were extremely ill with most of them having visible illnesses. I viewed illness as a stressful experience and was drawn towards that type of literature. My pre-understandings of what it's like to live with chronically ill siblings had been influenced by my personal and professional context, and as a result, I viewed my experience through an illness lens, which thus defined the experience, although at times rewarding, difficult and challenging. However, interpreting the adolescents' accounts in this study enabled me to recognize that in certain conditions, when illness can be perceived as invisible one is able to normalize their experience.

CHAPTER FIVE

ACKNOWLEDGING THE CONDITION

Viewing their family as normal did not mean the adolescents in this study were not able to acknowledge their sibling's condition. Twenty-two (or 23%) of the pictures the seven adolescents showed me made the illness visible. They included pictures of equipment and medication and of the sibling receiving treatment such as inhaled medication or physiotherapy.



Note: permission granted from my son

According to Deatrick, Knafl and Murphy-Moore (1999) an important attribute of normalization is acknowledging the condition and its potential to threaten the family's lifestyle: "You always have to know that things can turn around like that (snapping fingers) and you've always got to stay on top of her meds and everything" $_{Serge}$ because "if he doesn't

take his pills every single day he might die; and always going to the doctors to be checked out...sometimes the news is bad and sometimes it's good." Gabrielle

Advances in the diagnosis and treatment of CF have resulted in improved quality of life and improved chances of survival (Elborn, Shale & Britton, 1991; Hodgkinson & Lester, 2002; Lees & Smyth, 2000). Many forms of treatment are now administered in the family home and can be time-consuming, tiring and may intrude into the family routine. Thus, the family must learn to manage treatment demands while continuing to meet the demands of their daily lives (Foster et al., 2001). Daily treatment typically includes: 1) two daily 20-minute sessions of assisted chest physiotherapy, such as breathing exercises, tapping the chest, or postural drainage; 2) inhaled and oral medications; 3) high energy, vitamin-supplemented diet; and 4) enzyme capsules to enable digestion which are taken with all meals and snacks. Parents and the ill child need to be vigilant to changes in the child's health status as this can vary markedly throughout any one month.

The first sections of this chapter illustrate how the adolescents were well aware of their sibling's condition and what difference it made in their lives. They were also experiencing many concerns and negative feelings. The adolescents relied on the support and actions of others as well as personal strategies to help them live alongside the differences, concerns and negative feelings. Although the adolescents had experienced differences, concerns and negative feelings, they had also experienced many benefits of living with a sibling who has CF. A description of the transformation in my horizon concludes this chapter.

Experiencing Differences

Many of the adolescents identified differences in their lives that resulted from having a sibling with CF. These differences included: watching over their sibling, participating in their sibling's care, decreased parental attention and differential parental treatment.

Watching Over

Several adolescents spoke of the protective measures taken on behalf of their ill sibling. For example, Ayla explained that "when he's at the bar, [I don't] like him being at the bar for too long because of the smoke, and [I] smoke, but won't smoke when he's in the car or around. Nobody is allowed to smoke when he's around." Arliss also described how he always watched over his brother. He gave the following example: "I think it was minus three out, and I was just freezing...I'm telling him 'Jeez bud get a jacket on or something.' He'd just have a sweater on. I'm always watching out for stuff like that." Robbie also described how he "whipped the butt" of a boy who was "bugging [his] brother about CF." Gabrielle felt that she watched over her brother "big time. [She wants] to make sure he gets to the hockey rink, and he's playing hockey in order to be healthy. [She] always makes sure that he takes bottles that are clean so he doesn't catch anything...." Several studies have also reported that children of chronically ill siblings engage in protective behaviors (Bluebond-Langner, 1996; Faux, 1991; Menke, 1987).

Participating in Care

For a few of the adolescents, their sibling's CF treatment was inconvenient, something they didn't "really like doing." Krys Pamela explained, "She wakes you up in the morning because she has to get up really early, so she turns on the TV, and her nebulizer's making all this noise and stuff so I don't really like that waking up really." The increased

responsibility that came with helping with the treatment and with reminding their sibling to take their medication was at times an inconvenience for the adolescents:

> Two weekends ago [my parents] went away and I had to do [physio]. So if I'm going out for the night with friends I have to stay home 'til later because she has to get her therapy done because I HAVE to do it. I can't just be like, "Oh well, who cares?" I have to get up early in the morning so I can't go out late and I can't sleep over someone's house, I can't do it because I HAVE to be there for her physio in the morning so it really sucks. Romeo

Gabrielle took pictures of her brother's medication "to show that I'm the one that has to remind him." Serge explained that he not only helped out with the treatment, but he gave support to his sister: "The second time she found out she had to go to the hospital, I went with her outside, and she was crying, and I went through it with her." Serge

Four of the eight adolescents who participated in the card sort exercise placed the "I do extra stuff to help out" statement in the "Always like me" pile, and the other four adolescent placed the statement in the "Sometimes like me" pile. Most of the adolescents referred to the physiotherapy as the "extra stuff" they did to help out. Other adolescents made reference to extra chores. For example, Serge explained, "When my parents were with my [sister] in the hospital I did a lot of stuff here at home." Arliss also recalled "being in a grain bin late at night, and not being a fun thing. You don't want to be doing that especially when your brother's inside watching TV because he's exempt from it." In a study with well children of chronically ill siblings, the well children also talked about the "variety of special or extra tasks they performed or did for the ill child" (Gallo, Breitmayer, Knafl, & Zoeller, 1991, p. 24).

While some adolescents did not "feel that [they] needed [or wanted] to do more" Michelle others wished they could have been more involved in their sibling's care. Serge wished he "could do more, because you wish you could just go inside her body and get all this stuff out, and you know you can't, but you try to do as much as you can..." As a result, two of the eight adolescents who participated in the card sort exercise placed the statement "I wish I could be more involved in my sibling's care" in the "Always like me" pile, and four in the "Sometimes like me" pile. At least two other studies with children who have a chronically ill brother or sister reported that the well children expressed a wish to help and to support their parents in caring for their ill sibling (Chesler et al., 1991; Pit-Ten & Loots, 2000).

Decreased Parental Attention

The decrease in attention and being forgotten were threats for some of the adolescents. However, this decrease in attention was mostly felt when they were younger. Michelle explained, "for me just dealing with all the attention she did get when she was younger, and my parents having to spend a lot of time with her. And, then I would have to go to baby-sitters or to a friend's house after school when they wanted to be with her." Ayla also remembered her brother being hospitalized and receiving presents. She remembered her Aunt bringing her a present and spending time with her. She no longer felt forgotten and she would encourage families with a chronically ill child not to "forget about that other kid. Don't. Even if they seem to be doing fine, you don't want to let it overcome that other child."

Although the adolescents viewed this decrease in attention as a threat at a younger age, by the time of the interview, the majority of the adolescents did not feel that they should

be getting more attention. Five of the eight adolescents who participated in the card sort exercise placed the statement "I feel that I should be getting more attention than I'm getting right now" in the "Never like me" pile and two in the "Sometimes like me" pile. The two adolescent who placed the statement in the "Sometimes like me" pile referred to how they felt when they were younger or to differential parental treatment. Arliss said that he placed the statement in the "Always like me pile" because he was "suffering middle child syndrome."

Differential Parental Treatment

Two of the ten adolescents felt that their sibling was receiving special treatment. Pamela explained, "my Mom always buys fatty foods for [my sister]; she'll have like bread and fatty milk and chocolate bars and stuff like that. And I go. 'How come we don't get any chocolate bars?'...And sometimes I get mad." Gabrielle also felt that her brother had received special treatment. She felt that her brother was "favored more. He gets what he wants...he gets away with a lot more...Sometimes I feel that I'm getting no attention." Derouin and Jessee (1996) concluded that 60% of the 15 siblings of children with CF or asthma were jealous of the special treatment that their siblings were receiving, a larger proportion than found in the current study.

However, at the time of the current interviews, the majority of the adolescents did not feel that they were being treated differently; they recognized that their siblings needed different treatment because of their illness. Four of the eight adolescents who participated in the card sort exercise placed the statement "My parents treat my sister/brother differently because she's/he's got CF" in the "Always like me" pile, three in the "Sometimes like me"

pile, and only one adolescent placed it in the "Never like me" pile, stating that his "parents treat [them] equally...but they will direct their attention to [his sister] because she has CF." When he was younger, Arliss felt jealous of the extra attention his brother received from his parents, but with time, he "respected the attention [his brother] got because [he] knew that his Mom and Dad loved [him] for what [he] did and they loved [his brother] for what he did. I no longer worried about it." Other adolescents also recognized the need for the extra attention. Dave explained, "They give him, of course, a lot more attention. It's good that they do. He sometimes does need more attention and more help." In a study by Menke (1987), 71% of the 72 children ages six to twelve who had siblings with a variety of chronic illnesses stated that their parents gave more attention to the ill child; however, the majority (59%) said it did not bother them. Davies (1993) concluded that children, ages two to sixteen, with a sibling affected with CF received the same amount of attention as children in families with only well siblings. Thus, studies have shown that although siblings of children with chronic illnesses perceive differential parental treatment, their responses may vary. By the time children are in their late elementary years, they have developed principles of benevolence, recognizing that certain individuals deserve more than an equal share of resources because of their condition (Santrock, 2000). Many adolescents in this study and others may have adopted this principle when interpreting the extra attention given to their siblings.

Concerns About the Illness

The adolescents voiced concern about the prognosis of the illness, concern about the differences the illness imposed on the ill child and their parents as well as concern about their own future.

Illness Prognosis

The prognosis of the illness and the fear of death were major concerns for many of the adolescents. Arliss explained how "a lot of people can look forward to having their brothers and sisters for really long life spans. Whereas it's sort of planted in our mind at a young age that have fun now because your brother might not be there." According to Dave, "a lot of people that have CF die at 20, 19" which has him scared; he is glad because his brother is slightly older and he "hasn't lost him yet as a brother (emotional)." Many adolescents found it difficult to hear their sibling cough. "Just make her stop right now" wished Serge because "it's really hard to hear her cough." In a study by Gardner (1998), children with chronically ill siblings said that seeing their sibling in pain and being aware of their sibling's potential death were important stressors related to the illness.

Concerns for Ill Sibling

According to Admi (1996), children with CF must adhere to a difficult and time-consuming regimen. The adolescents in this study were aware of the many challenges the illness placed on their siblings and as a result, they were concerned. Pamela explained that her sister had to do physiotherapy "two times a day, sometimes three and two nebulizers...and she has to take her enzymes everyday. She has an Epi-pen because she's allergic to nuts. So, she has to carry a medicine bag around." Serge took eight pictures of his sister receiving CF treatment or medication. He explained that he wanted to show me the "things that [his sister] does throughout the day with her CF...taking medication, her lung physio...her diet to keep her weight up...things that she has to do to keep her healthy." Arliss explained how adhering to treatment had become important to his brother:

> He realized that, okay, if he doesn't do this then there's going to be consequences. Like, he had a friend that he went to CF camp with, who went and lived with his brother for a summer, and didn't do physio and didn't do Ventolin and died at the end of the summer. They got along pretty well at CF camp and so that really shocked him. That really scared him into doing, you know, being serious about his medication and being serious about staying healthy.

The adolescents also recognized how stressful the visits to the CF clinic and at the hospital must have been for their siblings. Gabrielle explained that her brother had to go to the CF clinic "all the time," which was usually a "very stressful" experience for him because "it's often related to blood work." According to Romeo, when his sister was hospitalized, "it must of sucked for her. Having to put up with all those things in her and then all those constant annoying beeps, and the smells, and the food's gross...being away from home must have been the worst for her."

They also recognized the suffering their siblings had to endure because of their illness. For example, two adolescents described their sisters' pain when health care professionals were attempting to start an intravenous line. Serge stated, "My sister was asking for my Dad when they poked her about nine or ten times. We were at home when it happened. They kept on poking her, and she was crying."

The adolescents also noted the restrictions the illness imposed on their siblings. Romeo explained that "sometimes [his sister] can't last at playing sports. She can't last as long as [me] because she'll get short of breath." Robbie stated that his brother "says it's [treatment] bad for him because his friends don't have to do it, and he says whenever he wants to play, he has to do it, and then he gets mad." Another adolescent described how his

brother was unable to participate in work around the farm because of his condition: "He couldn't go anywhere where there was dust because he was really bad, allergic to dust. He never really did much of the work. Once he wanted to do some tractor work, but he found that just doing the day's work it really hurt him." Dave

The struggle between dependence and independence was also mentioned by two of the adolescents. They felt that because of the illness, the adolescents had extra threats to face in order to reach independence. Ayla did not feel that her twenty-year-old brother would be "leaving [home] for a very long time" because his mother had been taking care of him, had "taken such caution" with him, "babied" him and had so much "influence" on him compared to her. "My mom does absolutely everything for him" explains Ayla, "from breakfast to cleaning up after him, she does his laundry to just everything. He gets an allowance. He doesn't have a job. Like it's bad, it's bad." Following an exacerbation, Arliss felt that his brother, who was leaving for College, had "realized that he's got to be independent about stuff like [exacerbations]. He doesn't have Mom and Dad watching over him." Romeo felt that his sister was "more dependent on [him]." He explained, "if my mother goes away, I have to do [physiotherapy]...She's dependent on me to do it, to make her healthier." According to Romeo, when his sister leaves home, she will have to find someone else to take care of her.

As a result of recognizing the many illness differences their siblings were experiencing, the adolescents worried about them. Seven of the eight adolescents placed the statement "I worry about my sister/brother" in the "Sometimes like me" pile, and one placed it in the "Always like me" pile. Michelle explained, "When she spends all night coughing. Her room is above mine, and I can hear that, and it's hard. I just listen to her cough and

know that it's one o'clock in the morning and she has to get up at five to have her meds and stuff...and is [her sister's cough] going to get any worse, or is it just a cold, or is it a really bad infection?"

The influence of the illness on their sibling's future was also a concern for the adolescents. "I worry that she won't be able to get married and have kids," stated Michelle. Other adolescents also worried about "what's going to happen to [their brother]"$_{\text{Dave}}$ or how "he will be when [he] grows old." $_{\text{Gabrielle}}$ Serge explained, "A lot of times I hear things like the average age is up to 30 and that scares me sometimes. I get concerned that it could happen to her." Gabrielle felt that her relationship with her brother would be different if he did not have CF because she "wouldn't have to worry about him getting sick. With somebody that didn't have CF, I wouldn't worry that much...but with CF, if he got sick and died or something." Several other researchers have found that children and adolescents who have a chronically ill sibling will worry about that child's health and future (Bluebond-Langner, 1996; Chesler et al., 1991; Damiani, 1999; Derouin & Jessee, 1996; Gallo, Breitmayer, Knafl, & Zoeller, 1991; Menke, 1987; Pit-Ten Cate & Loots, 2000).

Concerns for Parents

The adolescents were concerned about their parents because they were aware that the illness had been "lots of work" $_{\text{Michelle}}$ for their parents. The adolescents described their parents' involvement in everyday treatment of the illness: "Dad used to always get up. He'd knock on [my brother's] door, and he would already have everything set up. Dad would go and do [the physio] when my brother would sleep, and when the alarm would go off, it'd be time to flip over then Dad would do the other side." $_{\text{Dave}}$ Serge's pictures included those of his parents helping his sister with her treatment. The adolescents also acknowledged their

parents' vigilance in the treatment process: "My Mom's always constantly making sure she takes it [her medication]" Krys, and "My Mom would have to be like, you can't go outside because of the pollen." Romeo

Although Michelle recognized that the administration of home intravenous antibiotics helped maintain a "normal" family life, she also recognized the inconveniences that it had imposed on her family, especially on her parents. Michelle explained that "it's [home IV] a little bit more stressful when she's on it but it's because it's a lot of work." She described her parents' routine for home intravenous administration:

> We just get the bags, and my parents run it through every eight hours. So that way she doesn't have to spend two weeks in the hospital. And, then, if she gets really sick, then they'll either bump it [antibiotic dose] up or kind of move it around or give her an extra treatment. I mean, my Dad made an IV pole so we have that out, and my Mom sets out a TV tray and stuff with everything on it, and we've got like a sharp's container and alcohol swabs and all that stuff... and different needles and her medicines in the fridge and the little IV bags, so yeah, it looks kind of funny.

However, she did recognize that "even though it's inconvenient, it's way better than her being in the hospital. I mean she can still go to school, she can still go out and play, she can still have friends over."

According to the adolescents, their parents also spent a lot of time educating others about the illness, fundraising and advocating for their sibling's illness. Dave spoke about when his mother came to their school after receiving a donation from them for CF, and she gave "a demonstration showing the kids what it's [CF] like and that he has it." Another adolescent described her mother's involvement in fundraising as well as in the CF

Foundation. Arliss recalled how his mother became a strong advocate for his brother. He explained how "Mom was really strong when it came to doctors. If doctors tried to tell her what to do, she relied on the specialist. So, if anyone went against Dr. [specialist], like don't try to do it to my Mom (laughs). Like, she'd go nuts. Like, don't mess with my kid."

The adolescents also talked about the extra "planning" Michelle that was required especially during outings. Romeo explained, "When we go on a trip, there's a whole hell of a lot more stuff that goes along. Like, the therapy board, the respirator, yeah, and then you have to get all the drugs and stuff like that. And, then when you go to a hotel, we have to get a fridge." Ayla also remembered, "when we would stay in hotels, my Mom would have to warn the people because they'd do pounding [physiotherapy], and sometimes we'd get complaints."

Hospitalization was an especially difficult time for the families. It brought concern and uncertainty as well as a need for reorganization and flexibility. Serge explained how "the hospitalizations are very scary, and you don't always know what was going to happen." "Dad stayed with him for about a week" stated Arliss, "...and then he had to come home and work...Mom would go in every day, so she had to change her schedule around to be with him." The flexibility that was required during hospitalization was also needed on a day-to-day basis. An adolescent explained that because his sibling had been "two weeks in hospital and missed a lot of stuff" his mother "home schooled him for a year."

During the card sort exercise, one adolescent placed the statement "I worry about my parents" in the "Always like me" pile, and four adolescents in the "Sometimes like me" pile. Michele explained, "I know my mom gets worried...I can see the way [her mother] acts and in her mood. I just get nervous." Arliss also felt that "it always affected [him] when Mom

and Dad were really worried about it because then [he] knew it was serious..." In a study by Derouin and Jessee (1996), 13 of the 15 (89%) children who participated in the study perceived their parents to be very worried. Dave reported that he worried about his parents when "they freaked out about [exacerbations]...how they take it, how they're feeling, how they're taking the pressure." Serge stated that he worried about his parents and the "stress levels" that his sister's hospitalization caused because "being worried and thinking your daughter's in the hospital and that's got to be really stressful." In her study with children who had a sibling with CF, Bluebond-Langner (1996) found that siblings were concerned about their parents. Other researchers have also found that children experience concerns for their parents when one of their siblings has a chronic illness (Chesler et al., 1991).

Concerns About Own Future

Only one of the older adolescents spoke of the concerns he had about his own future. Arliss explained,

> I also worry about growing up as a parent, what kind of parent will I become if I have a kid with CF because I haven't been tested to see if I'm a carrier, but what if? There's still a possibility, so I wonder what kind of decisions am I making right now that if I have a kid with CF will I be able to handle it...It scares me because what if my wife is positive too. Does that mean that we're not going to have kids...I don't want to say that I can't handle having a kid with CF because I know what it's like having a brother with CF, and it's not as bad as it looks. But, it's not easy; it's no picnic.

Fanos (1996) also found that during late adolescence and early adulthood, carrier concerns were voiced by the participants in her study with knowledge of the statistical chances of having affected offspring and reasonable decisions as to childbearing were being made.

Negative Feelings

A few adolescents in this study said that they experienced negative feelings towards their sibling's illness. Pamela explained, "Well, sometimes it makes me like a little mad because she always gets like more special treatment." Having to do physiotherapy on their siblings when they had already made plans or the extra attention their siblings were receiving from their parents was at times "annoying" Pamela, Ayla, "irritating" Romeo or "upsetting" Gabrielle for some adolescents. Other studies have reported that when siblings are expected to assume care-giving responsibilities for a chronically ill sibling, they may feel angry and resentful (Foster et al., 2001; Orsillo, McCaffery, & Fisher, 1993; Williams et al., 1997).

A few of the adolescents also felt "sorry" Romeo, Robbie for their ill sibling. Pamela stated, "Why did it have to happen to her? Why couldn't it be somebody else in somebody else's family?" In a study by Gallo, Breitmayer, Knafl, and Zoeller (1991), six of the 27 (20%) children who had a chronically ill siblings said they were sorry or sad that the child was ill.

Ways of Living with Differences, Concerns and Negative Feelings

The adolescents voiced the need for strategies to help them live with the differences, concerns and negative feelings of having a sibling who has CF. The adolescents relied on the help and actions of their parents, their ill siblings and others and noted gaps in the help they received. They used personal strategies such as hope, getting involved, re-interpreting the illness situation and managing emotions to facilitate living with the differences, the concerns and the negative feelings.

Help from Parents

Parents' use of normalizing efforts such as integrating the illness in everyday life, taking time to acknowledge the well child and being supportive, all helped the adolescents live with the differences imposed by the illness. Pamela noted that her parents' ability to do home intravenous "helps." Michelle remembered how her parents attempted to celebrate her sister's second birthday in the hospital; "All of our family and friends and stuff came, and we had a little picnic out on the patio at the back of the hospital...even though she was still in the hospital, we still had that normal birthday party, trying not to let it [hospitalization] interfere too much." Parents planned family holidays around their ill child's clinic appointments so that the other children would not be left behind.

When the ill child needed more attention, due to hospitalizations for example, a few adolescents felt it was important that they were not forgotten. Michelle explained how "every time [her sister] would have to be in [hospital], my parents would get me like a new doll or something just to say like, You know, we're not forgetting about you and that's usually what it meant to me. When she would go in the hospital like, 'Oh, I get a new toy!' or something. So, like I said, it didn't really bother me all too much."

Being supported by their parents was also important for some adolescents. Gabrielle explained that her mother helped her the most "...by telling me stuff and encouraging me." One parent would even pay her son to do physiotherapy on his sister. Many researchers have found that supportive and committed family contributes to a lower level of stress and to psychological adjustment (Compas, 1987; Seiffge-Krenke, 1995; Holahan et al., 1995). Arliss explained how his parents "flexibility" was a key element in his family's, as well as

his own ability to manage the differences imposed by the illness. According to Rolland (1993), flexibility is the key variable in optimal family functioning.

Sibling Efforts

Five of the ten adolescents clearly stated that their sibling's efforts to remain healthy, independent and to have a positive outlook on life had helped them with the differences imposed on their lives by the illness. That is, they worried less about their siblings because of these efforts. Serge explained that when his sister is in the hospital, "she's always in high spirits so we always talk, spending time with her talking. She's never saying, "poor me, I'm sick"...She's always in good spirits and telling me that everything will be OK." These sibling efforts are ways to minimize the impact of the illness on the family, which facilitated the adolescents' ability to live alongside illness differences.

Help from Others

The adolescents acknowledged that knowing that other people shared similar experiences was helpful. Two adolescents mentioned the positive experience they had when they talked to other people who had CF. Having experienced CF activities, Michelle concluded that "it's always good if people who are having common experiences can get together and talk about it and share their different things. I think that's always helpful no matter what situation you're in."

A few adolescents said that hearing other people's success stories and their belief in a cure were helpful. Ayla was not worried about her brother's illness because "I've heard all my life from [different people] that they're going to find a cure...I'm convinced that they're going to find a cure. I'm not worried about anything else." Arliss and his brother had met a

40-year-old cyclist who had CF at a fundraising activity, and noticed that this person was in "really good shape. There are people out here who have made it...So that really helped me."

A few adolescents also mentioned help from extended family. Serge explained that his extended family was "also major involved with [my sister's] CF and her care...my cousin, my aunt and my uncle, and my grandparents are huge. Just as big as parents when it comes to [my sister's] care. They can do everything...helping with meds...getting everything ready or sometimes they'll do her physio." Arliss appreciated the professional medical advice his family received from a family member who was a health care professional.

The adolescents also appreciated non-family support. For example, "knowing that a lot of people are praying for her to get better," Serge knowing "that people actually care," Gabrielle receiving money from a women who has lost her child to CF "to pay for his medicine," Dave and being able to talk to someone who has "gone through a lot of similar things" Arliss. These findings are congruent with those of Murray (1998; 2000a; 2001a; 2002) who described the benefits of emotional and instrumental support from extended family members and the community for children and adolescents who have a chronically ill sibling.

Gaps in External Help

As mentioned in chapter four, the majority of the adolescents placed the statement "I don't talk to my parents about the illness or my feelings" in the "Always like me" pile or the "Sometimes like me" pile (7/8). Although one reason for not talking to their parents about the illness was that they often did not think of talking about the illness because it was invisible, some adolescents opted not to talk to their parents because they felt their parents "can only tell me so much," "[the father] doesn't care" Gabrielle or "my parents worry a lot."

Dave Other authors found that children and adolescents chose not to talk to their parents about the illness because they did not want to impose their worries on their parents (Bluebond-Langner, 1996; Hefferman & Zanelli, 1997). The findings of the present study also support Gardner's (1998) findings. The adolescents in her study claimed that poor parental response to their needs and questions increased the impact of their sibling's illness.

Although some of the adolescents talked to their friends about what it was like to have a sibling with CF, they did not feel that their friends understood. Arliss explained that he could not turn to his friends because

> when he [brother] was having the problems just last month, I was sort of saying to my friends "I just got off the phone with my Mom. My brother's really sick." And, they were like, "Oh well, that's a real bummer" and it's sort of weird looking at these people and they're sort of, I don't know, it's flabbergasting that I can sit here and talk about my brother's probably going to die within the next couple of years, and I can't deal with it so I'm not going to get emotional about it, but they can't imagine it. Like, "Oh well, that's a bummer," whereas I'm like, "Okay, you really don't care do you? I have to sit here and listen to your girlfriend problems, but here my brother's really sick" And...it's strange.

Gabrielle also felt that "some of [her friends] are just really self-centered, and they don't want to hear about it...they just don't understand, like they'll say don't worry about it. It just makes me frustrated." These findings are similar to those I found in my earlier work with adolescents (Larocque, 1993). Although the adolescents used "Investing in close friends" as a coping strategy to deal with the demands of their sibling's CF, they found this strategy rarely to moderately helpful.

During the card sort exercise, four of the adolescents placed the statement "I think health care professionals should care more about how I'm feeling" in the "Never like me" pile. Three of the four adolescents did not think it was the health care professionals' responsibility to care about them because they had not cared for them in the past. The only thing they recalled from their visits at the CF clinic was receiving cookies and chocolate milk as they waited for their siblings. If adolescents do not perceive health care professionals as potentially helpful, it is not surprising that in this study and in my earlier work (Larocque, 1993), adolescents did not seek professional help when experiencing differences, concerns and negative feelings.

Although Gardner (1998) found "support seeking" to be a strategy that emerged from her conversations with adolescents who had chronically ill siblings, it is not clear from whom the adolescents were seeking support. In my earlier study, adolescents felt that seeking professional help would be one of the least helpful coping strategies (Larocque, 1993). A few adolescents in this study said they felt ignored by the health care professionals. When explaining why he had placed the card statement "I think health care professionals should care more about how I'm feeling" in the "Always like me" pile, Arliss said that "[this interview] is the first I've ever heard of health care professionals dealing with the siblings. I've never heard of that happening before. We were just sort of brushed out of the clinic and told to wait in the waiting room." Arliss believed in the importance of including siblings in the visits because health care professionals should realize that "Okay this is their problem. It's not just the kid with CF, it's also the sibling's problem too. Like they're eventually going to have to deal with it. And, the more they know about it, the more they can help out." As a result of these gaps in external help, many adolescents attempted to use personal ways

to live alongside the differences, concerns and negative feelings imposed by their sibling's illness.

Personal Ways

Hoping

The majority of the adolescents in this study chose to be hopeful; they believed that their sibling would get better or that someday they would find a cure for CF. According to the adolescents, seeing their sibling get better with medication and after hospitalizations gave them reason for hope. Romeo explained, "I just know that she's always on drugs that make her better, so I have a feeling that there is going to be drugs that make her better and better, and there is probably going to be a drug soon or in a while that will cure it. I have the hope." Survivors of CF had also given the adolescents a reason for hope "because there are a lot of people with CF that are alive," Ayla and "able to do stuff like people who don't have CF." Gabrielle For this reason, the majority (6/8) of the adolescents placed the statement "I want to hear how other people with CF are doing" in the "Always like me" pile.

Advancements in CF treatment, such as stem cell transplants, had one of the adolescents hoping that his "brother could have his life saved." According to Jevne and Miller (1999), hope is "essential to the quality of our life – as essential as breath to our physical existence...With hope we can find meaning in how we respond to what has happened to us" (p. 11). Having hope permitted some adolescents not to worry about their siblings. Ayla explained, "I've already convinced myself about a cure so that's maybe why I'm not so worried about it."

Getting Involved

The adolescents stayed involved by participating in their sibling's care, watching over their sibling and making altruistic gestures. Although Serge knew that he could not "really go into her body and make it go away and fix everything," he participated in his sister's care because "it is the most I can do to make her feel better...to do my part." "Well [being involved in his brother's care] helped me" explained Robbie. Likewise, it made Pamela feel "important." Michelle said "it's nice that I can, that I am able to do it [help with the care] or I can help out and that my parents will trust me with it [physiotherapy]." Congruent with previous findings (Larocque, 1993), these adolescents did not see the care-giving responsibility as a burden; they felt good about being able to help their siblings feel better. According to Meyer and Vadasy (1994), "the responsible attitudes that so many siblings seem to have are, in part, a result of successfully handling duties performed in service to their siblings and families" (p. 30).

Although watching over their sibling was perceived to be an undesirable difference for many adolescents, for others it made them feel helpful. For example, some adolescents asked people not to smoke around their sibling and encouraged their siblings to be involved in sports and wear warm clothing when outside because they "want the best" Arliss for their chronically ill sibling. In my previous study (Larocque, 1993), the adolescents also found it helpful to watch over their sibling.

Other adolescents made altruistic gestures or made decisions to help their siblings have a better life. These gestures or decisions made the adolescents feel good, which helped them live with the differences imposed by their sibling's illness. Pamela, like many other adolescents, volunteered "to help out with fundraising, selling raffle tickets, calendars and

present wrappings." For Pamela's birthday, "instead of giving gifts, [she] asked for money to be donated towards CF." Arliss spoke about how he made the decision not to smoke and not to "be around people who smoke just because I've got to keep my lungs healthy" if ever his brother needed a transplant. "I'd give up my lung," stated Arliss, "even if it means I'd never be able to run the Iron Man, but still, if it meant my brother could live two more months, yeah I'd do it, right away." Michelle also spoke of her decision to donate a lobe to her sister, "If it helps her then I'd rather have her here and me have a scar than her be dead and me be fine. I couldn't do that." Another adolescent spoke of how living with a chronically ill brother influenced her decision to become a health care professional and how happy she was with her decision. Other authors have noted that adolescents who have chronically ill siblings frequently choose a career in a helping profession (Dickens, 1991; Meyer & Vadasy, 1994).

Two studies with adolescents who had chronically ill siblings also found that the adolescents used similar ways to help them live with differences imposed by their siblings' illness (Gardner, 1998; Madan-Swain et al., 1993). In Eisenberg, Spinrad and Sadovsky's review (2006), empathy and sympathy have increased with age suggesting that, with development, children increasingly have the capacity for behavior that is sensitive to the welfare of others. If children or adolescents experience sympathetic concern, such as the concern for an ill sibling, then they are more likely to be motivated to behave in a prosocial and altruistic manner. Carlo, Hausmann, Christiansen, and Randall (2003) found that adolescents' ability to sympathize was strongly related to self-reported altruistic prosocial behaviors. The adolescents are aware that organ donation is common practice and while

neither family nor health care professionals may place expectations, the siblings themselves may take on a sense of obligation to donate. This is a field that needs to be explored.

Re-Interpreting the Illness Experience

The adolescents also chose to re-interpret the illness experience by thinking positively, by comparing their sibling's illness to worse cases and by finding advantages to being ill. An adolescent who described his relationship with his sister as difficult explained that "sometimes it's nice to have her in the hospital because actually she's away from you, out of the home. You don't have to put up with her." This same adolescent also noted that although he does not like to have to do his sister's physiotherapy, "every time I get to do therapy, I get to hit her. If she makes me mad, I'll just hit her harder. That's probably the best benefit that I can get out of it." Other adolescents admitted that when their sibling is hospitalized, they were allowed to miss school and to watch cable TV. Another adolescent did not mind doing extra work around the farm because "more work for me, more money." Dave

A few adolescents compared their sibling's illness to worse cases in order to manage the illness threats. Ayla felt that, to date, she had dealt very well with her brother's illness because her "experiences haven't been as hard as others." "It's not as bad as some other illnesses, or what other people have to live with," explained Serge. He added, "Even with CF, some people are even worse than my sister. Some kids are really bad.... who basically can't go to school because they need like 24-hour oxygen." Being ill themselves also helped some of the adolescents not to feel "as different," Michelle and to "know what it feels like" Dave to be ill. Serge explained, "Sometimes you don't feel as bad because she has everything [CF treatments], but you have something too [Ventolin treatment for asthma]."

A few adolescents reinterpreted what was happening in the family in an attempt to rationalize their experience, and to analyze the influence it may have on their own future. In particular, they reframed their parents' differential treatment to decrease or to eliminate negative feelings. Dave explained, "I grew up and kind of got wise I guess (laugh). I realized, hey, he does need more attention and more help sometimes because he's got a harder life than I do." Serge also recognized that "when she's [his sister] in the hospital, I understand that I will not get the same amount of attention as I do normally...I just think if I had two kids, and one of them was in the hospital, of course, I'd stay with him."

Reflecting on his future, Arliss realized the importance of his friendship with his brother who had CF, "If I don't do something about [my brother's] CF then I might not have a best friend if he dies later...where am I going to be then?" Pamela believed that having a chronically ill sibling had prepared her should she "ever had a kid who had CF." Serge ended his conversation with me by acknowledging that he has been "blessed to have a sister who has CF, it's such a rewarding experience to be able to see what it's like. I can't wait to see what's next." He encouraged people who have similar experiences to "live life to the fullest. Love every minute of it. Just make sure you take advantage of your life and the people in it. Spend a lot of time with your loved ones."

Re-interpretation of a stressful situation by adolescents has been observed by many authors (Lazarus & Launier, 1978; Patterson & McCubbin, 1987; Seiffge-Krenke, 1995; Smith & Carlson, 1997). In the literature this re-interpretation is often referred to as "appraisal-focused coping" and is directed at redefining demands to make them more manageable. Other researchers found that adolescents chose cognitive re-appraisal and

logical analysis as a strategy to manage the challenges of their sibling's illness (Gardner, 1998; Madan-Swain, Sexson, Brown, & Ragab, 1993; Pit-Ten Cate, & Loots, 2000).

Dealing with Negative Emotions

Ways for dealing with negative emotions included spending time with the ill child, giving explanations or talking about the illness as well as not always thinking about the illness. These have been referred to as emotion-focused coping strategies and are commonly used by adolescents in order to manage the tension which is felt as a result of experiencing demands (Patterson & McCubbin, 1987; Seiffge-Krenke, 1995; Smith & Carlson, 1997).

As in my previous study, adolescents said that they felt better when they were able to "Spend as much time as I can with my [the ill sibling]." Pamela Although the majority of the adolescents did not often speak about their experience of having a chronically ill sibling, when they did talk about the illness or their feelings, they felt better. Other researchers have found that emotional discharge was helpful for adolescents in dealing with their sibling's illness (Gardner, 1998; Madan-Swain, Sexson, Brown, & Ragab, 1993; Pit-Ten Cate, & Loots, 2000). Serge had conversations with his sister about her illness and thought it was also beneficial for her "to have somebody to talk to because she doesn't share that information with a lot of people." Talking about the illness with others also made some adolescents feel that they themselves acquired a better "understanding about it," Serge and made other people more aware of its existence. Again, this finding was congruent with my previous study (1993).

The adolescents tried not to think about their sibling's illness. "The [sibling's illness] can't be everything that you're always thinking about," explained Michelle, "because otherwise you'll just get weighed down." Michelle was the only adolescent who admitted

that she always tried not to think about her sister's illness. Three other adolescents placed the statement "I try not to think about my sister's/brother's illness" in the "Sometimes like me pile." Ayla explained her choice,

> I don't want to think about it all the time. I don't want to let myself get down...I don't try to block the thought of his death out, but I don't try to let it overcome anything else because when I look at him, I don't want to say, "Oh I have to appreciate you because you're going to die...If he dies, I am going to have more than enough time to be sad about it. I'd like to just enjoy whatever's left.

Gabrielle stated when she placed the statement "I try not to think about my brother's illness" in the "Sometimes like me" pile, "Yeah sometimes I try not to think about it, like if I'm having fun."

Were the adolescents who were trying not to think about their sibling's illness actually trying to avoid the situation? In her study with adolescents who had a chronically ill sibling, Gardner (1998) found that adolescents used avoidance, such as blocking and denial, to manage the challenges of their sibling's illness. According to Ebeta and Moos (1991), a danger with avoidance coping is that it may prevent or interfere with appropriate action. The four adolescents who placed the statement "I try not to think about my brother's/sister's illness in the "Always like me pile" or "Sometimes like me" did so not because they were attempting to avoid the situation; they recognized the differences imposed by the illness but explained that they wanted to continue with their lives.

According to Knafl and Deatrick (1986), family members who normalize their situation acknowledge the child's impairment, whereas family members who engage in denial maintain the belief that the impairment does not exist. In the present study, four of the

adolescents placed the statement "I don't think my sister's illness is that big of a thing" in the "Never like me" pile. The four other adolescents who placed the same statement in the "Sometimes like me" pile explained that they recognized the seriousness of the illness but, 1) "you can't always notice it," Romeo 2) "it's not consuming," Michelle 3) "I don't really think about it that much," Dave and 4) "it's perhaps not as bad as other illnesses." Arliss The adolescents recognized the existence of the illness but attempted to decentralize it, "I know it's [the illness] a big deal", stated Ayla, "but I don't want it to be the only thing that I think about."

The adolescents also benefited perhaps, in part, as a result of the many ways they chose to live alongside the differences, concerns and negative feelings. The benefits included: increased sensitivity/empathy, increased maturity/independence and increased sibling closeness. The adolescents also shared some of the perks of having a sibling who has CF that is, being included in special events.

Benefits

Increased Sensitivity/Empathy

A few adolescents said they were more sensitive or empathic towards other people with a chronic illness. Pamela explained, "...it does prepare you for people that have differences like an illness...you know what they are going through." Arliss was able to look beyond a young girl's illness when others discriminated against her. He explained, "There was one girl in our class who had muscular dystrophy...she walked funny, she didn't look like everyone else. She was a perfect candidate to be picked on. Whereas I'd sit back and I couldn't think of anything to pick on about. People are sort of like, 'How can you be friends with her?' I can look beyond whatever limitations people have." Other researchers who

studied children and adolescents with a chronically ill sibling also found increased empathy and sensitivity in these siblings (Hefferman & Zanelli, 1997; Kramer, 1984; Lardieri, Blacher, Swanson, 2000; Pit-Ten Cate & Loots, 2000).

Increased Maturity/Independence

Only a few adolescents felt they were more mature/independent then the average teen their age or their ill sibling. Although I did not actually ask the adolescents if they felt more mature as a result of having a chronically ill sibling, I observed an increased level of maturity when interviewing these adolescents compared to other adolescents with whom I had worked. "I'm more independent than I would say my sister is or even two of my friends," explained Michelle. Growing up, Michele would "go on sleep-overs and spend the weekend at my friend's house" at the age of eight when her sister was hospitalized. Her sister "did not start going for one night until she was probably thirteen." Ayla also considered herself "totally self independent. I'm leasing my own car, I go to school, I work every weekend, I've always had a job...I've always been able to take care of myself." She compared this to her brother who needed to be "babied and taken care of." Arliss felt that he could cope with almost anything in his life because of his experience of having a chronically ill brother, "I was raised with this kid with a disease so I know how to deal with it...there's really nothing that will scare me anymore." In Chesler, Allswede and Barbarin's (1991) study with 17 children who had a sibling with cancer, the children claimed that they had greater maturity and coping ability than their peers. Other researchers have also found increased maturity as a benefit of having a chronically ill sibling (Haverman & Eiser, 1994; Kramer, 1984; Murray, 1998).

Increased Sibling Closeness

Although the majority of the adolescents (5/8) did not feel that their relationship with their sibling who had CF had changed because of the illness, three adolescents noted changes. The changes they reported were related to the increased closeness the illness may have imposed on their sibling relationship. For example, Michelle felt that her involvement in the care of her sister "probably brings us a bit closer...I mean I'm there, and I'm like there to support her and stuff like while [starting intravenous treatment] is going on, and there's that trust there." Arliss admitted that, "[the anticipated death of his brother is] probably why [my brother] and I are such good friends." Minagawa (1997) also found that although relationships among diabetic children and their siblings are similar to those among healthy children, there was more sibling interaction when an illness was present. In a study with a variety of chronic illnesses, 26 of the 72 (36%) children who participated reported that they had changed since the onset of their sibling's illness because they helped out more and got along better with their siblings (Menke, 1987).

Inclusion in Special Events

According to the adolescents in this study, a perk of having a chronically ill brother or sister was being included in special events. Michelle showed many pictures of the different events in which she participated and noted "this [referring to picture] is from one of the CF Christmas parties, and I went to them all the time, and all the kids would get presents and stuff, and I would too. I didn't feel left out at all even though I wasn't one of the CF kids. I would always be included which was really nice." Ayla also had pictures of different events in which she participated because of her brother's illness. "This [picture], explained Ayla "is from '99. The Oiler's Golf Tournament or their Alumni. And, that's me, him

[brother] and Wayne. It was so much fun." Other adolescents described how their parents would plan a week's holiday around their sibling's visit to the CF clinic, and they would "go to the mall and the zoo type of thing." Arliss At least two other studies found that getting to go to special events and going on special holidays were perks of having a chronically ill sibling (Derouin & Jessee, 1996; Pit-Ten Cate & Loots, 2000).

In summary, the adolescents were able to recognize the differences, concerns and negative feelings imposed by their sibling's illness on their lives. However, the adolescents only spoke about these differences, concerns and feelings on their lives after being asked directly "What are some of the struggles/challenges you (and your family) have lived with because you have a brother/sister that has CF?" When asked "Tell me what it's like to live in your family," the adolescents spoke of normalcy, and illness was not central in their experience. They had de-emphasized the differences in an effort to normalize their experience of having a chronically ill sibling.

Transformation of My Horizon of Meaning

As an adolescent I was also able to identify the many illness differences, concerns, negative feelings as well as positive outcomes my brother's illnesses had on my life. I also used many ways to live alongside these differences. Despite my efforts, my family and I were unable to de-emphasize the differences due to the severity of the illnesses and the uncontrollable societal, medical and other circumstances. I was unable to do so, in part, because of the visibility of my brothers' illnesses, and also because our family accepted institutionalization as the only option and the accepted norm. I felt guilty for being healthy, for being unable to help them, and for leaving them at the institution every time we visited. Thus, I attempted to seek help from God and prayers in an attempt to manage my guilt. I am

now able to recognize that although as a child and an adolescent I felt that my prayers went unheard and perhaps my Catholic faith was intensifying my feelings of guilt, I was also gaining from my faith and continue to gain courage and strength to manage the differences imposed by the illness, which included the death of one of my brothers. Only one of the adolescents mentioned praying as a means of support. Was religion not important to the adolescents or was it not a dominant theme in their lives? Perhaps,...or maybe prayer and religion were not being considered by the adolescents during the interview due to the illness' trajectory. That is, none of the ill siblings were hospitalized or were experiencing illness exacerbation at the time of the interview. This could also explain why they did not mention experiencing guilt. Other reasons have been found in the literature that have explained guilty feelings in siblings. Guilt has been reported in research with children who have a sibling who has CF, but only when the illness has become visible due to exacerbations or death. For example, guilt was mentioned once by one of the participants in Bluebond-Langner's study (1996) because he felt he had transmitted pneumonia to his sibling who had CF. Two studies found that siblings of children with CF experienced guilt when faced with the death of their ill sibling (Dooley, 1973; Fanos, 1996).

Researchers have shown that some illness situations are so serious that normalization efforts such as decentralization may not be possible for family members (Clarke-Steffen, 1997; Cohen, 1993; Haase & Rostad, 1994; Hatton, Canam, Thorne & Huges, 1995). My inability to decentralize the threats also influenced the lens from which I was viewing the experience of having a chronically ill sibling. Thus, in questioning the adolescents, I expected the many illness challenges or differences, but what I had not expected was the adolescents' ability to decentralize the differences. Interpreting the adolescents' account

enabled me to recognize that in certain conditions, when normalization is possible, one is able to decentralize differences imposed by the illness.

CHAPTER SIX

NOT ALWAYS ON MY MIND

The majority (9/10) of the adolescents in this study admitted that they "don't think about [their sibling's] illness all the time." Romeo, Michelle, Serge Although "not thinking about their sibling's illness" was used by some adolescents as a way to live alongside the every day differences imposed by the illness, it was also described as a way of living with the illness. To help them make sense of the illness experience, the adolescents described how the illness would shift back and forth in their thoughts. This chapter describes this shifting of their thoughts between illness in the background and illness in the foreground, and concludes with a transformation of my horizon of meaning.

Not On My Mind: Illness in the Background

During the first interviews, the adolescents did not seem to be preoccupied by their sibling's illness. The "think cloud" exercise confirmed this interpretation. During the exercise, the adolescents were asked to write down the things about which they could not stop thinking. Although the adolescents were being interviewed about what it is like to live with a sibling who has CF, the majority (7/8) did not include their sibling's illness as something they could not stop thinking about. They wrote and spoke about the many preoccupations: school, friends, sports, family, careers, etc... (see Appendix L). The think cloud found in Appendix L is an example of a think cloud completed by one of the adolescents in this study. It exemplifies the think clouds that were completed by the seven other adolescents. The adolescents were preoccupied with typical developmental tasks and current life events.

Developmental Tasks

According to developmental theorists, many developmental tasks need to be accomplished for adolescents to mature into adulthood. These tasks include: 1) achieving new and more mature relations with peers of both sexes; 2) achieving economic independence; 3) selecting and preparing for occupation; and 4) desiring and achieving socially responsible behaviours (Collins, Gleason, & Sesma, 1997; Duvall & Miller, 1986). All of these development tasks were preoccupations for the adolescents.

Relations with Peers

Friendship was a common preoccupation for the adolescents in this study "because that's who I spend my time with and my spare time with." Michelle Serge wrote the name of his friend as one of things he cannot stop thinking about because "she's in my class and she's such a great person. She's one of my best friends." Arliss, on the other hand, was questioning his choice of friends and wrote "problems with my friends" as one of the things he cannot stop thinking about. In another exercise, I asked the adolescents to show me what it was like for them to live in their family. A few adolescents showed me pictures of their friends. Gabrielle explained, "just to show other things I do, and these people are my favorite friends."

Economic Independence

Older adolescents were preoccupied with economic independence. "Bills" were important to Michelle because "working my tail off and making whatever amount, like $7 an hour, isn't that great when you have car payments and insurance." "Summer employment" was one of the preoccupations Arliss listed. He explained, "I'm really looking to get a job and stay here because I don't want to move back home for the summer."

Selecting and Preparing For Occupation

The older adolescents were also preoccupied with their career choices. Arliss was questioning if he had made the right career choice, "What kind of money bracket am I going to be comfortable with?...Am I going to have a nervous breakdown when I turn 40 because I'm not happy with the decision I've made?" Other adolescents were concerned about succeeding in the educational path for their chosen career. Michelle chose "schooling" as a preoccupation because "there's always something that needs to be done and just kind of getting through it. And I'm closer to the end now, but just trying to get done and do well."

Socially Responsible Behaviours

One of the adolescents spoke at length about how he was preoccupied with his addiction to alcohol and how he was attempting to deal with his addiction because it was affecting many of his daily activities and decisions. This adolescent was attempting to achieve personally and socially acceptable behaviours. The previous examples demonstrate that the adolescents' preoccupations with friendship, career, finance and socially acceptable behaviours were all typical for their developmental stage.

Current Life Events

The adolescents were also preoccupied with current life events. Spring break or upcoming snowboarding trips were common preoccupations for the adolescents. According to Edelman and Mandle (2002), besides developmental changes during adolescence, other stresses may include competition, such as in sports, and in school achievement. Thus, it is not surprising that the adolescents had similar things on their mind. For example, Romeo had soccer practice on his mind because "I have soccer at 7:30 tonight and so I have to remember that, I have to run and stuff like that and I don't feel like running today." "The Oilers making playoffs is another

[preoccupation]," explained Serge "because it's my favorite team." Upcoming school projects and exams were also a common preoccupation. Ayla explained, "Exams. Well, because they're right away. Because they're the most immediate things I have to worry about. I've been studying every day so of course they're on my mind, and I dream about them, and it's annoying."

When I asked the adolescents why their sibling's illness was not on their minds, they all responded in a similar fashion, "I actually do worry about him but not always." Robbie Arliss elaborated,

> [The illness has] never been a thing where I worry about it for months on end, you know. But when he was coughing up blood a couple of months ago, I was really scared of that. Because it was putting theory into practice, you know. Like, if something more serious would have happened with that [bleeding], life would have changed, as I know it right now.

Every one of the adolescents who participated in the think cloud exercise said that their sibling's illness was in the background of their thoughts and would become a preoccupation with illness exacerbations or external reminders.

Sometimes On My Mind: Illness in the Foreground

Only one of the adolescents wrote illness related statements as a preoccupation during the think cloud exercise. The following statements were included among his preoccupations, "I just hope that [my brother] gets good health and grows up later to have a family," and "I am looking forward to getting to see [my brother] again and take him to supper so he doesn't eat cafeteria food." Dave Dave explained that he would be visiting his brother, who he had not seen in months, thus he was thinking about him. As Dave elaborated, "He does have good health, but I hope it

stays that way and that he doesn't have any problem because...a few weeks ago, he was having chest pains." The other adolescents, when asked if the illness was ever on their minds, also identified illness complications, coughing and hospitalizations as exacerbations that would prompt the illness into the foreground. The adolescents also identified external reminders which would prompt the illness in the foreground of their thoughts. They described their reactions to illness exacerbations and to external reminders and how they dealt with these reminders.

Illness Exacerbations

I wrote their "sibling's illness" on one of the post-it notes and asked each adolescent who had not identified their sibling's illness as a preoccupation if their sibling's illness was ever on their mind, and all the adolescents responded "yes." It became a preoccupation when their sibling was coughing, had illness complications, or was hospitalized.

Coughing

A few of the adolescents said that their sibling's illness was on their mind "especially when she starts her hacking and stuff." Serge Arliss also became really concerned

> ...when [his brother] started coughing up blood, when he had bronchitis, and he was just a kid then. I actually saw one of the towels soaked with blood. That was probably one of the only times that I was really scared of it...I was probably only in grade seven at the time so, not only was I dealing with junior high issues I was dealing with my brother coughing up blood.

Illness Complications

Gabrielle said that her brother's illness became a preoccupation "last year because there was like news coming when he went to the doctor's, something about his lungs, they were filling up with water or something (emotional)...He had to take all these medicines, and he wasn't

getting better, he was getting worse, and I was really scared." "It's tough," explained Serge, "At times you're getting bad news, cause she wasn't doing so well."

Hospitalizations

For some adolescents, hospitalization also brought their sibling's illness into the foreground. The illness was on Ayla's mind once "when he was in the hospital. His blood wasn't clotting and he was losing a lot of blood. I think he had polyps removed from his nose...I think that was the only time where I got really concerned about it." "Just when she has to go to the hospital," said Romeo who admitted thinking about his sister's illness during her hospitalizations because, "you just say, Oop, she's back in again."

External Reminders

Many external reminders prompted the sibling's illness into the foreground of the adolescents' thoughts. These external reminders included: 1) hearing about someone dying of CF, 2) unwanted responsibilities, 3) parental differential treatment, 3) smoking, 4) parental concerns and even 5) a cartoon.

Hearing about Someone Dying of CF

Many of the adolescents mentioned that they were preoccupied with their sibling's illness when they heard about someone else who had died from CF. "Then the guy died and he was 16 or something," explained Arliss, "...you do know that your brother's going to die, or whatever, but when will it happen...So yeah, it sort of does put it in your mind a little bit." According to Bluebond-Langner (1996), it is only when deterioration becomes more marked (for example, when the sibling becomes oxygen dependent) that well siblings will acknowledge that their own sibling will die from CF. The ill siblings in this study did not have marked deterioration; however, the adolescents did acknowledge that their own sibling could die in the near future.

Thus, the results of this study indicate that adolescents may be well aware of the severity and consequences of their sibling's illness even if there is no marked deterioration. According to Piaget (1969), adolescents develop the ability to think abstractly and are able to project to the future and see the potential, long-term consequences of actions and illnesses. This increased cognitive ability allows adolescents to have a greater understanding of their ill sibling's condition, treatment and prognosis (Murray, 2000b).

Unwanted Responsibilities and Parental Differential Treatment

Since he was responsible for doing his sister's physio that evening, Romeo put his sister's illness in the "middle [of the think cloud] for now. Well I didn't really think of it but then I thought I have to do her physio tonight because [my parents are] leaving to go for the weekend...and I hate getting up." Gabrielle explained that she gets preoccupied by her brother's "pills because if I don't remind him then I also get in trouble because I didn't remind him and he didn't take them. Or, because sometimes I tell him but he just doesn't take them." Differential parental treatment also became a preoccupation for Gabrielle. She explained, "Sometimes he gets favoured more because that's just the way it's going to be. He's got CF, and my parents try to give him what he wants...that really gets me mad."

Smoking

For some of the adolescents, their sibling's illness came in the foreground when they were smoking. Michelle admitted, "When I'm alone and smoking, then that comes up in my thoughts. Like I've got fairly healthy lungs, and here I am like doing this on purpose pretty much where [my sister] has no choice, and hers are wrecked. And, what if someday she may need a transplant, and I'm doing this to mine, so that's a big thing." Arliss was extremely upset when he caught his brother who had CF smoking. He explained, "I caught him smoking once

and flipped on him. Just flipped on him...here he is, a guy with a lung problem doing the worst thing he can."

Parental Concerns

Their sibling's illness became a preoccupation when they saw their parents worried or upset, "I worry about [my parents] worrying because then I knew it was serious," Arliss and "because when they're sad then I think something bad is happening." Gabrielle Robbie explained that he was often reminded by his mother to be nicer to his brother so, "sometimes like when I'm fighting with [my brother who has CF] it just comes into my mind, Oh, I should be more nice to him...because he might die, he doesn't have as long of a life span as us."

Cartoon

For Arliss, watching a cartoon "about this guy who's just out of college and his younger brother actually comes to move with him" caused him to think about his brother and his illness. He explained,

> I got sort of thinking that [my brother who has CF] life is limited. If he makes it to 30, I'll be absolutely amazed. Worst-case scenario, it might just happen that [my younger brother] and I will be the only ones left...Are we going to drift apart or are we going to get a closer relationship. And, watching these cartoons, it sort of helped me to deal with [my younger brother] and taking the time to talk to him...

When asked about how they felt or reacted to the illness when it was in the foreground of their thoughts, the adolescents experienced different emotions and a few struggled with school. They attempted to manage the demands of illness exacerbations and external reminders in various ways.

Reacting To the Illness in the Foreground

Different Emotions

When experiencing illness differences, adolescents spoke of feeling mad, annoyed, irritated and sorry. The emotions described by the adolescents when their sibling's illness came in the foreground of their thoughts were different. They were worried about their sibling's or their parents and experienced fear, guilt and anger. "I worry when she got sick and when things aren't going so well," admitted Michelle. "Is she going to be okay?" questioned Pamela. Arliss was also "really concerned about [his brother coughing up blood] because there was a time before, about four years ago, when he coughed up blood, and he had a really bad bronchitis. He had to spend two weeks in hospital so I was really concerned about that. I was really scared." Bluebond-Langner (1996) concluded that additional exacerbation brings a renewed sense of fear and concern about their sibling's well being.

Many of the adolescents admitted feeling scared and sad when experiencing illness exacerbations or external reminders. "It's a little scary because she coughs a lot," said Pamela. "I feel very scared and sad that his condition could get worse," voiced Gabrielle. Hearing about other people dying of CF was also "scary" Pamela, Dave for some adolescents. The adolescents said that they felt guilt and anger about their sibling and smoking issues; "guilt because look at him, he didn't choose [to have damaged lungs] and I'm sitting here, and I choose [to smoke] and I do it out of my own free will." The adolescents spoke of being angry and frustrated particularly in relation to unwanted responsibilities or perceived differential parental treatment.

Struggling With School

Two of the adolescents said that they struggled with school when they worried about illness exacerbations or external reminders. "My grades started to go because I wasn't trying

hard. I was just really scared about him dying or getting really sick," explained Gabrielle. When Serge's sister was in the hospital, Serge reported

> my marks dropped because I couldn't concentrate...It's hard not having my parents around, and at times, my grandma would pick me up from school and drive me to the hospital, and I had to do my homework in the car or at the hospital...It was hard to concentrate, and it's hard to get the homework done...your sister is sick, and it really drains you. I'd just think about my sister a lot. How is she doing? And, I couldn't really concentrate on my schoolwork.

Other researchers found that children and adolescents had difficulty concentrating on schoolwork when they were worried about their sibling's health, and as a result, their grades decreased (Williams, Lorenzo & Borja, 1993; Chesler et al., 1991; Gardner, 1998; Hefferman & Zanelli, 1997). Serge said that there were only two things on his mind during his sister's hospitalization, his sister and school.

Dealing with Exacerbations and External Reminders

When the adolescents had their sibling's illness on their mind, they worried, were concerned about their sibling's well being and experienced negative feelings. They attempted to deal with the illness exacerbations and external reminders using similar ways to those they used when living alongside the daily differences of their sibling's illness.

The adolescents were less involved in their sibling's care during illness exacerbations, perhaps because the level of care required was beyond their expertise which was out of their control. According to Rolland (1994), it is not uncommon for a family member to adhere to a different set of beliefs about control when dealing with illness exacerbations compared to other day-to-day problems. For example, with daily challenges, some adolescents participated in their

sibling's care, but this strategy was not mentioned when managing illness exacerbations. Only one of the adolescents mentioned trying to be involved during an illness exacerbation. "I tried to be a good son, to try to help out," explained Arliss. The adolescents re-interpreted the situation and lived with their emotions when faced with illness exacerbations and external reminders.

Remaining Hopeful and Planning One's Future

Many of the adolescents remained hopeful that their sibling would recover from the illness exacerbations. "There's always new treatments," explained Michelle, "she's on Toby right now which makes a HUGE difference, and you can see it in her. They're coming out with new things and they have found the gene already...There are just advancements so fast, and she is only 15 right now, so there's still hope." When Gabrielle's brother was in the hospital, and she was feeling really sad, she also "tries to think about the positive things...how a lot of new medicine is coming out, and there's people that are surviving CF and living longer..." "I basically pray that my sister will get better," explained Serge. According to Rolland (1994), a healthy dose of hope is useful for family members "while they are trying to become accustomed to the idea of living with an illness; it helps them through an inevitable period of trial and error in learning how best to cope with an ongoing condition without giving up" (p. 143).

External reminders had Arliss talking about and planning for his future. He explained that his parents "wrote in their will that we would go to live with relatives...and there was no way [Arliss] wanted to do that." He asked his parents to change their will as soon as he could become the legal guardian of the other children. According to Arliss, this would allow him to take care of his ill sibling and have a positive influence on his other sibling.

Living with Emotions

The adolescents were forced to live with different emotions. They attempted to live with the emotions on their own, or they talked to someone about their feelings, or tried not to think about the exacerbations or external reminders. When asked who has helped him the most to manage the illness exacerbations, Dave said that he helped himself by "taking walks by himself or with the dog." Another adolescent explained that when feeling angry, she went to her room, "I listen to music. I just clean my room." Gabrielle She even took a picture of her radio in order to show me that "whenever I get really mad or just frustrated, I go to my room, and I listen to music just to get away."

Serge recounted a time when his class assignment was to write a sad story. This occurred soon after his "sister had gone into the hospital for a lung infection" and it had been a "pretty emotional time." Serge decide to write a story about a young boy who gave his lung to save the life of another young boy who had CF.

Arliss admitted that he did not "express things, I just build it up...and get frustrated," and eventually, he "acts out" his frustration. For Arliss, and for many of the others, not wanting to worry their parents remained a deciding factor and they usually did not to talk to their parents about their feelings. As previously noted, other researchers have found that children and adolescents will not talk to their parents about their feelings because they know the pain their distress may cause their parents (Bluebond-Langner, 1996; Chesler et al., 1991).

Although "effective communication is absolutely vital to family mastery of illness" (Rolland, 1994), only a few of the adolescents spoke about their feelings to a family member or a friend. They were very selective when choosing a confidant. They sought people who had

experienced a similar situation, who were empathetic and caring. Serge explained, "A lot of my friends know my sister and just coming to school and telling them, they make me feel better."

None of the adolescents mentioned talking to a health care professional about their feelings. Serge described feeling ignored by the health care professionals when his sister was hospitalized, "I know sometimes I feel really down and just need somebody to talk to and sometimes they're giving explanations to my parents because they're there with her, and they don't even notice that I'm there. Just ask if I have any questions. So it seems like they forget we're there."

Three of the adolescents tried not "to think about it [exacerbations or external reminders]" Michelle, Arliss, Gabrielle. When I asked if their efforts helped to put thoughts of the illness in the background of their thoughts, they all agreed that it helped, especially with the external reminders, but the only thing that would put the illness in the background, or no longer on their mind, was when the exacerbation had subsided.

No Longer On My Mind: Returning to Background

The adolescents explained what happened when their sibling's illness was no longer on their minds. When their sibling's exacerbation subsided, "everything would be okay after a few weeks." Arliss "We found out that he was getting better" explained Gabrielle, "so I started trying to calm down but still it was there. It was hard, but I started doing things to get my grades back up. Face reality. It was a hard thing to do, and I'm sure I'll always have to deal with that, ups and downs."

Transformation of My Horizon of Meaning

When interviewing the adolescents and after reading the text, I recall having difficulty understanding why the majority of the adolescents (7/8) were not preoccupied with their

sibling's illness. They were aware of the severity of their sibling's illness but had chosen to talk about typical adolescent stressors. They did say that illness exacerbations or external reminders would return their sibling's illness to the foreground of their thoughts.

Why did I have such difficulty, at first, understanding the adolescents' experience? I expected the adolescents to describe their experience based on the differences imposed by their sibling's illness. I was not expecting the adolescents to describe their lives as normal and that their sibling's illness would not be a constant preoccupation. My own experience of having two chronically ill siblings, of being a paediatric nurse, as well as the literature on children who have a chronically ill sibling was making a claim on me. Although I was open to both positive and negative experiences, I had come into this study privileging the perspective that the sibling's illness would always be in the foreground of the adolescent's thoughts. However, the adolescents' stories helped me recognize that, in reality, my brothers' illness was not always on my mind. For example, during periods of institutionalization or when interacting with peers, I was able to have typical adolescent thoughts and concerns.

Although my prejudices or privileged perspective determined my vantage point, it did not shut me off from the horizon of the adolescents. I was able to recognize that in some instances, perhaps when the illness is invisible or stable, adolescents are able to have the illness in the background of their thoughts, thus allowing them to have typical adolescent thoughts or concerns and remain hopeful. They are able to hope for healthy siblings and even a cure for CF. The illness may be prompted in the foreground of the adolescents' thoughts by illness exacerbations and external reminders. As a result, the adolescents may become concerned and worried about their sibling's illness. Only when medical control of the illness exacerbations is achieved or

when adolescents succeeded in back-grounding the external reminders were adolescents able to once again have age-typical thoughts and concerns, and remain hopeful.

CHAPTER SEVEN

WANTING TO KNOW MORE

The adolescents in the present study described having "growing up knowledge" about their sibling's illness. However, as they got older, this type of knowledge was no longer sufficient. The majority of the adolescents wanted more information and attempted to access more. At times, their attempts were successful but more often not. This chapter presents the growing up knowledge the adolescents described having, their need to know more, their successful and unsuccessful attempts at accessing information and the types of information they were accessing. A transformation of my horizon of meaning concludes this chapter.

Growing Up Knowledge

The adolescents described how they learned about their sibling's illness by growing up with it. "I kind of grew up with it," stated Pamela. "It's been part of every day sort of thing... and from being around her all the time," is how Krys described getting to know about his sister's illness. A few of the adolescents did not remember being told about the illness. Romeo explained, "I don't think I was really told, I would see what would happen, and as I got older I just kinda got more detail about what was going on." An adolescent described how he did not "really know all that much about CF until [he] was an adolescent." Arliss Another adolescent admitted that he "didn't know that [his brother] had CF 'til later." "I grew up," he explained "and I started realizing okay, this is what CF is. That's why he coughs so much." Dave

The adolescents also described getting to know about the illness through observation. "I wasn't really sure," explained Pamela, "but I knew there was something. She'd always take those little pills, she couldn't swallow them because she was too small so she'd mix them in with her applesauce then she'd eat gum." Arliss also explained that his parents "never explained to us

what the medication was for. You just sit there and watching my brother and say 'Wow man, you pop a lot of pills." During hospitalizations, the adolescents said that they would learn about their sibling's illness by observing "the doctors" Dave and the "stuff going on." Michelle

A few adolescents acknowledged the information they received from their parents. For example, Serge explained that he learned about the illness "just growing up and my parents telling me that it's a lung disease, and I hear a lot of other things like about her treatments and why she needs to do that stuff." Pamela remembered that her mother was involved in the CF Foundation. Pamela explained that her mother "brought pamphlets home" that she could read. Other adolescents also recalled receiving information from their parents via brochures or explanations. The information they received from their parents or written material was, according to the adolescents, "simple" Michelle and dealt with the illness as a genetic illness, its effects on certain bodily organs, and the medication and treatment that were needed to help with the illness.

Bluebond-Langner's findings (1996) were similar. In order to contain the intrusion of the illness, "parents give well siblings only the most rudimentary information about the disease and their ill sibling's condition" (p. 218). She concluded that parents limit the information they give healthy siblings, especially when the child with CF is doing well, but as the well children are getting older, they are often ready for more information. Other studies have found that parents give incomplete or selective information to children who have a chronically ill sibling (Brett & Davies, 1988; Kruger, Shawver, & Jones,1980; Taylor, 1980). Parents' lack of information sharing with their well children may be due to 1) their need to maintain normalcy, 2) taking for granted that the siblings have enough information, 3) parental uncertainty about what information should be shared, 4) parental anxiety about talking about painful and distressing

events, and 5) parental need to protect their children (Bluebond-Langner, 1996; Craft, Cohen, Titler & DeHammer, 1993; Fanos, 1996; Kleiber, Montgomery, & Craft-Rosenberg, 1995; Stallard, Mastroyannopoulou, Lewis, & Lenton, 1997; Titler, Cohen, & Craft, 1991). In this study, one parent admitted that she did not want her adolescent to participate because she had not yet told him that his sibling had CF.

A study by Clarke-Steffen (1997) found that parents withheld information from siblings of chronically ill children because they did not feel adequately prepared to provide information or because they wanted to protect them from potentially frightening or harmful information. Furthermore, De Braekeleer et al. (2001) assessed parents' knowledge of CF and found that they were "lacking some important facts although they had received basic medical information from the staff at the CF clinic and pamphlets published by the Canadian Cystic Fibrosis Foundation" (p. 267). A few of the adolescents in this study did not feel that their parents had the knowledge to answer all their questions. Thus, five of the eight adolescents in this study were unsatisfied with the growing up knowledge they had acquired. They felt they did not have enough information and wanted to know more.

I Wish I Had More Information

Of the eight adolescents who participated in the card sort exercise, five placed the statement "I wish I had more information about my sister's illness" in the "Always like me" or the "Sometimes like me" pile. Arliss commented during the exercise, "I wish there was a conference where all the CF families could get together and have presentations on CF...because I'm sure that others [siblings] are not as knowledgeable as they should be, because I definitely know that I'm not as knowledgeable about it as I should be."

Six of the eight adolescents also placed the statement "I try to make sense of the things that happen because of my sister's illness" in the "Always like me" or "Sometimes like me" pile. Michelle, for example, said "I always ask questions or 'How did the doctor's visit go?' in order to understand what is happening with my sister's condition." Other studies have also identified the informational needs of well siblings. For example, in a study by Pit-Ten Cate and Loots (2000), siblings of children with a variety of chronic illnesses felt they needed help primarily in the form of information. One of the themes that emerged from a phenomenological study of the lived experience of children who have a sibling who has cancer was the need for emotional and informational support (Murray, 1998). In a study by Gardner (1998), a stressor identified by well siblings of children with a chronic illness was lack of knowledge about the illness. Lack of information, or insufficient parental communication with the well children about their sibling's condition and insufficient existing resources for providing siblings with informational, emotional, social and peer support was identified from the literature by Williams et al. (1997) as major etiological themes explaining well sibling adjustment problems.

Although the majority (5/8) of the adolescents in this study wanted to know more about their sibling's illness, others "never had the need to know more about [the illness]." Michelle Two of the three adolescents who did not wish to have more information about their sibling's illness explained "I know quite a bit about it," Michelle and "I think I've got whatever information I need and if I need anymore I can just go and get it. It's not like I have a problem having access to it really."Ayla Both of these adolescents had access to accurate information about CF via the Foundation or other medical literature. The other adolescent, although he admitted not being knowledgeable about the illness, did not want more information. He explained, "I just don't

really care about learning about it. I just know that she has it, and it sucks for her, but I don't really care to know what it's about." Romeo

For those who wanted to know more about the illness, their informational needs were similar, that is illness focused. One adolescent wanted to know "more on how to take care" Dave of his brother; others wanted to know more about the pathophysiology of the illness such as "how it affects the lungs," the etiology of signs and symptoms (e.g., "why he's coughing up a lung" Gabrielle), and how the medication and physiotherapy "works" Arliss on their sibling's body. A few adolescents were also curious about the ongoing research and new treatments. The adolescents felt that this type of information would either help them "understand it more," Serge "deal with it," Arliss or help them care for their sibling. For example, Robbie explained that he "just watched this show about this kid who had CF and what could happen to you if you didn't do your physio and Ventolin and stuff, and it helped me by reminding me to remind him to take his meds." Serge also felt that it would be helpful for him to "hear from other kids and their experiences with brothers and sisters with CF...and how other kids deal with the illness."

However, informational needs seemed to vary when it came to illness prognosis. Although the majority of the adolescents placed the statement "I want to hear how other people with CF are doing" in the "Always like me" pile (6/8), they specified which type of information they would feel comfortable receiving. Some of the adolescents wanted to know about those who were doing well as well as those who were not doing so well. Michelle explained, "It's always better, whether it's a good experience or a bad experience because you can always learn something...and have information so you can prepare, if anything is inevitably going to go wrong...to help you get through it if it ever came up on your family." Arliss felt that knowing

about "the bad, acts as a comparison" because it would allow him to compare his brother's health with the health of others before they died.

Other adolescents did not want to hear about the people who were not doing so well. Gabrielle had difficulty deciding which pile to place the statement, "I'm not too sure because sometimes I do, and sometimes I don't, unless you have something good then I want to hear about it. But, if it's something bad, then...(pause)...I don't want to hear about it." Hearing about the people with CF who were not doing so well or who had died "would be too scary" for Dave and Gabrielle. Robbie also described how, when his mother talked about the things that worry her about his brother's illness, sometimes he did not want to know "because if it's something bad, I get mad." Some of the adolescents were attempting to limit certain types of information (e.g. prognosis) in order to protect themselves from negative feelings.

Another reason for adolescents' reluctance to access certain types of information may be their fear of negative feelings. Amongst the motives for seeking information that have been identified in the literature, self-protection seemed to be guiding these adolescents' informational needs. The self-protective perspective posits that individuals are guided by a desire to promote, maintain, and defend a positive view of themselves and others thus to protect the selves from potentially aversive information (Brown, 1990; Sedikides, 1993; Taylor & Brown, 1988). People engaging in self-protection tend to ignore information with unfavorable consequences. A few adolescents in this present study were reluctant to hear about the people with CF who had died or who were not doing well. One adolescent did not want to hear about the complications of his brother's illness. Such decisions defend the self against distressing affect and are a way of coping with the threat of a negative experience (Chesser & Anderson, 1975; Ditto & Lopez, 1992; Leventhal & Diefenbach, 1991).

The adolescents' reluctance to ask for more information may also be due to their need to protect their parents (Bluebond-Langner, 1996) or perception that their parents or health care professional were not available. In a study with 52 siblings of children with life-threatening conditions, Stallard, Mastroyannopoulou, Lewis, and Lenton (1997) concluded that although the majority of well children want information about their ill sibling's condition, they feel unable to talk about this with their parents or anyone else.

Accessing Information

Many of the adolescents attempted to access information about their sibling's illness by reading pamphlets, watching documentaries, searching on the Internet, or asking their parents. When describing their experiences of accessing information, some of the adolescents felt they had been successful and others felt unsuccessful.

Arliss felt he attained a better understanding of his brother's illness as an adolescent because of the documentaries he watched. Michelle, Ayla and Serge felt they could easily access information about their sibling's illness by asking their parents for explanations or through the pamphlets their parents would bring home from the CF Foundation. During the card sort exercise, Serge placed the statement "I try to make sense of things that happen because of my sister's illness" in the "Never like me" pile because "if something happens with my sister, my parents or my sister tell me. I don't have to figure it out." Only one of the adolescents felt that a health care professional had helped him understand more about his sister's illness and treatment. The other adolescents did not remember receiving any sort of information from health care professionals during their visits at the CF clinic.

The adolescents did not consider the CF clinic and Foundation to be part of the family's formal network. I explored formal networks during the drawing of the ecomaps. Only one

adolescent mentioned the CF Foundation as being a strong connection that his mother had due to her involvement with the Foundation. Otherwise, no other adolescent mentioned any family member having a connection with the CF system (clinic or hospital). Only when I asked if the siblings had regular visits at the CF clinic did the adolescents consider adding this system to the ecomap, and they described the connection between the CF clinic and their sibling or a parent as being "very slightly connected" or "stressful." The reasons given by the adolescents for the stressful connection with the CF clinic and their siblings were that they hated having blood work and testing done, or that it reminded the sibling that they had the illness.

During my four-month observation of families at the CF clinic, I noticed that older well children rarely accompanied their parents and siblings to the clinic. I also noticed that when a well child did accompany his of her parents, they were rarely offered any information about the illness and were not encouraged to ask questions. Furthermore, the adolescents themselves did not inquire about their sibling's illness. At a young age the CF clinic had been appealing for many of the children because of the cookies and chocolate milk; by adolescence the majority did not feel the need to accompany their parents and siblings to the clinic. According to Arliss, "we weren't really encouraged to go into the doctor's appointment...you were made to feel that you didn't belong...so, as soon as I turned 13, I said the heck with it, and I walked up and down [the tourist avenue] during his appointments." When asked what he would have liked during the visits, he replied, "They're in a good position to give information, so they should. The parents can only give you so much information because they're going on emotions, a nurse or someone could be explaining the downside of it to the siblings or whatever." Serge said that "sometimes [his] parents don't really know what's going on...so, I need somebody like a nurse to sit me down and tell me what's going on...but they don't ever ask me questions." Health care

professionals may not be aware of the adolescents' growing need for information. Perhaps discussion of illness with well siblings was not an expectation in the past, thus "growing up knowledge" had been taken for granted.

Other adolescents tried to access information on the Internet and the CF newsletter but felt their efforts were unsuccessful. Gabrielle explained, "I tried going on the Internet but I couldn't really find anything." Arliss had read the CF newsletter that his parents received but commented "how much can you find out from that...I'd like to see in the newsletter more stuff about research and accomplishments they've made because it's mainly about fund raising. I don't really care about when it's going on." To understand the adolescents' lack of interest in the CF newsletter, I read issues dating from 1986 to 2005. Although the newsletters were very informative about a variety of subjects, the focus was on fundraising which may have a strong parental appeal, but little appeal to siblings. In a study on experiences and support needs of well siblings of children with cancer, older children and teenagers commented, as did the adolescent in this study, on the lack of suitable forms of information (Sloper, 2000).

A few of the adolescents in the present study had advice on how to meet their informational needs. Michelle felt that it would be helpful for parents or health care professionals to "sit down and tell them what it's about and what to expect. Like all the treatments and all the time that parents need to take care of the child." Arliss felt that there was "not all that much to help you deal with [your brother's illness] or to help you prepare for it." He recommended making the CF clinic more friendly by 1) having a waiting area for well siblings with "CF based stuff like cartoons that explains the illness and how to deal with it which could even be distributed to families, and children could keep it in their video collection so they can watch it more then once"; and 2) letting well siblings "watch the PFT (pulmonary function test)

[for example] and give them explanations." One adolescent suggested having workshops and conferences on new findings.

Transformation of my Horizon of Meaning

Similar to the adolescents in this study, I had growing up knowledge about my brothers' condition. The small amount of information I did have was from my parents. However, I do not recall asking or attempting to acquire more information about their condition. Perhaps, I felt I had received enough information from my parents, but most likely I did not feel comfortable or feared asking my parents questions in an attempt to protect them. No formal network for accessing information was available to us. I don't recall ever being offered information by health care professionals when we visited our brothers at the institution. I do, however, recall experiencing many different emotions, such as fear when Luc had grand mal seizures and anger when Paul would tear up the drawing I had just completed for my parents. In retrospect these feelings could have been alleviated if I had a better understanding of my brothers' conditions.

As I grew older and contemplated having a family of my own, the need to know more about the underlying genetic components of my brothers' illnesses became necessary because I feared for my own children's wellbeing. I read my brothers' medical files and researched their conditions. I recognized that although my motive for seeking information had remained the same, that is one of protection, it had shifted from wanting to protect my parents to wanting to protect myself and my future. Some adolescents wanted to know everything about their sibling's illness while others only wanted certain types of information. My own experiences and the experience of the adolescents have shown me the importance of motive when seeking information about our sibling's chronic illness.

CHAPTER EIGHT

SHIFTING HORIZONS

This work began with the question, what is it like for adolescents to live with a sibling who has Cystic Fibrosis? In responding to the question in a hermeneutic way, I have considered some of the adolescents' feelings, concerns and struggles; some of their joys, hopes and rewards; what they found helpful and unhelpful in dealing with the differences of their siblings' illness, how they thought their families were influenced by the illness and how family and contacts outside the family influenced the adolescents' interpretations. My interpretive account of what it is like for adolescents to live with a sibling who has CF was based on four significant meanings: 1) We are normal; 2) Acknowledging the condition; 3) Not always on my mind, and 4) Wanting to know more.

Hermeneutically, interpretation is never final or complete (Geanellos, 1998) because it may vary from interpreter to interpreter. This diversity exists, according to Geanellos (1998) because of differences in "1) the perspective from which the interpreter approaches the text, or how the text is questioned; and 2) the embodied linguistic, cultural, historic and sociopolitical pre-understandings each interpreter brings to the text or how the text is listened to" (p. 158). Thus, the conversation is never finished, the interpretation is never finished... but "keeps open the possibility and the responsibility of returning, for the very next instance might demand of us that we understand anew" (Jardine, 1992, p. 57). It is now time for me to stop "spinning out of implications of meaning" (Jardine, 1992, p. 52) and to ask the following questions: How has this interpretive account reframed my horizons? How can scholars and clinicians shift their horizons to meet the needs of adolescents who have a sibling who has CF? In this final chapter, I will explore my response to these questions.

Reframing Horizons

The social and historical context of living with a sibling who has CF is continuously evolving. Although, according to the adolescents' interpretive account, living with a sibling who has CF had been ultimately influenced by their family, the pervasive social expectations to normalize the illness experience combined with the historical context of medical advancement that prolongs the stability and invisibility of the illness had also enabled the adolescents to interpret their experience as normal. Thus, adolescents experienced typical adolescent life, while concurrently living with differences, concerns and negative feelings due to their siblings' illness. Although I spoke with adolescents over a short time span, I do not attempt to interpret the adolescents' ability and willingness to view their experience as normal as a static experience. Families are known to move in and out of normalized patterns, often depending on the changing demands of the child's condition (Knafl, Breitmayer, Gallo & Zoeller, 1996). The adolescents' interpretations are ever changing, as are the factors enabling them to interpret their experiences as normal. Furthermore the perceived benefits, threats and negative consequences associated with normalized interpretation may also change. For example, after an illness exacerbation, both illness and family may stabilize in a new pattern: thus "normal" may need to be re-interpreted in order to enable the adolescents to view their experience through a re-constructed, and thus different lens.

As health care professionals we must be aware of the ever-changing lens that may be adopted by children and adolescents to interpret their siblings' illness and that this view is influenced by social and historical context. The adolescents are social beings (Gadamer, 1989), thus it is important to view the adolescents within a family context because family was an important meaning in the adolescents interpretation of living with a sibling who has CF.

Furthermore, heath care professionals must be aware that adopting a normalcy lens can have both positive and negative consequences. Furthermore, for some adolescents, adopting a normalcy lens may not be possible or even recommended as the illness progresses. Furthermore, changes in the illness and family context must be taken into account. The Shifting Perspectives Model of Chronic Illness (Paterson, 2001) helped me gain a new perspective on the life of adolescents who have a sibling with CF.

The Shifting Perspectives Model was derived from a metasynthesis of qualitative research about the experiences of adults with a chronic illness. The experience of living with chronic illness had been described as a series of phases in which the person follows a predictable trajectory. The Shifting Perspectives Model (Paterson, 2001) shows how living with chronic illness is an on-going, continually shifting process in which people experience a complex dialectic between themselves and their "world," between elements of illness in the foreground and wellness in the foreground. New disease-related symptoms will force a person to attend to the illness, thus the illness is in the foreground. In comparison, when wellness is in the foreground, the self and others become the source of preoccupation. According to Paterson (2001), any threat to control that exceeds the person's threshold of tolerance will cause a shift of the illness into the foreground. When the focus is no longer on the illness, for example, if the threat has been resolved "bouncing back" to the wellness in the foreground occurs (Dewar & Morse, 1995; Paterson, 2001).

The conflicting results in studies with children who have a chronically ill sibling suggest that the researchers may have privileged either an illness in the foreground perspective or a wellness in the foreground perspective. Furthermore, researchers may have used cross sectional designs with a single data collection point which would not have captured the shifting

perspectives (Paterson, 2003). Although Bluebond-Langner (1996) has contributed enormously to our understanding of the experience of children who have a sibling with CF, her interpretation of a predictable trajectory for the experience of well siblings may be overlooking the ever-changing perspective of living with CF. Rolland (1994) categorized CF as a progressive-relapsing-gradual-fatal illness. He explains that the episodic nature of the illness may require a flexibility that permits movement back and forth between crisis and non-crisis. The Shifting Perspective Model recognizes this ongoing shifting between wellness and illness, but seems to negate the importance of the potential progression of certain illnesses.

I believe that it is important to consider both. The illness may be more often in the foreground of the well children's or adolescents' thoughts as the illness progresses and further complications appear. Michelle confirmed this pattern: "When she is in good health, it's not really there. If she did get sick and or if it was really bad, it would definitely be on my mind a lot." However, it is also important to recognize that external reminders such as hearing about the death of a child who has CF can prompt the illness in the foreground even at the beginning of the illness trajectory. In Paterson's (2001) model, a shift to an illness perspective occurs in response to life events and situations, the cumulative effect of the disease-related loses and incongruent messages from others. Thus, I offer an adaptation of the Shifting Perspectives Model which I have entitled a Shifting-Progressive-Relapsing Perspective in which the illness-in-the foreground or illness-in-the background progresses and relapses due to the illness trajectory. This perspective differs from previous literature that describes what it is like for adolescents to live with a sibling who has CF.

Shifting-Progressive-Relapsing Perspective

Adolescents living with a sibling who has CF experience elements of both typical adolescent life events as well as living with differences, concerns and negative feelings. This perspective is illustrated in the following schematic representation of how adolescents respond to their siblings' illnesses.

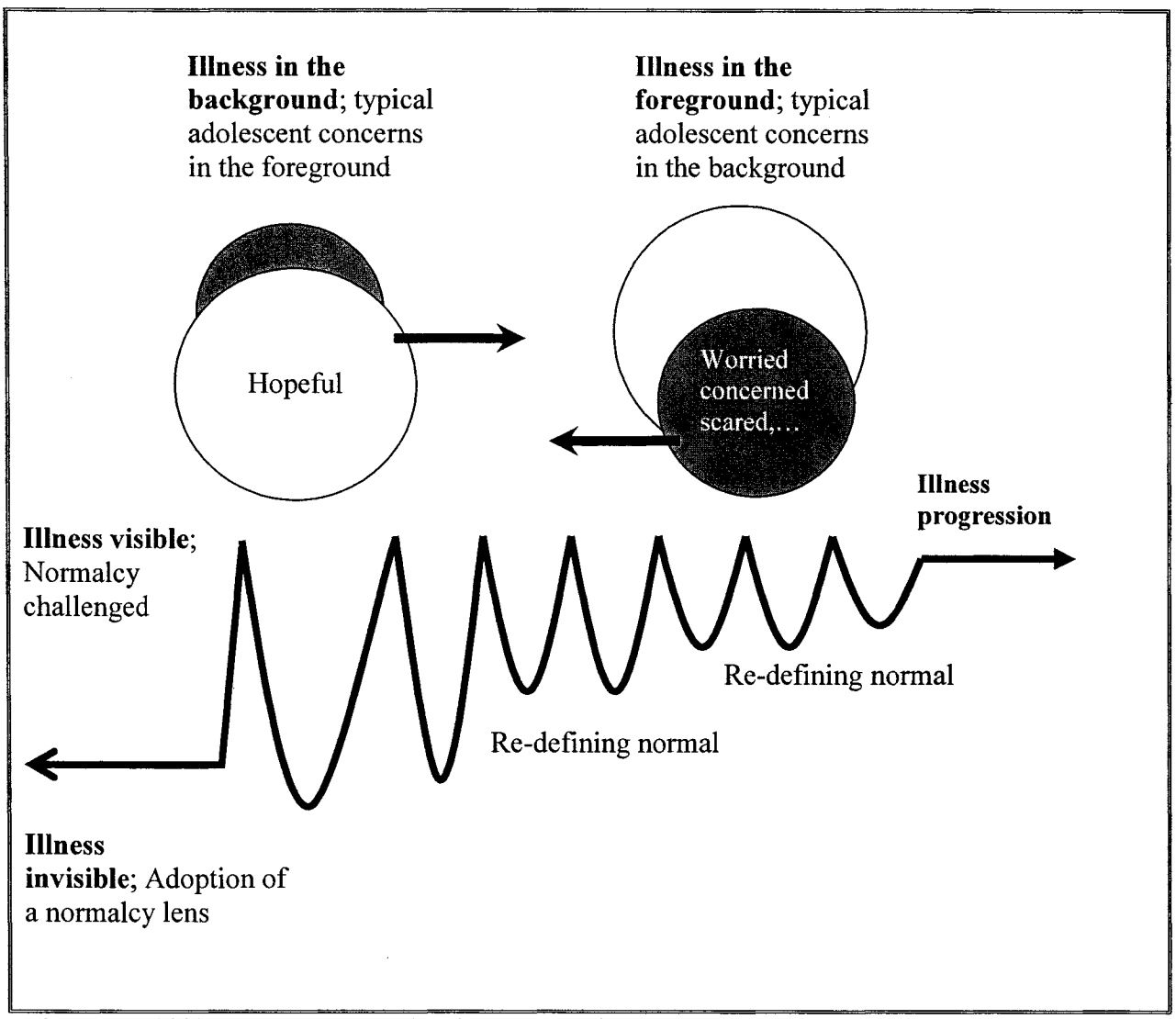


Figure 2. Shifting-progressive-relapsing perspective.

An individual's perspective is a composite of beliefs, perceptions, expectations, attitudes and experience; the perspective of an adolescent who has sibling who has CF is located within a specific historical and social context. The overlapping circles depict whether the illness is in the background or in the foreground. According to Paterson (2001), perceptions of reality, not the reality itself, is how people living with chronic illness interpret and respond to the illness. From a Gadamarian perspective, it is through language that the adolescents will interpret the meaning of their reality or lived experience.

Illness in the Background

The white circle in diagram is much larger then the grey circle, representing the adolescents' continuous emphasis during the interviews of being normal. The majority of adolescents in this study (7/8) said their sibling's illness was in the background during the interview process because the adolescents interpreted the illness as invisible at the time. That is, their sibling was not experiencing illness exacerbations that would be apparent to the general public or external reminders such as learning about someone who has died of CF. With CF, diagnosis and treatment occur at birth or early in childhood, and a large part of the care is now being done within the home, making it part of everyday life. For many years, the illness remains invisible because there is no apparent visual attributes to the illness. The adolescents believed that their sibling's CF was not visually apparent to anyone. They did, however, recognize that the cough was occasionally noticeable, but they were convinced that others saw it as a less serious illness (e.g., usually asthma). As a health care professional, I would have recognized the cough as distinctive to CF. On the whole, the children with CF were quite healthy. From a professional perspective relative lack of visibility is an index of severity and how far the disease process has progressed. To the adolescents visibility was a marker of

whether their siblings could pass as "normal". This perceived invisibility of the illness enabled the adolescents to describe their families, their siblings, and their sibling relationships as normal. The invisibility was perpetuated through their ill sibling's actions (e.g. not talking or complaining about the illness), and medical advancements enabled home treatment, fewer hospitalizations and greater illness stability. The adolescents attributed many advantages to their situated meaning of invisibility, including their ability to adopt a normalcy lens and to remain hopeful.

Advantages to illness invisibility. The most important advantage of having an invisible illness was the lack of stigmatization experienced by their ill sibling, which made inclusion in community activities possible. Even when the illness became visible due to the audible cough, the symptom was often ignored or assumed to be the result of a less severe illness, which prolonged illness invisibility. Other authors have also found that when an ill person's symptoms are invisible or others are unaware of the disease, they may reap considerable benefits, such as being able to engage in normal interaction because nobody will define him or her as non-normal (Joachim & Acorn; 2000a; Strauss et al., 1984).

The invisibility of the illness also enabled the adolescents to experience a "typical" sibling relationship. Since the relationship between siblings is one of the most powerful and long lasting human relationships, and since childhood is often a time for developing deep bonds, it is important that sibling relationships be maintained. It is within the sibling relationship that many children and adolescents learn to share, compete and compromise. Sibling relationships lay the groundwork for developing peer and other intimate relationships and are important to the development of self-esteem and self-concept (Bank & Kahn, 1982).

Another advantage of prolonged illness invisibility was that it enabled the adolescents to view their ill sibling as normal and to adopt attributes of normalization. According to Rehm and Franck (2000), the cognitive process of normalization is more easily attained in families raising a child with relatively stable chronic conditions. We know from practice and research that normalization promotes the chronically ill child's development as a member of the family unit and society (Bossert et al.,1990; Deatrick, Knafl, & Walsh, 1988; Strauss et al., 1984; Thorne, 1993) as well as "normal" development in siblings (Fanos, 1996). Indeed, the adolescents in this study were engaged in normal developmental activities, such as participating in sports and spending time with friends. Furthermore, family closeness and doing family activities together enabled adolescents to view their family as normal. This sense of attachment and closeness in family relationships is believed to be precursor of adaptive adolescent coping (Ainsworth, 1989; Armsden & Greenberg, 1987; Brack, Gay & Matheny, 1993; Seiffge-Krenke, 1995; Moos, 1974; Shulman, Seiffge-Krenke & Samet, 1987).

The adolescents were hopeful and were not worried or concerned about their siblings' illness. They were preoccupied with typical adolescent concerns such as upcoming exams or sports. According to Jevne (2000), remaining hopeful is key to continuing with life. Being hopeful and having typical adolescent preoccupations and concerns while reaping the benefits of normalization did not prevent the adolescents from recognizing the disadvantages of having an invisible illness or acknowledging the condition and its associated differences.

Disadvantages to illness invisibility. The adolescents described a variety of disadvantages associated with an invisible illness including, conflicting opinions regarding illness disclosure, lack of public awareness, and limited family communication.

Ill siblings preferred not to disclose their illness so that they would "fit" into their social world and be viewed as normal without discrimination. They did not want to risk being ignored, rejected, and stigmatized if they disclosed their illness (Goffman, 1963; Schneider & Conrad; 1983). According to Charmaz (1991), young adults risk loosing acceptance by disclosing their illness. Although the adolescents in this study were aware of the benefits of illness concealment, they were also concerned that by avoiding disclosure, their siblings were opting for non-compliant behaviors as an attempt to conceal their illness. These behaviors were unacceptable for many adolescents because of the effects it could have on their siblings' well-being and because of their fear of losing their sibling. Most of the adolescents in this study (5/8) believed that illness concealment may lead to discrimination (e.g., the CF cough may be perceived as contagious) and that public portrayal or disclosure of the illness is needed in order to increase public awareness and support (Thorne, 1993). The conflicting priorities and motivations for disclosure or concealment was a source of tension among some siblings.

Theoretically, if an illness is invisible, the public remains unaware of the differences the illness imposes on the ill child and their family and feels no social obligation to help. According to Falvo, Allen, and Maki (1982), a common problem with invisible disabilities or conditions is the lack of social validation. Consequently, CF families often attempt to gain public awareness, empathy and support by educating the public. According to Serge, when people do not know what CF is, "I don't go into explicit details about it but I tell them what it's about" so that they can understand that "it's a serious illness." The adolescents felt that the general public did not know what CF was and were unaware of the illness' severity; consequently they believed that the general public lacked empathy and a sense of collective responsibility. Ayla admitted that her obligation would be different if her brother did not have CF. She stated, "I'm obligated to help

with CF... [if my brother did not have CF], my sympathy would take me more along poverty because there's so much of it..." Public obligation to help others who have an illness, or who are faced with tragedy, is a function of awareness. For example, after the tragedy of the World Trade Center destruction, the media created public awareness, and as a result, empathy and help efforts were abundant. After experiencing this tragedy, Keigher and Jurkowski (2001) concluded that the nation badly needed "better public understanding of the pervasiveness of illness and disability and the resultant needs of normal human beings who suffer..."

The majority of adolescents believed that CF's invisibility contributed to reduced family communication about the illness. During periods of illness stability this may not be a problem, but it raises the question of whether family communication patterns will change with the illness trajectory. Due to its progressive nature, the illness will become more and more visible over time and present new challenges for the family and for each family member. According to Bluebond-Langner (1996), a set pattern of communication can be difficult to change over time even with illness progression. Limited family communication could be detrimental since according to many researchers, keeping communication lines open and truthful is essential for sibling psychosocial adaptation to the illness experience (Bluebond-Langner, 1996; Fanos, 1996; Murray, 2002; Gardner, 1998; Henley & Hill, 1990; Weir, 1999). Ongoing conversation is needed to better understand the changing patterns of family communication with illness trajectory, and how to identify and help families at risk of upholding limited family communication.

Despite the disadvantages of living with an invisible illness, the adolescents adopted a normalcy lens. According to Knafl and Deatrick (2002), when the benefits are perceived to outweigh the negative consequences, adopting a normalcy lens to view the experience of living

with a chronically ill sibling is possible. Perhaps the adolescents had adopted a normalcy lens because they perceived the benefits of having a sibling who has CF, invisible at the time of the interview, as outweighing the disadvantages. As illustrated in the diagram, the larger white circle on top of the smaller grey circle represents the adolescents' present ability to adopt a normalcy lens and to sustain typical adolescent concerns and thoughts in the foreground. The adolescents' ability and desire to adopt a normalcy lens did not stop them from acknowledging the condition and its impact.

Acknowledging differences. The adolescents described many differences in their lives, concerns and negative feelings they had experienced from living with a sibling who has CF. The smaller grey circle behind the larger white circle represents the adolescents acknowledgement of the differences imposed by the illness. The differences experienced by the adolescents included watching over the ill child, participating in care, decreased parental attention and differential parental treatment. The adolescents were concerned about the illness prognosis, about the ill child and their parents as well as their own future. These differences and concerns made some of the adolescents feel angry, resentful and sorry. Although the adolescents in the study recognized the differences imposed on their family by their sibling's illness, they strengthen their normalcy lens by decentralizing the differences.

Decentralizing differences. Michelle concluded her interview with the following advice: "just treat them like normal kids cause they are...so the illness doesn't consume the whole family and that you can still be able to deal with it." In one study Gallo, Breitmayer, Knafl and Zoeller (1991) found that 9 of the 27 children who had siblings with a chronic illness were able to enhance their siblings' normalcy by "de-emphasizing the differentness" (p. 24). Rolland

(1994) contended that externalizing the chronic illness by putting it in the proper perspective promoted functional boundaries between the illness and the family.

In order to decentralize the differences the adolescents used a variety of ways to facilitate living with the differences, concerns and negative feelings. They chose to rely on help from others as well as personal ways such as hoping, getting involved and re-interpreting the illness situation. Although illness specific, these efforts are similar to those used by other adolescents who do not have a chronically ill sibling, which suggests good adjustment in these adolescents (Jevne & Miller,1999; Lazarus & Launier, 1978; Patterson & McCubbin, 1987; Seiffge-Krenke, 1995; Smith & Carlson, 1997). These findings are congruent with other studies reporting good coping and adjustment in pediatric chronically ill patients and their families (Engstrom, 1992; Madan-Swain, Sexson, Brown, & Ragab, 1993; Thompson, Curtner, O'Rear, 1994). This may explain the many positive outcomes experienced by the adolescents such as increased sensitivity/empathy, increased maturity/independence and increased sibling closeness.

Unlike previous studies (Gardner, 1998; Pit-Ten Cate, & Loots, 2000), the majority of the adolescents in this study did not mention seeking emotional support as a way of dealing with the illness differences, their concerns and negative feelings. Perhaps the adolescents did not feel the need for emotional support due to the present stability of the illness. The adolescents who did seek emotional support from their parents, friends and professionals (3/10) said that when they attempted to seek this type of support their efforts were unsuccessful; they felt unsupported...often forgotten. Yet, emotional support has been identified as important for meeting the psychosocial needs of well siblings (Murray, 2001a).

Another type of support the adolescents attempted to seek was informational support. Although all the adolescents in this study possessed "growing up knowledge" of their sibling's

illness, the majority sought such information as etiology, pathophysiology, how to care for their ill sibling and ongoing research. However, they had difficulty accessing suitable information. The adolescents attributed this difficulty to 1) unsuitable information in the existing resources, 2) parental reluctance or inability to share information, and 3) lack of professional involvement. At times, the adolescents were reluctant to seek information. This reluctance seemed to be attributed to protective motives, the need to protect their parents as well as themselves from potentially harmful information. Ongoing conversation is needed to better understand the context-specific informational needs and motives of children and adolescents who have a sibling with CF and how to better help health care professionals and parents meet the informational needs of well children.

Despite the difficulties some adolescents' experienced accessing information about the sibling's illness, their stories during the interviews were predominantly those of being normal, represented by the large white circle in the diagram. Schematically, the size of the circle will change over time depending on the adolescents' experiences. For example, one adolescent in particular spoke of the difficulties she had keeping illness in the background. She felt that her parents treated her sibling and herself unequally and she was struggling with her role in the family. She believed that her parents favoured her brother because he had CF and became very emotional when talking about this differential parental treatment. Although only one of the adolescents in this study experienced differential parental treatment, the potential impact makes it important to consider when caring for children and adolescents who have a chronically ill sibling. According to several researchers, differential parenting practices and assigning increased unwanted care or protective responsibilities to the healthy siblings may create additional sibling stress (Dunn, Slomkowski & Beardsall, 1994; Faux, 1991; Gallo, 1988).

Furthermore, study results indicate that when siblings are expected to assume care-giving responsibilities for the ill child, they might feel angry and resentful (Orsillo, McCaffery, & Fisher, 1993) especially if it interferes with sibling interaction.

Differential parental treatment and unwanted participation in the care of the ill sibling had become an external reminder of her sibling's illness and for this adolescent it brought the illness in the foreground of her thoughts. The illness also shifted to the foreground of the other adolescents' thoughts with illness exacerbations and external reminders.

Illness in the Foreground

External reminders, such as smoking, coughing, parental concerns, illness exacerbations and hospitalizations brought the sibling's illness into the foreground of the adolescents' thoughts. When the illness was in the foreground, the adolescents became preoccupied by their concerns and worries about their siblings' health and experienced many negative feelings and negative consequences. The smaller grey circle on top of the larger white circle represents the present stability of the illness, despite the external reminders and illness exacerbations. The relative size of these circles may change over time as the illness progresses.

When the illness exacerbations subsided or the adolescents found ways to successfully manage the specific external reminders, the illness would shift to the background. They were able to remain hopeful and focus on typical adolescent concerns.

The arrow under the illness in the foreground/background diagram represents the illness trajectory. At the beginning of the illness trajectory the illness may be invisible due to the lack of publicly perceptible symptoms. Therefore, the arrow's line is flat, uneventful and the left head of the arrow represents the unpredictable length of illness stability and invisibility. As the illness progresses, the relapsing-exacerbation nature of the illness is illustrated by an undulating

line. The peaks illustrate illness exacerbations, hospitalizations and external reminders (illness visibility). The valleys represent illness remission with a return to invisibility and the adolescents' ability to adopt a normalcy lens. Wikler, Wasow and Hatfield (1981) identified these patterns of peaks and valleys in a study with parents who were living with a mentally challenged child. Damrosch and Perry (1989) also used a schematic of peaks and valleys to represent mothers' experience of caring for a child with Down Syndrome. Although Rolland (1993) did not consider "mental retardation" to be a relapsing illness, the periodic crises associated with this disability explained the pattern of peaks and valleys. For example, peaks were identified by mothers of children with Down Syndrome at the time of diagnosis and when the child turned 21 years of age.

The progressive and relapsing nature of CF, not only increases its visibility, but also increases the number of peaks over time. As the child's condition deteriorates the valleys will not return to their baseline level. Thus, the model illustrates the need to re-define "normal" as the illness progresses. The adolescents will need to re-adjust their normalcy lens by redefining what constitutes, for example, a normal sibling relationship. The ability to find hope and normalcy in their experience, however minute, becomes possible by reinterpreting the criteria for normal.

Illness visibility may pose threats to the adolescents' ability to adopt a normalcy lens (Knafl & Deatrick, 2002; Deatrick, Knafl & Walsh, 1988). According to Joachim and Acorn (2000b), "the severity and visibility of the symptoms, along with the degree of unpredictability determine whether normalization is possible" (p.42). Morse, Wilson and Penrod (2000) found that the degree of severity restricted participation in the "everyday-as-normal world". As Michelle explained, as long as her sister could do the things other children her age did, she

would view her sister as normal. Michelle would no longer be able to view her sister as normal "if she didn't have the energy to get up and go down the block to her friend's house. If she couldn't go camping one summer because there was too much stuff going on (referring to her sister's illness); that might make it different." Michelle's statement and other research findings (Bluebond-Langner, 1996; Gallo and al., 1993) support the claim that the severity and visibility of the illness affect the way children and adolescents' view or experience their sibling's illness. As a result, the illness may eventually remain in the foreground of the adolescents thoughts due to the progression and fatal nature of CF. Viewing the illness experience through a normalcy lens may be difficult and for some adolescents even impossible. Thus, for these adolescents, adopting an illness lens or focus may become necessary and appropriate. Schematically, the grey circle representing the illness in the foreground would increase in size. The right head of the arrow represents the progressive nature of CF and the straight line preceding this arrow head represents the eventual continuous visibility of the illness.

A Gademarian approach has enabled me to gain and offer a new perspective, the Shifting-Progressive-Relapsing Perspective, on what it is like for adolescents to live with a sibling who has CF. With this new perspective in mind, I offer the following recommendations to future nursing researchers who are interested in children and adolescents who have a sibling with a chronic illness, progressive and relapsing in nature.

Shifting Research Horizons

This study identifies four areas for future research. The findings reinforce prior work that reframes our understanding of the lives of adolescents with a seriously ill sibling. It suggests the need to examine siblings' experiences from a perspective that is open to both positive and negative consequences. The shifting-progressive-relapsing perspective offers new direction for

designing studies with siblings and identifies variables that may explain variations in siblings' ability to adopt a normalcy lens. The data from siblings suggests that the ill child, parents and siblings may have conflicting needs and motivations that need to be studied in a family context.

The Need for a Balanced Perspective

Not withstanding the methodological limitations of the earlier studies with well siblings, the conflicting results in the sibling literature (Van Riper, 2003; Williams, 1997) can be explained by the research lens with which investigators viewed the experience of children living with a sibling who had a chronic or life threatening illness. The shifts in the historical and social context and the way we view childhood chronic illness has influenced the way researchers, including myself, have posed research questions and how results have been interpreted. For example, early research clearly identifies childhood chronic illness as a burden or stressor for the family and as a result, the siblings' stories and the investigators interpretation of their stories were those of negative effects and thus negative outcomes. The more recent societal shift towards illness integration (Wright, Watson, & Bell, 1996) and normalization (Deatrick, Knafl, & Murphy-Moore, 1999) is increasingly evident in practice and research. More recent research has recognized the family's ability to live alongside the illness and to normalize the illness experience. This change could explain why a mixture of positive and mixed effects is being found in the well sibling literature. Research is needed to explore the shifting influence of historical and social context on our understanding of what it is like for children and adolescents to live with a chronically ill sibling and why both positive and negative experiences are simultaneously possible.

A Shift towards a Trajectory and a Developmental Perspective

At the time of the interviews, their sibling's illness was invisible; the adolescents were able to adopt a normalcy lens to interpret their experience of living with a sibling who has CF. However, they also recognized that the progressive-relapsing fatal nature of their sibling's illness, which would make the illness visible, made it difficult and perhaps eventually impossible to sustain a normalcy lens. Thus, the shifting-progressive-relapsing perspective emerged from my interpretation of their stories. A deeper understanding of the experience of children and adolescents living with a sibling who has CF could be accomplished by testing this model.

Cross sectional designs did not capture the changing perspective that is needed to understand the experience of living with a progressive-relapsing fatal illness. Although the present research was cross sectional in nature, the results call for research designs that capture the trajectory of the illness and developmental interpretations of well siblings. Indeed, longitudinal designs have been recommended by two researchers following integrative reviews of studies concerning the experience of well sibling of children with a chronic illness or disability (Sharpe & Rossiter, 2002; Van Riper, 2003). A longitudinal design or a stratified sampling of different age groups at different times during the illness trajectory to test the validity of the Shifting-progressive-relapsing perspective could capture the time-dependent complexity that is needed to better understand the experience of living with a progressive-relapsing and fatal illness such as CF. Adopting a developmental perspective captures the influence of developmental influences on the children's'/adolescents' interpretation as the illness progresses. For example, most adolescents felt jealous as younger children but jealousy was no longer an issue as they matured and were able to appreciate their sibling's need for parental attention. In addition, a trajectory perspective could help determine, for example, when it is no longer

possible for adolescents to adopt a normalcy lens; that is, when the negative consequences outweigh the benefits of normalization.

The Shifting-progressive-relapsing model could guide investigators interested in the well siblings' need for emotional support. According to the proposed model the most appropriate times to offer support is during illness exacerbations or external reminders when adolescents are concerned and worried about their siblings. This assumption regarding optimal timing needs to be tested.

Testing Invisibility, Severity and Stability as Predictors of Normalcy

The adolescents in this study viewed their sibling's illness as invisible, thus allowing them to adopt a normalcy lens. In an attempt to compare the adolescents' interpretation with the experience of other children/adolescents living with a sibling who has a visible illness, I reviewed the literature to categorize the experiences according to the visibility of the illness. I recognized early in the process that the visibility lens had not been used as a defining construct in this literature. That is, the majority of the researchers had not chosen to study sibling illness experiences according to its visibility thus combining and not distinguishing, between visible and invisible illnesses. In fact, the children's perspective on how they viewed the visibility of their siblings' illness had often not been considered or mentioned.

As researchers, we often consider other illness variables such as onset, duration, progression and prognosis when researching illness experiences. Yet, according to the adolescents' interpretation, illness visibility which was influenced by illness severity and stability is also a very important characteristic. Thus, as researchers we need to examine the importance of visibility in the illness experience without negating the complexity and nature of an illness. For example, we need to better understand the influence invisibility and stability have

on children's and adolescents' interpretation over time as the illness progresses and becomes more visible and severe. Furthermore, a better understanding of the influence visibility has on the interpretation of children and adolescents of different age groups are also needed in the testing of the Shifting-progressive-relapsing model.

Researching Conflicting Needs

This study suggests that different family members may have different personal needs and motivations related to CF. Adolescents and the ill sibling had conflicting desires and rationales for disclosing or not disclosing the illness. Although the adolescents had a need to disclose their siblings' illness to reap the benefits of social and public support, they recognized and at times disagreed with their siblings need not to disclose, especially when their siblings would try to conceal their illness through non-compliance. A better understanding of disclosure preferences and consequences on sibling relationships is needed prior to offering recommendations for practice.

Although informational support has been shown to be important for reducing the psychosocial distress of well siblings (Murray, 1993; Murray, 2001a), the modes of accessing information as well as the types of information that is appropriate to meet the specific needs of different age groups is not known. Conversely, we do not know what support parents need to assist their children/adolescents in accessing different types of information. A better understanding of the conflicting needs of adolescents and family members regarding types, amount and modes of accessing information is needed. Once these issues are understood, interventions designed at meeting informational needs can be developed, tested and implemented to promote healthy functioning.

For parents and health care professionals to share information about the illness with well siblings, not only do they need to acquire the information, but open communication within the family and between health care professionals and well siblings is essential. Protective motives have been identified as one of the main barriers to open communication between family members (Bluebond-Langner, 1996; Craft, Cohen, Titler & DeHammer, 1993; Fanos, 1996; Kleiber, Montgomery, & Craft-Rosenberg, 1995; Stallard, Mastroyannopoulou, Lewis, & Lenton, 1997; Titler, Cohen, & Craft, 1991). Decrease communication about the ill sibling's condition has also been identified by many researchers as potentially leading to misinformation and misunderstanding, and a feeling of emotional isolation from their parents (Bluebond-Langner, 1996; Chesler et al., 1991). According to Scott et al. (2005) "there have been few reported studies which have evaluated the effects of interventions to enhance communication for adolescents about a family members' illness and its treatment" (p. 13). Thus, researchers need to consider the following question: How do you lay the communication groundwork, both within the family, and with health professionals, so that adolescents are able to obtain the informational support they need when they need it the most?

Shifting Practice Horizons

While the need to consider every family member when a child has a chronic illness is more and more evident in research and literature, the adolescents in this study when faced with illness exacerbations or external reminders lacked some form of emotional or informational support from family members, friends or health care professionals. Murray (1999b, 2002) argues that, to date, the psychosocial needs of healthy siblings have been overlooked. Yet, family centered care (FCC), a health care delivery model that seeks to fully involve families in the care of children (Bruce et al., 2002), has been officially adopted by the majority of Canadian pediatric

hospitals. One of the aims of this approach is to meet the sibling's emotional and informational needs. Thus, nurses working with children who have CF have not only the opportunity but also the responsibility to see that comprehensive FCC is integrated in their care of children and families, including siblings. Murray (1993, 1999a) identified barriers that pediatric nurses had in providing support to siblings. These barriers included: staffing shortages, lack of access to healthy siblings, institutional constraints, role boundary issues and lack of support for healthy children support groups. To be able to implement FCC, barriers within the work environment must be eliminated. Otherwise, the following recommendations for practice will be difficult and at times impossible for health care providers to implement.

Include Siblings in Your Approach to Care

To address the siblings' emotional and informational needs, they should be included in the care planning (Murray, 2002). The siblings' needs should be re-assessed periodically and noted in the care plan. Recognizing the difficulty in organizing face-to-face meetings with older siblings due to school and other commitments, telephoning them and asking to talk about their specific needs or sending a questionnaire home with their parents would be a creative way of communicating with this population. This approach will remind health care professionals to consider needs of siblings as they reach developmental milestones and as the illness progresses. For example, it cannot be assumed that the information they received at time of diagnosis or through observing their sibling's care at home will suffice as they mature.

Offer Situational Appropriate Support

According to the adolescents in this study, emotional support was needed during illness exacerbations and external reminders. Although the adolescents needed support, they did not always seek support perhaps because they did not want to concern their parents or friends.

Furthermore, those who did seek support were not satisfied with the support they received from their parents, friends or health care professionals.

Social support as defined by House (1981) and later tested by Murray (2000d), involves providing empathy encouragement, understanding, caring, love and trust. In a study of support interventions for healthy siblings of children with cancer, interventions directed at their emotional needs were most helpful (Murray, 2002). These results are consistent with the findings of other researchers (Haverman & Eisser, 1994; Kramer, 1981; Spinetta, 1981). According to Williams et al. (1997), screening for the need for emotional support may prevent mental health problems among well siblings. Therefore, adolescents should be encouraged to express their emotional needs and appropriate emotional support should be available. For example, simply acknowledging the unique experience of well siblings may not only encourage them to express their feelings but may show them that someone cares.

Knowledge of the progressive perspective model may also make health care professionals and parents aware of the shifting needs of siblings. That is, even if a sibling does not need to express his or her feelings for days or months, because the illness is in the background of his thoughts, it does not mean he will not have a need the following day or month when faced with external reminders or illness exacerbations. Letting siblings know that they can e-mail the CF clinic at any time about their concerns regarding the illness or their informational needs recognizes the periodic nature of their needs. Furthermore, the model could help parents and health care professionals recognize the ever-changing developmental needs of well-children and adolescents. For example, when adolescents were younger they were satisfied with "growing up knowledge" but as they matured most wanted more information about their sibling's illness.

Studies of children who have siblings with chronic illnesses have shown that providing information is a key component of support (Brett & Davies, 1988; Bluebond-Langner, 1996; Craft, Wyatt, & Sandell, 1985; Murray, 2000c, d; Ross-Alaolmolki; Heinzer, Howard & Marszal, 1995, Taylor, 1980). In a study with survivor siblings of children with CF, the clearest message from nearly all of the survivors was "it would have been so helpful if only their parents had been able to discuss the illness with them" (Fanos, 1996, p. 136). Rolland (1994) concluded that although well siblings can easily become forgotten family members when another child is ill or disabled, direct and clear information and supportive reassurance from parents were often the determining factors in how well siblings adjusted to the child with chronic illness or disability.

The informational needs of well siblings must be assessed based on their developmental milestones and protective motives. A range of age appropriate materials could be developed, such as story, work books, videos or a web page, whereby information can be communicated to children through familiar media (Stallard, Mastroyannopoulou, Lewis & Lenton, 1997). Parents and siblings should have easy access to these resources so they can access what they want when they want it. They should also feel welcome to attend clinic visits and different medical tests when appropriate as well as workshops/seminars according to their informational needs and motives. Thus, in order to meet the different informational needs of well siblings, it must be made easily accessible so parents and adolescents can access the type and amount of information that meets their needs and motives when they are ready to do so.

Without negating the uniqueness of each adolescents' experience, the need for emotional and informational support will likely increase as the illness progresses. Parents may be preoccupied with their ill child's needs, thus health care professionals should make themselves available to adolescents as they attempt to manage increasing illness exacerbations and the

potential death of their ill sibling. When parents or health care professionals are preoccupied or unavailable, sibling groups should be considered whereby siblings have an opportunity to meet others in a similar situation in order to share their experience and feelings of what it's like to live with a sibling who has a chronic illness, thus reducing feelings of isolation (Stallard, Mastroyannopoulou, Lewis & Lenton, 1997). If face-to-face meetings are impossible, chat rooms on the internet could be created, for adolescents especially, who have a sibling who has CF. According to Murray (2001b), being in or participating in a group with children with similar experiences validates that it is acceptable to candidly share feelings (Murray, 2001b). One of the major benefits of a chat group is that it can be accessed at any time. According to Murray (2002), well siblings "frequently ask to have additional support groups solely for the purpose of being with other children to share their feelings..." (p. 333). Special topics could be posted to encourage communication about feelings, for example, have you ever felt this way or how did you feel when your brother was hospitalized?

Foster the Use of Normalcy Efforts

Adoption of a normalcy lens had a considerable impact on the way adolescent siblings defined their family, their siblings and their sibling relationship. The use of a normalcy lens reveals the power of the norm in our society as a whole (Thorne, 1993), and reflects values embedded in assumptions of health care professionals and society that being normal is a universally positive attribute that everyone should strive for. However, the adolescents' stories illustrated how interpretation of illness as normal, is a double-edged sword, a mind set that can have beneficial consequences under some circumstances but negative ones under others. For example, adoption of a normalcy mind set supported typical adolescent development, but could inhibit family communication about the illness and its consequences. These paradoxical

consequences of normalization are recognized in the literature (Deatrick, Knafl, & Walsh, 1988; Knafl & Deatrick, 2002; Robinson, 1993). Thus, health care professionals must first recognize the paradoxical and ever-changing process of normalization and that it is not an either-or situation (Knafl & Deatrick, 2002).

If adolescents choose to adopt a normalcy lens, they should be encouraged to do so because there is some evidence of the adaptive benefits of this approach (Cohen, 1993; Gallo & Knafl, 1998; Knafl & Gilliss, 2002). According to Robinson (1993), the story of normalcy supports hope, enabling "persons and families to carry on through adversity because of the hope for a brighter or more livable future" (p. 23). Furthermore, hope has therapeutic value in illness and has been linked to health indicators such as quality of life (Rustoen, 1995), coping (Raleigh, 1992), and mental health (Nunn, 1996). Keeping hopeful in an illness situation "is key to doing what is possible and enjoying life while we wait for and contribute to whatever good may come tomorrow" (Jevne, 2000). The experience of hope was evident in the adolescents' stories of normalcy. The adolescents hoped their ill sibling would recover from illness exacerbations; they even hoped for a cure.

However, describing one's experience as normal is not a life story that works for every person or family living with a chronic illness (Robinson, 1993). In circumstances where adopting a normalcy lens is difficult, health care professionals should help adolescents re-define or re-interpret normal. In some contexts an illness lens or focus may be more appropriate. However, adopting an illness lens does not negate the need for hope. Thus, health care professionals need to consider the following question: How will I help them continue to find hope as their sibling's illness becomes more severe and visible?

It is important for health care professionals to understand the changing nature of normalization, its benefits, and negative consequences and assure adolescents that what they are experiencing is typical. Recognizing the negative consequences of adopting a normalcy lens, health care professionals should make themselves available to help adolescents recognize and find ways to live alongside the negative consequences. For example, healthy adolescents may seek guidance about the advisability of disclosing or not disclosing their sibling's illness. Health care professional's knowledge of the possible disclosure conflicts that may exist between siblings when it comes to disclosing or not may be useful in assisting individuals to make informed decisions (Joachim & Acorn, 2000a; b). Furthermore, parents should be encouraged to treat their children equally, to keep the communication lines open, and to avoid imposing unwanted care-giving responsibilities on their well-children in an effort to maintain their well-children's use of a normalcy lens.

Concluding Remarks

The purpose of this study was to develop an in-depth understanding of the experience of adolescents living with a sibling who has CF. In the previous pages, I have attempted to offer a clear and precise interpretation what it's like for adolescents to live with a sibling who has CF recognizing that the interpretation is never finished. Thus, in my life as a nursing professor and researcher interested in the experience of children, adolescents and families I will continue to keep the conversation open with them, as well as with my students, with caregivers, with other researchers and with anyone interested in what it's like for children and adolescents to live with a sibling who has a chronic illness and how we can best support them through challenging times.

REFERENCES

Abbott, J., Dodd, M., Gee, L., & Webb, K. (2001). Ways of coping with cystic fibrosis: Implications for treatment adherence. *Disability and Rehabilitation. 23*(8), 315-324.

Achenbach, T., & Edelbrock, C. (1983). *The Child Behavior Checklist and Revised Child Behavior Profile.* Burlington, VT: Queen City Press.

Admi, H. (1996). Growing up with a chronic health condition: A model of an ordinary lifestyle. *Qualitative Health Research, 6*(2), 163-183.

Ainsworth, M.D.S. (1989). Attachments beyond infancy. *American Psychologist, 44,* 709-716.

Allen, D. (1995). Hermeneutics: Philosophical traditions and nursing practice research. *Nursing Science Quarterly, 8*(4), 174-182.

Armsden, G., & Greenberg, M. (1987). The inventory of parent and peer attachment: Individual differences and their relationship to psychological well-being in adolescence. *Journal of Youth and Adolescence, 16,* 427-453.

Baker-Ward, L., Gordon, B. N., Ornstein, P. A., Larus, D. M., & Clubb, P. A. (1993). Young children's longterm retention of a pediatric examination. *Child Development, 64*, 1519-1533.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychology, 37*, 122-147.

Bank, S., & Kahn, M. (1975). Sisterhood-brotherhood is powerful: Sibling subsystems and family therapy. *Family Process, 14,* 311-337.

Bank, S., & Kahn, M. D. (1982). *The sibling bond.* New York: Basic Books.

Barber, B.K., & Thomas, D.L. (1986). Dimensions of fathers' and mothers' supportive behavior: The case for physical affection. *Journal of Marriage and the Family, 48*, 783-794.

Bat-Chava, Y., & Martin, D. (2002). Sibling relationships of deaf children: The impact of child and family characteristics. *Rehabilitation Psychology, 47*(1), 73-91.

Bearison, D. (1991). *They never want to tell you: Children talk about cancer.* Cambridge: Harvard University.

Bee, H. (1998). *Lifespan Development*, (2nd ed.). New York: Longman.

Bendor, P.C. (1990). Anxiety and isolation in siblings of pediatric cancer patients: The need for prevention. *Social Work in Health Care, 14*, 17-35.

Betz, C. L. Hunsberger, M. M., & Wright, S. (1994). *Family-centered nursing care of children* (2nd ed.). Philadelphia: W.B. Saunders.

Bluebond-Langner, M. (1996). *In the shadow of illness: Parents and siblings of the chronically ill child.* New Jersey: Princeton University Press.

Boer, F. (1990). *Sibling relationships in middle childhood.* Leiden: DSWO, University of Leiden.

Bossert, E., Holaday, B., Harkins, A., & Turner-Henson, A. (1990). Strategies of normalization used by parents of chronically ill school age children. *Journal of Child Psychiatric Nursing, 3*(2), 57-61.

Brack, G., Gay, M.F., & Matheny, K.B. (1993). Relationships between attachment and coping resources among late adolescents. *Journal of College Student Development, 34*, 212-215.

Breslau, N., & Prabucki, K. (1987). Siblings of disabled children: Effects of chronic stress in the family. *Archives of General Psychiatry, 44,* 1040-1046.

Brett, K. M., & Davies, E. M. (1988). What does it mean? Sibling and parental appraisals of childhood leukemia. *Cancer Nursing, 11,* 329-338.

Brown, J. D. (1990). Evaluating one's abilities: Shortcuts and stumbling blocks on the road to self-knowledge. *Journal of Experimental Social Psychology, 26,* 149-167.

Bruce, B., Letourneau, N., Ritchie, J., Larocque, S., Dennis, C., Elliott, M. R. (2002). A multisite study of health professionals' perceptions and practices of family-centered care. *Journal of Family Nursing, 8*(4), 408-429.

Cadman, D., Boyle, M., & Offord, D. R. (1988). The Ontario child health study: Social adjustment and mental health of siblings of children with chronic health problems. *Developmental and Behavioral Pediatrics, 9,* 117-121.

Callery, P. (2001). Families with parents and children living with HIV described strategies to meet 3 common goals for normalization. *Evidence-based nursing, 4*(3), 92.

Canadian Cystic Fibrosis Foundation (2003). www.ccff.ca

Carlo, G., Hausmann, A., Christiansen, S., & Randall, B. A. (2003). Sociocognitive and behavioral correlates of a measure of prosocial tendencies for adolescents. *Journal of Early Adolescence,* 23, 107-134.

Carpenter, P. J., & Sahler, O. J. (1991). Sibling perception and adaptation to childhood cancer: Conceptual and methodological considerations. In J. H. Johnson & S. B. Johnson (Eds.), *Advances in child health psychology* (pp. 193-205). Gainesvill, FL: University Press of Florida.

Caty, S., Larocque, S., & Koren, I. (2001). Family-Centered Care in Ontario general hospitals: The views of pediatric nurses. *Canadian Journal of Nursing Leadership, 14*(2), 10-17.

Chesler, M. A., Allswede, J., & Barbarin, O. O. (1991). Voices from the margin of the family: Siblings of children with cancer. *Journal of Psychosocial Oncology, 9*(4), 19-42.

Chesler, M.S., & Barbarin, O. A. (1987). *Childhood cancer and the family.* New York: Brunner/Mazel.

Chesser, E. S., & Anderson, J. L. (1975). Treatment of breast cancer: Doctor/patient communication and psychosocial implications. *Proceedings of the Royal Society of Medicine, 68,* 793-795.

Christian, B. J., & D'Auria, J. P. (1997). The child's eye: Memories of growing up with cystic fibrosis. *Journal of Pediatric Nursing, 12*(1), 3-12.

Cicirelli, B. G. (1995). *Sibling relationships across the life span.* New York, NY: Plenum.

Clarke-Steffen, L. (1997). Reconstructing reality: Family strategies for managing childhood cancer. *Journal of Pediatric Nursing, 12*(5), 278-287.

Cohen, D., Freidrich, W., Jaworski, T., Copeland, D., & Pendergrass, T. (1995). Pediatric cancer: Predicting sibling adjustment. *Journal of Clinical Psychology, 50,* 303-319.

Cohen, M. H. (1993). The unknown and the unknowable: Managing sustained uncertainty. *Western Journal of Nursing Research, 15*, 77-96.

Collier, J. (1967). *Visual anthropology: Photography as a research method.* New York: Holt Rinehart & Winston.

Collins, W. A., Geason, T., & Sesma, A. (1997). Internalization, autonomy, and relationships: Development during adolescence. In J. E. Grusec & L. Kuczynski (Eds), *Parenting and children's internalization of values: A handbook of contemporary theory (pp.78-99). New York: Wiley.*

Compas, B. E. (1987). Coping with stress during childhood and adolescence. *Psychological Bulletin, 101,* 393-403.

Compas, B. E., Worsham, N. L., & Ey, S. (1992). Conceptual and developmental issues in children's coping with stress. In A. M. La Greca, L. J. Siegal, J. L. Wallander, & C. E. Walder (Eds.), *Stress and coping in child health* (pp. 56-72). New York: Guilford.

Coyne, I. T. (1997a). Chronic illness: The importance of support for families caring for a child with cystic fibrosis. *Journal of Clinical Nursing, 6,* 121-129.

Coyne, I. T. (1997b). Sampling in qualitative research. Purposeful and theoretical sampling; Merging or clear boundaries? *Journal of Advanced Nursing, 26*, 623-630.

Craft, M. J. (1979). Help for the family's neglected "other" child. *MCN: American Journal of Maternal-Child Nursing, 4,* 297-300.

Craft, M. J., Wyatt, N., & Sandell, B. (1985). Behavior and feeling changes in siblings of hospitalized children. *Clinical Pediatrics, 24,* 374-378.

Craft, M., Cohen, M., Titler, M., & DeHammer, M. (1993). Experiences in children of critically ill parents: A time of emotional disruption and need for support, *Critical Care Quarterly, 16,* 41-46.

Cuskelly, M. (1999). Adjustment of siblings of children with a disability: Methodological issues. *International Journal for the Advancement of Counseling, 21*, 111-124.

D'Auria, J. P., Christian, B. J. & Richardson, L. F. (1997). Through the looking glass: Children's perceptions of growing up with cystic fibrosis. *Canadian Journal of Nursing Research,* 29(4), 99-112.

Damiani, V. (1999). Responsibility and adjustment in siblings of children with disabilities: Update and review. *Families in Society: The Journal of Contemporary Human Services, 80*(1), 34-40.

Damrosch, S. P., & Perry, L. A. (1989). Self-reported adjustment, chronic sorrow, and coping of parents of children with Down Syndrome. *Nursing Research, 38*(1), 25-30.

Davies, G. (1991). Research on children's testimony: Implications for interviewing practice. In C.R. Hollin & K. Howells (Eds.), *Clinical approaches to sex offenders and their victims* (pp. 93-115). New York, NY: Wiley.

Davies, L. K. (1993). Comparison of dependent-care activities for well siblings of children with cystic fibrosis and well siblings in families without children with chronic illness. *Issues in Comprehensive Pediatric Nursing,* 16, 91-98.

De Braekeleer, M., Bellis, G., Rault, G., Allard, C., Milot, M, & Simard, F. (2001). Disease knowledge in a high-risk population for cystic fibrosis. *Patient Education and Counseling, 43,* 263-268.

Deatrick, J. A., Knafl, K. A., & Murphy-Moore, C. (1999). Clarifying the concept of normalization. *Image: Journal of Nursing Scholarship, 31*(3), 209-214.

Deatrick, J. A., Knafl, K. A., & Walsh, M. (1988). The process of parenting a child with a disability: Normalization through accommodations. *Journal of Advanced Nursing, 13,* 15-21.

Dell Clark, C. (1999). The autodriven interview: A photographic viewfinder into children's experience. *Visual Sociology, 14*, 39-50.

Derouin, D., & Jessee, P. O (1996). Impact of chronic illness in childhood: Siblings' perceptions. *Issues in Comprehensive Pediatric Nursing, 19*, 135-147.

Dewar, A. L., & Morse, J. M. (1995). Unbearable incidents: Failure to endure the experiences of illness. *Journal of Advanced Nursing, 22*, 957-964.

Dickens, R. (1991). *Notes for siblings/adult children.* (Available form Nation Alliance for the Mentally Ill, 2101 Wilson Blvd. Suite 302, Arlington, VA 22201).

Ditto, P. H., & Lopez, D. F. (1992). Motivated scepticism: Use of differential decision criteria for preferred and non-preferred conclusions. *Journal of Personality and Social psychology, 63, 568-584.*

Docherty, S., & Sandelowski, M. (1999). Focus on qualitative methods: Interviewing Children. *Research in Nursing & Health, 22*, 177-185.

Dooley, R. (1973). Management of the terminal adolescent and one family. In *Psychosocial aspects of cystic fibrosis.* P.R Patterson, C.R. Denning, and A.H. Kutscher (Eds). New York: Columbia University Press.

Dunn, J. & Kendrick, C. (1982). *Siblings: Love, envy and understanding.* Cambridge, MA: Harvard University Press.

Dunn, J. (1988). Sibling influences on childhood development. *Journal of Child Psychology and Psychiatry, 29*, 119-127.

Dunn, J., Slomkowski, C., & Beardsall, L. (1994). Sibling relationships from the preschool period through middle childhood and early adolescence. *Developmental Psychology, 30,* 315-324.

Duvall, E., & Miller, B. (1986). *Marriage and family development* (6th ed.). New York: Harper & Row.

Dyson, L.L. (1989). Adjustment of siblings of handicapped children: A comparison. *Journal of Pediatric Psychology, 14*, 215-229.

Ebeta, A. T., & Moos, R. H. (1991). Coping and adjustment in distressed and healthy adolescents. *Journal of Applied Developmental Psychology, 12,* 33-54.

Edelman, D. L., & Mandel, C. L. (2002). *Health promotion through the lifespan* (5th ed.). Toronto: Mosby.

Eder, D., & Fingerson, L. (2002). Interviewing children & adolescents. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research* (pp. 181-201). London: Sage Publications.

Eisenger, N., Spinrad, T., & Sadovsky, A. (2006). Empathy-related responding in children. In M. Killen & J. Smetana (Eds.), *Handbook of Moral Development* (pp. 517-549). London: Lawrence Erlbaum Associates.

Elborn, J. S., Shale, D. J., & Britton, J. R. (1991). CF: Current survival and population estimates to the year 2000. *Thorax, 46*, 881-885.

Ellis, J. L. (1998a). Narrative inquiries with children and youth. In J. L. Ellis (Ed.), *Teaching from understanding: Teacher as interpretive inquirer* (pp. 33-55). New York: Garland.

Ellis, J. L. (1998b). Interpretive inquiry as a formal research process. In J. L. Ellis (Ed.), *Teaching from understanding: Teacher as interpretive inquirer* (pp. 15-32). New York: Garland.

Ellis, J. L. (1998c). Introduction: The teacher as interpretive inquirer. In J. L. Ellis (Ed.), *Teaching from understanding: Teacher as interpretive inquirer* (pp. 5-13). New York: Garland.

Engel, S. (1995). *The stories children tell: Making sense of the narratives of childhood.* New York: W.H. Freeman.

Engstrom, I. (1992). Psychological problems in siblings of children and adolescents with inflammatory bowel disease. *European Child and Adolescent Psychiatry, 1*(1), 24-33.

Esmond, G. (2000). Cystic fibrosis: Adolescent care. *Nursing Standard. 14*(52), 47-52.

Falvo, D. R., Allen H., & Maki, D. R. (1982). Psychosocial aspects of invisible disability. *Rehabilitation literature, 43*(2), 2-6.

Fanos, J. (1996). *Sibling loss.* Mahwah, NJ: Lawrence Erlbaum Associates.

Faux, S. A. (1991). Sibling relationship in families with congenitally impaired children. *Journal of Pediatric Nursing, 6*(3), 175-184.

Faux, S. A. (1993). Siblings of children with chronic physical and cognitive disabilities. *Journal of Youth and Adolescence, 8*(5), 305-317.

Feeman, D. J., & Hagan, J. W. (1990). Effects of childhood chronic illness on families. *Social Work in Health Care, 14*, 37-53.

Feetham, S. (1991). Conceptual and methodological issues in research of families. In A. Whall & Fawcett (Eds.), *Family theory development in nursing: State of the science and art* (pp. 55-68). Philadelphia: F.A. Davis.

Ferrari, M. (1987). The diabetic child and well sibling: Risks to the well child's self-concept. *Children's Health Care, 15*, 141-148.

Foster, C., Eiser, C., Oades, P., Sheldon, C., Tripp, J., Goldman, P., Rice, S., & Trott, J. (2001). Treatment demands and differential treatment of patients with cystic fibrosis and their siblings: patient, parent and sibling accounts. *Child: Care, Health and Development, 27*(4), 349-364.

Frey, C. U., & Rothlesberger, C. (1996). Social support in healthy adolescents. *Journal of Youth and Adolescence, 25*(1), 17-31.

Gadamer, H. (1975). *Truth and method.* New York: Seabury Press.

Gadamer, H. (1979). *Truth and method* (2nd ed.). London: Sheed and Ward.

Gadamer, H. (1982). *Truth and method.* New York: Crossroad.

Gadamer, H. (1986). On the scope and function of hermeneutical reflection. In B. R. Wachterhauser (Ed.), *Hermeneutics and modern philosophy* (pp. 277-299). Albany, NY: State University of New York Press.

Gadamer, H. (1989). *Truth and method.* (2nd ed.). New York: Crossroad.

Gallison, M. (1992). *Confronting the Medical Model: A Hermeneutic View of the Quest for Health Care by Gay Men with HIV and AIDS.* Unpublished Doctoral of philosophy dissertation: University of Washington.

Gallo, A. M. & Knafl, K. (1998). Parents' reports' of tricks of the trade" for managing childhood chronic illness. *Journal of the Society of Pediatric Nurses, 3,* 93-100.

Gallo, A. M. (1988). The special sibling relationship in chronic illness and disability: Parental communication with well siblings. *Holistic Nursing Practice, 2*(2), 28-37.

Gallo, A. M., Breitmayer, B. J., Knafl, K. A., & Zoeller, L. H. (1991). Stigma in childhood chronic illness: A well sibling perspective. *Pediatric Nursing, 17(*1), 21-27.

Gallo, A. M., Breitmayer, B. J., Knafl, K. A., & Zoeller, L. H. (1992). Well siblings of children with chronic illness: Parents' reports of their psychologic adjustment. *Pediatric Nursing, 18*(1), 23-28.

Gallo, A. M., Breitmayer, B. J., Knafl, K., Zoeller, L. H. (1993). Mother's perceptions of sibling adjustment and family life in childhood chronic illness. *Journal of Pediatric Nursing: Nursing Care of Children and Families, 8*(5), 318-24.

Gardner, E. (1998). Siblings of chronically ill children: Towards an understanding of process. *Clinical Child Psychology and Psychiatry, 3*(2), 213-227.

Geanellos, R. (1998). Hermeneutic philosophy. Part I: Implication of its use as methodology in interpretive nursing research. *Nursing Inquiry, 5*, 154-163.

Gick, M., & Holyoak, K. (1983). Schema induction and analogical transfer. *Psychology, 15*, 1-2.

Gil, K. M., Williams, D.A., Thompson, R.J., & Kinney, T.R. (1991). Sickle cell disease in children and adolescents: The relation of child and parent pain coping strategies to adjustment. *Journal of Pediatric Psychology, 16,* 643-663.

Goffman, E. (1963). *Stigma. Notes on the management of spoiled identity.* Englewood Cliffs, New Jersey: Prentice-Hall.

Goldbeck, L., & Babka, C. (2001). Development and evaluation of a multi-family psychoeducational program for cystic fibrosis. *Patient Education and Counseling, 44*, 187-192.

Götz, I., & Götz, M. (2000). Cystic fibrosis psychological issues. *Pediatric Respiratory Reviews, 1,* 121-127.

Gravelle, A. M. (1997). Caring for a child with a progressive illness during the complex chronic phase: Parents' experience of facing adversity. *Journal of Advanced Nursing, 25,* 738-745.

Haase, J.E., & Rostad, M. (1994). Experiences of completing cancer therapy: Children's perspectives. *Oncology Nursing Forum, 21*(9), 1483-94.

Habermas, J. (1972). *Knowledge and human interest.* Boston: Beacan Books.

Hatton, D. L., Canam, C., Thorne, S., Huges, A. (1995). Parents' perceptions of caring for an infant or toddler with diabetes. *Journal of Advanced Nursing, 22*(3), 569-77.

Haverman, T., & Eiser, C. (1994). Siblings of a child with cancer. *Child: Care, Health and Development, 20,* 309-322.

Hayes, V. E. (1993). Nursing science in family care, 1984-1990. In S. L. Feetham, S. B. Meister, J. M. Bell, & C. L. Gillis (Eds.). *The nursing of Families: Theory, research, education and practice* (pp. 18-29). London: Sage Publications.

Hefferman, S. M., & Zanelli, A. S. (1997). Behavior changes exhibited by siblings of pediatric oncology patients: A comparison between maternal and sibling descriptions. *Journal of Pediatric Oncology Nursing, 14*(1), 3-14.

Heidegger, M. (1968). *What is called thinking?* New York: Harper and Row.

Hekman, S. J. (1986). *Hermeneutics and sociology of knowledge.* Cambridge: Polity Press.

Henley, L. D., & Hill, I. (1990). Global and specific disease-related information needs of cystic fibrosis patients and their families. *Pediatrics, 85,* 1015-1021.

Hockenberry, M. J., Wilson, D., Winkelstein, M. L., Kline, N. E. (2003). *Wong's nursing care of infants and children* (17th ed.). Toronto: Mosby.

Hodgkinson, R. & Lester, H. (2002). Stresses and coping strategies of mothers living with a child with cystic fibrosis : Implications for nursing professionals. *Journal of Advanced Nursing, 39*(4), 377-383.

Holahan, C.J., Valentiner, D.P., & Moos, R.H. (1995). Parental support, coping strategies, and psychological adjustment: An integrative model with late adolescents. *Journal of Youth and Adolescence, 24*(6), 633-649.

House, J. S. (1981). *Work stress and social support.* Reading, MA: Addison-Wesley.

Iles, J.P. (1979). Children with cancer: Healthy siblings' perceptions during the illness experience. *Cancer Nursing, 2,* 371-377.

Irwin, L. G., & Johnson, J. (2005). Interviewing young children: Explicating our practices and dilemmas. *Qualitative Health Research, 15*(6), 821-831.

Jardine, D. W. (1992). The fecundity of the individual case: Considerations of the pedagogic heart of interpretive work. *Journal of Philosophy of Education, 26*(1), 51-61.

Jardine, D. W. (1998). "The fecundity of the individual case": Considerations of the pedagogic heart of interpretive work (1992). In D. W. Jardine (Ed.), *To dwell with a boundless heart* (pp. 33-51). New York: Peter Lang.

Jardine, D. W. (2000). Learning to love the invalid. In D. W. Jardine (Ed.), *"Under the tough old stars": Ecopedagogical essays* (pp. 193-199). Brandon, VT: The Foundation for Educational Renewal.

Jessop, D., & Stein, K. (1989). Meeting the needs of individuals and families. In R. Stein (Ed.), *Caring for children with chronic illness* (pp. 63-74). New York: Springer.

Jevne, R. F., & Miller, J. E. (1999). *Finding hope: Ways to see life in brighter light.* Indiana: Willowgreen Publishing.

Jevne, R. (2000). *Hoping, coping & moping: Handling life when illness makes it tough.* California: Health Information Press.

Joachim, G., & Acorn, A. (2000a). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing, 32*(1), 243-248.

Joachim, G., & Acorn, S. (2000b). Living with chronic illness: The interface of stigma and normalization. *Canadian Journal of Nursing Research. 32*(3), 37-48.

Keigher, S. M., & Jurkowski, E. (2001). Life after a national nightmare: coping with invisible illness and disability. *National Association of Social Workers, 26*(4), 211-215.

Kleiber, C., Montgomery, L. A., & Craft-Rosenberg, M. (1995). Information needs of the siblings of critically ill children. *Children's Health Care, 24*(1), 47-60.

Kliewer, W., &. Lewis, H. (1995). Family influence on coping processes in children and adolescents with Sickle Cell Disease. *Journal of Pediatric Psychology, 20*(4), 511-525.

Knafl, K. A., & Deatrick, J. A. (1986). How families manage chronic conditions: An analysis of the concept of normalization. *Research in Nursing & Health, 9,* 215-222.

Knafl, K. A., Deatrick, J. A. (2002). The challenge of normalization for families of children with chronic conditions. *Pediactric Nursing, 28*(1), 9-53.

Knafl, K., Breitmayer, B. Gallo, A., & Zoeller, L. (1996). Family response to childhood chronic illness: Description of management styles. *Journal of Pediatric Nursing, 11* (5), 315-326.

Knafl, K, A., & Gillis, C. L. (2002). Families and chronic illness: A synthesis of current research. *Journal of Family Nursing, 8*(3), 178-198.

Konopa, G. (1980). Coping with the stresses and strains of adolescence. *Social Development Issues, 4*(3), 1-17.

Kortesluoma, R.-L., Hentinen, M., & Nikkonen, M. (2003). Conducting a qualitative child interview : methodological considerations. *Journal of Advanced Nursing, 42*(5), 434-441.

Kotzer, A. M. (1990). Creative strategies for pediatric nursing research: Data collection. *Journal of Pediatric Nursing, 5*, 50-53.

Kowal, A. & Kramer, L. (1997). Children's understanding of parental differential treatment. *Child Development, 68*, 113-126.

Kramer, R. (1984). Living with childhood cancer: Impact on the healthy siblings. *Oncology Nursing, 11*, 44-51.

Kramer, R. F. (1981). Living with childhood cancer: Healthy siblings' perceptive. *Issues in Comprehensive Pediatric Nursing, 5,* 155-165.

Kruger, S., Shawver, M., & Jones, L. (1980). Reactions of families to the child with cystic fibrosis, *Image, 12,* 67-72.

Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing.* London: Sage.

Lamorey, S. (1999). Parentification of siblings of children with disability or chronic disease. In N. D. Chase (Ed.), *Burdened children: Theory, research, and treatment of parentification* (pp. 75-91). Thousand Oaks, CA: Sage.

Lardieri, L. A., Blacher, J., & Swanson, H. L. (2000). Sibling relationships and parent stress in families of children with and without learning disabilities. *Learning Disability Quarterly, 23*, Spring, 105-116.

Larocque, S. (1993). *Efficacité des stratégies adaptatives utilisées par des adolescent(e)s dont un membre de la fratrie est atteint de la fibrose kystique.* (mémoire de maîtrise) Montréal: Presses de l'université de Montréal.

Larocque, S. (1995). L'impact de la maladie chronique sur la fratrie adolescente. C. Bernier, S. Larocque, & M. Aumond (Eds.), *Actes du colloque: Famillies francophones, Multiples realites* (pp. 151-170). Sudbury: Institut Franco-Ontarien/Collection fleur de trille.

Lazarus, R.S., & Launier, R. (1978). Stress related transactions between person and environment. In L.A. Pervin & M. Lewis (Eds.). *Perspectives in interactional psychology.* New York: Plenum.

Lee, E. J., Phoenix, P. D., Brown, W., & Jackson, B. S. (1997). A comparison study of children with sickle cell disease and their non-diseased siblings on hopelessness, depression, and perceived competence. *Journal of Advanced Nursing, 25*, 79-86.

Lees, C.M., & Smyth, R. L. (2000). The current management of cystic fibrosis. *International Journal of Clinical Practice, 54*(3), 171-179.

Leventhal, H., & Diefenbach, M. (1991). The active side of illness cognition. In J. A. Skelton, & R. T. Croyle (Eds.), *Mental representation in health and illness* (pp. 247-272). NY: Springer-Verlag.

Loutzenhiser, J. K., & Clark, R. (1993). Physical activity and exercise in children with cystic fibrosis. *Journal of Pediatrics, 8,* 112-119.

Madan-Swain, A., Sexson, S. B., Brown, R. T., & Ragab, A. (1993). Family adaptation and coping among siblings of cancer patients, their brothers and sisters, and nonclinical controls. *The American Journal of Family Therapy, 21*(1), 60-70.

McCubbin, H. I., & Patterson, J. M. (1981). A-COPE Adolescent-Coping orientation for problem experiences. H. I. McCubbin & A. I. Thompson (Eds.), *Family assessment inventories for research and practice* (pp. 225-243). Madison, Wisconsin: The University of Wisconsin-Madison.

Menke, E. M. (1987). The impact of a child's chronic illness on school-aged siblings. *Children's Health Care, 15*(3), 132-140.

Meyer, D. J., & Vadasy, P. F. (1994). *Sibshops: Workshops for siblings of children with special needs*. Toronto: Paul H. Brookes Publishing.

Meyerowitz, J. W., & Kaplan, H. B. (1967). Familial responses to stress: The case of cystic fibrosis. *Social Science and Medicine, 1*, 249-266.

Miller, S. (1996). Living with a disabled sibling: A review. *Pediatric Nursing, 8*(8), 21-24.

Minagawa, M. (1997). Sibling relationships of Japanese children with diabetes. *Journal of Pediatric Nursing, 12*(2), 311-316.

Monsen, R. B. (1999). Mothers' experience of living worried when parenting children with spina bifida. *Journal of Pediatric Nursing, 14*(3), 157-163.

Moos, R. H. (1974). *The human context: Environment determination of behavior.* New York: Wiley.

Morse, J. M. (1991). Strategies for sampling. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 117-131). Rockville, Maryland: Aspen Publishers.

Morse, J. M. (1998). Editorial: The contracted relationship: Ensuring protection of anonymity and confidentiality. *Qualitative Health Research, 8*(3), 301-303.

Morse, J. M., Wilson, S., & Penrod, J. (2000). Mothers and their disabled children: Refining the concept of normalization. *Health Care for Women International, 21*, 659-676.

Murray, J. S. (1993). Social support for siblings of children with cancer. *Dissertation Abstracts International, 31*, 1746.

Murray, J. S. (1998). The lived experience of childhood cancer: One sibling's perspective. *Issues in Comprehensive Pediatric Nursing, 21,* 217-227.

Murray, J. S. (1999a). Methodological triangulation in a study of social support for siblings of children with cancer. *Journal of Pediatric Oncology Nursing, 16,* 194-200.

Murray, J. S. (1999b). Siblings of children with cancer: A review of the literature. *Journal of Pediatric Oncology Nursing, 16,* 25-34.

Murray, J. S. (2000a). Attachment theory and adjustment difficulties in siblings of children with cancer. *Issues in Mental Health Nursing, 21,* 149-169.

Murray, J. S. (2000b). Understanding sibling adaptation to childhood cancer. *Issues in Comprehensive Pediatric Nursing, 23*, 39-47.

Murray, J. S. (2000c). A concept analysis of social support as experienced by siblings of children with cancer. *Journal of Pediatric Nursing, 15*(5), 313-322.

Murray, J. S. (2000d). Development of two instruments measuring social support for siblings of children with cancer. *Journal of Pediatric Oncology Nursing, 17*(4), 229-238.

Murray, J. S. (2001a). Social support for school-aged siblings of children with cancer: A comparison between parent and siblings perceptions. *Journal of Pediatric Oncology Nursing, 18*(3), 90-104.

Murray, J. S. (2001b). Self-concept of siblings of children with cancer. *Issues in Comprehensive Pediatric Nursing, 24,* 85-94.

Murray, J. S. (2002). A qualitative exploration of psychosocial support for siblings of children with cancer. *Journal of Pediatric Nursing, 17*(5), 327-337.

Nastasi, B. K., & Berg, M. J. (1999). Using ethnography to strengthen and evaluate intervention programs. In J. J. Schensul, M. D. Le Compte, G. A. Hess, B. K. Nastasi, M. J. Berg, L. Williamson, J. Brecher & R. Glasser. *Using ethnographic data: Interventions, public programming, and public policy* (pp. 1-56). Walnut Creek, CA: Altamira Press.

Nelms, B. (1990). Sibling relationships. *Journal of Pediatric Health Care, 4*, 57-58.

Nunn, K. (1996). Personal hopefulness: A conceptual review of the relevance of the perceived future to psychiatry. *British Journal of Medical Psychology, 69*, 227-245.

Olson, C. (1993). Circumplex model of marital and family systems: Assessing family functioning. In F. Walsh (Ed.), *Normal family process* (2nd ed., pp. 104-137). New York: Guilford Press.

Orellana, M. F. (1999). Space and place in an urban landscape: Learning from children's views of their social worlds. *Visual Sociology, 14*, 73-89.

Orsillo, S. M., McCaffery, R J., & Fisher, J. M. (1993). Siblings of head-injured individuals: A population at risk. *Journal of Head Trauma Rehabilitation, 8*(1), 102-105.

Packer, M. J., & Addison, R. B. (Eds.). (1989). *Entering the circle: Hermeneutic investigation in psychology.* Albany: SUNY Press.

Palmer, R. E. (1969). *Hermeneutics: Interpretation theory in Schleiermacher, Dilthey, Heidegger, and Gadamer.* Evanston: Northwertern University Press.

Pascoe, E. (1996). The value to nursing research of Gadamer's hermeneutic philosophy. *Journal of Advanced Nursing, 24,* 1309-1314.

Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Image: Journal of Nursing Scholarship*, 33(1) 21-26.

Paterson, B. L. (2003). The koala has claws: Applications of the Shifting Perspectives Model in research of chronic illness. *Qualitative Health Research, 13*(7), 987-994.

Patterson, J. M., & McCubbin, H. I. (1987). Adolescent coping style and behaviors: Conceptualization and measurement. *Journal of Adolescence, 10,* 163-186.

Peterson, G. W., & Leigh, G. K. (1990). The family and social competence in adolescence. In T. P. Gullotta, G. R. Adams, & R. Montemayor (Eds.), *Developing social competency in adolescence* (pp. 97-138). London: Sage.

Piaget, J. (1969). *The theory of stages in cognitive development.* New York: McGraw-Hill.

Piaget, J., & Inhelder, B. (1958). *The growth of logical thinking from children to adolescence.* New York: Basic Books.

Pit-Ten Cate, I. M., & Loots, G. M. P. (2000). Experiences of siblings of children with physical disabilities: An empirical investigation. *Disability and Rehabilitation, 22* (9), 399-408.

Pless, I. B., & Pinkerton, P. (1975). *Chronic childhood disorder: Promoting patterns of adjustment*. Chicago: Yearbook Medical

Powell, T.H., & Gallagher, P.A. (1993). *Brothers and sisters: A special part of exceptional families* (2nd ed.). Baltimore, MA: Brookes.

Price, D. W., & Goodman, G. S. (1990). Visiting the wizard: Children's memory for a recurring event. *Child Development, 61*, 664-680.

Prosser, J., & Schwartz, D. (1998). Photographs within the sociological research process. In. J. Prosser (Ed.), *Image-based research* (pp. 115-130). London: Falmer Press.

Raleigh, E.D.H. (1992). Sources of hope in chronic illness. *Oncology Nursing Forum, 19*(3), 443-448.

Ray, L. (1997). *Promoting the health of families raising a child with a chronic condition: Directions for outcomes research.* Unpublished doctoral dissertation, University of Washington, Washington.

Rehm, R. S., & Bradley, J. F. (2005). Normalization in families raising a child who is medically fragile/technology dependent and developmentally delayed. *Qualitative Health Research, 15(6)*, 807-820.

Rehm, R. S., & Franck, L. S. (2000). Long-term goals and normalization strategies of children and families affected by HIV/AIDS. *Advances in Nursing Sciences, 23(1)*, 69-82.

Report of the Tri-Council Working Group. (1997). *Tri-Council Working Group Draft Code of Ethical Conduct for Research Involving Humans.*

Rich, M., & Chalfen, R. (1999). Showing and telling asthma: Children teaching physicians with visual narrative. *Visual Sociology, 14,* 51-71.

Robinson, C. S. (1993). Managing life with a chronic condition: The story of normalization. *Qualitative Health Research, 3*(1), 6-28.

Rolland, J. S. (1993). Mastering family challenges in serious illness and disability. In F. Walsh (Ed.). *Normal family processes (pp. 445-473).* New York: Gilford Press.

Rolland, J. S. (1994). *Families, illness and disability: An integrative treatment model.* New York: Norton.

Rollins, J. A. (1990). Childhood cancer: Siblings draw and tell. *Pediatric Nursing, 16*(1), 21-26.

Roos, G. (1998). Pile sorting: "Kids like candy." In V. C. deMunck & E. J. Sobo (Eds.), *Using methods in the field: A practical introduction and casebook* (pp. 97-110). Walnut Creek. CA: Altamira Press.

Ross-Alaolmolki, K., Heinzer, M. M., Howard, R., & Marszal, S. (1995). Impact of childhood cancer on siblings and family: Family strategies for primary health care. *Holistic Nursing Practice, July,* 66-75.

Rustoen, T. (1995). Hope and quality of life, two central issues for cancer patients: A theoretical analysis. *Cancer Nursing, 18*(5), 355-361.

Ryan, R.M., & Lynch, J.H. (1989). Emotional autonomy vs. detachment: Revisiting the vicissitudes of adolescence and youth adulthood. *Child Development, 60*, 340-356.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science, 16*(2), 1-8.

Santrock, W. (2000). *Children (6h ed.).* New York, NY: McGraw-Hill.

Schneider, J., & Conrad, P. (1983). *Having. epilepsy: The experience and control of illness* Philadelphia: Temple University Press.

Scott, J. T., Prictor, M. J., Harmsen, M., Broom, A., Entwistle, V. Sowden, A., & Watt, I. (2005). Interventions for improving communication with children and adolescents about a family member's cancer. *The Cochrane Library: Oxford, 3,* 1-35.

Sedikides, C. (1993). Assessment, enhancement, and verification determinants of the self-evaluation process. *Journal of Personality and Social Psychology, 65,* 317-338.

Seiffge-Krenke, I. (1995). *Stress, coping, and relationships in adolescence.* Mahwah, New Jersey: Lawrence Erlbaum Associates, Publishers.

Sharkey, T. (1995). The effects of uncertainty in families with children who are chronically ill. *Home Health Nurse, 13*(4), 37-42.

Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Society of Pediatric Psychology,* 27 (8), 699-710.

Shulman, S. (1993). Close relationships and coping behavior in adolescence. *Journal of Adolescence, 16*, 267-283.

Shulman, S., Seiffge-Krenke, I., & Samet, N. (1987). Adolescent coping style as a function of perceived family climate. *Journal of Adolescent Research, 2,* 367-381.

Shuy, R. W. (2002). In-person versus telephone interviewing. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research* (pp. 537-555). London: Sage Publications.

Silver, E. J., & Frohlinger-Graham, M. J. (2000). Brief report: Psychological symptoms in healthy female siblings of adolescents with and without chronic conditions. *Journal of Pediatric Psychology, 25*(4), 279-284.

Sloper, P. (2000). Experiences and support needs of siblings of children with cancer. *Health and Social Care in the Community, 8*(5), 298-306.

Smith, D. G. (1991). Hermeneutic Inquiry: The hermeneutic imagination and the pedagogic text. In E. C. Short (Ed.), *Forms of Curriculum Inquiry* (pp. 187-209). Albany, NY: SUNY.

Smith, J. (1993). *After the demise of empiricism: The problem of judging social and education inquiry.* Norwood, New Jersey: Ablex Publishing Corporation.

Smith, R.H., & Smith, A.R. (1976). Attachment and educational investment of adolescence. *Adolescence, 11,* 349-357.

Smith, S., & Carlson, B. E. (1997). Stress, coping and resilience in children and youth. *Social Service Review, June,* 231-256.

Spradley, J. P. (1979). *The ethnographic interview.* New York: Holt, Rinehart and Winston.

Spinetta, C. (1981). The siblings of the child with cancer. In J. Spinetta and P. Spinetta (Eds.) *Living with childhood cancer* (pp. 181-236). St. Louis: Mosby.

Stallard, P., Mastroyannopoulou, K., Lewis, M., & Lenton, S. (1997). The siblings of children with life-threatening conditions. *Child Psychology & Psychiatry Review, 2* (1), 26-33.

Stawski, M., Auerbach, J. G., Barasch, M., Lerner, Y., & Zimin, R. (1997). Behavioural problems of children with chronic physical illness and their siblings. *European Child & Adolescent Psychiatry, 6,* 20-25.

Stein, R. (Ed.) (1989). *Caring for children with chronic illness.* New York: Springer.

Stein, R., & Jessop, D. (1989). What diagnosis does not tell: The case for a non-categorical approach to chronic illness in childhood. *Social Science in Medicine, 29,* 769-778.

Stern, M., & Zevon, M.A. (1990). Stress, coping, and family environment: Adolescents' response to naturally occurring stressors. *Journal of Adolescent Research, 5,* 290-305.

Stewart, K. S., & Dearmun, A. K. (2001). Adherence to health advice amongst young people with chronic illness. *Journal of Child Health Care, 5*(4), 155-162.

Stewart, M. J. (2000). *Community nursing: Promoting Canadians' health.* Toronto: W.B. Saunders.

Strauss, A. L. (1984). A basic strategy: Normalizing. In A. L. Strauss (Ed.). *Chronic illness and the quality of life* (pp. 58-65). St. Louis: Mosby.

Strauss, A. L., & Glaser, B. G. (1975). *Chronic illness and the quality of life.* St. Louis: C.B. Mosby Co.

Strauss, A.L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D., Susczed, B., & Weiner, C. L. (1984). *Chronic illness and the quality of life* (2nd Ed.) St. Louis: Mosby.

Taylor, S. (1980). The effects of chronic childhood illness upon well siblings. *Maternal Child Nursing Journal, 9,* 109-116.

Taylor, S. E., & Brown, J. D. (1988). Illusion and well-being: A social psychological perspective on metal health. *Psychological Bulletin, 103,* 193-210.

Tew, B., & Laurence, K.M. (1973). Mothers, brothers and sisters of patients with spina bifida. *Developmental Medicine and Child Neurology, 15 (Supplement),* 69-76.

Thompson, A. B., Curtner, M. E., & O'Rear, M. R. (1994). The psychosocial adjustment of well siblings of chronically ill children. *Children's Health Care, 23*(3), 211-226.

Thompson, J. L. (1990). Hermeneutic inquiry. In L.E. Moody (Ed.), *Advancing nursing science through research* (pp. 223-245). Newbury Park: Sage.

Thompson, R. J., & Gustafson, D. E. (1996). *Adaptation to chronic childhood illness.* Washington, DC: American Psychological Association.

Thorne, S. E. (1993). *Negotiating health care: The social context of chronic illness.* California: Sage Publications.

Titler, M., Cohen, M., & Craft, M. (1991). Impact of critical illness event on the family: Perceptions of patients, spouses, children and nurses. *Heart & Lung, 20,* 174-182.

Trahd, G. E. (1986). Siblings of chronically ill children: Helping them cope. *Pediatric Nursing, 12*(3), 191-193.

Tritt, S., & Esses, L. (1988). Psychosocial adaptation of siblings of children with chronic illness. *American Journal of Orthopsychiatry, 58*(2), 211-220.

Troster, H. (1997). Disclose or Conceal? Strategies of information management in persons with epilepsy. *Epilepsia, 38*, 1227-1237.

Turk, J. (1964). Impact of cystic fibrosis on family functioning. *Pediatrics, 78*, 67-71.

Turner, de S. (2003). Horizons revealed : From methodology to method. *International Journal of Qualitative Methods, 2*(1), 1-32.

Valliant, G. (1977). *Adaptation to life.* Boston: Little Brown.

Van der Zalm, J. E., & Bergum, V. (2000). Hermeneutic-phenomenology: Providing living knowledge for nursing practice. *Journal of Advanced Nursing, 31*(1), 211-218.

Van Riper, M. (2000). Family variables associated with well-being in siblings of children with Down syndrome. *Journal of Family Nursing, 6*(3), 267-286.

Van Riper, M. (2003). The sibling experience of living with childhood chronic illness and disability. In Miles, M. S. & Holditch-Davis, D. (Eds). Research on Child Health & Pediatric Issues, *Annual Review of Nursing Research* (Vol. 21), (pp. 279-302). NY: Springer Publishing.

Vance, J., Fazan, L., Satterwhite, B., & Pless, I. (1980). Effects of nephrotic syndrome on the family: A controlled study. *Pediatrics, 65*, 948-955.

Wachterhauser, B. R. (Ed.). (1986). *Hermeneutics and modern philosophy.* Albany, NY: State University of New York Press.

Walker, C. L. (1990). Siblings of children with cancer. *Oncology Nursing Forum, 17*(3), 355-360.

Weber, S. J. (1986). The nature of interviewing. *Phenomenology & Pedagogy, 4*(2), 65-72.

Weinsheimer, J. (1985). *Gadamer's hermeneutics: A reading of truth and method.* New Haven CT: Yale University Press.

Weir, A.E. (1999). *Impact of a child's brain injury on siblings.* Unpublished master's thesis. University of Alberta, Edmonton, Alberta, Canada.

Weiss, K. A., Schiaffino, K. M., & Ilowite, N. (2001). Predictors of sibling relationship characteristics in youth with juvenile chronic arthritis. *Children's Health Care, 30,* (1), 67-77.

Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs. professional depiction of the adjustment of parents of mentally retarded children. *American Journal of Orthopsychiatry, 51,* 63-70.

Williams, P. D. (1997). Siblings and pediatric chronic illness: A review of the literature. *International Journal of Nursing Studies, 34*(4), 312-322.

Williams, P. D., Hanson, S., Karlin, R., Ridder, L., Liebergen, A., Olson, J., Barnard, M. U., & Tobin-Rommelhard, S. (1997). Outcomes of a nursing intervention for siblings of chronically ill children: A pilot study. *Journal of the Society of Pediatric Nurses, 2*(3), 127-137.

Williams, P., Lorenzo, F., & Borja, M. (1993). Pediatric chronic illness: Effects on siblings and mothers. *Maternal-Child Nursing Journal, 21*, 111-121.

Wong, D. L. (1999). *Whaley & Wong's Nursing Care of Infants and Children* (6th ed.). Toronto: Mosby.

Wright, L. M. & Leahey, M. (2000). *Nurses and families: A guide to family assessment and interventions* (3rd ed.). Philadelphia: F. A. Davies.

Wright, L. M., & Leahey, M. (1987). *Families & chronic illness.* Springhouse, PA: Springhouse Corporation.

Wright, L. M., & Leahey, M. (1994). *Nurses and families: A guide to family assessment and intervention.* Philadelphia: F. A. Davis.

Wright, L. M., Watson, W. L., & Bell, J. M. (1996). *Beliefs: The heart of healing in families and illness.* New York: Basic Books.

Capital Health

Appendix A

Healthier people in healthier communities

University of Alberta Hospital

8440 – 112 Street
Edmonton, Alberta
Canada T6G 2B7
Phone: (780) 407-8822

September 24, 2001

Dear _____ (parent's name)

Sylvie Larocque is a Ph.D. student at the Faculty of Nursing, University of Alberta. She is interested in understanding the experience of teens living with a brother or sister who has cystic fibrosis. The Cystic Fibrosis Team has looked at Sylvie's research proposal and has agreed to support her project because very few studies have asked teens to talk about their experience. The Team also feels that more information is needed to help develop programs for teens in order to help them cope.

I have enclosed the Parents' Information Letter that describes the study in more detail. If you believe your daughter or son would be interested in participating in this study, please call Joan or Josette at 407-6745 to give me permission to give your name and telephone number to Sylvie. After receiving your name and telephone number, she will telephone you to answer any of your questions and to set up an interview with your daughter or son.

Thank you for the time you have spent considering participating in this study.

Sincerely,

P. Zuberbuhler, M.D., F.R.C.P. (C)
Director
Pediatric CF Clinic

05774

Appendix B

(On Letterhead)

Parents' Information about the Study

Project Title: Adolescents Living with a Sibling who has Cystic Fibrosis.

Investigator:
Sylvie Larocque, RN, MN

Faculty of Nursing
University of Alberta
Research Phone: (780) 492-3032

Supervisors:
Dr. Lynne Ray and
Dr. Margaret Harrison
Faculty of Nursing
University of Alberta
Office Phone: (780) 492-7558

Purpose of the Study:

My name is Sylvie Larocque. I am a pediatric nurse and a Ph.D. student at the Faculty of Nursing. I am interested in understanding the experience of teens living with a brother or sister who has cystic fibrosis.

Background:

Chronic illness, such as cystic fibrosis, affects everyone in the family. Very few studies have asked children or teens to talk about what it is like to grow up with a brother or sister who has a chronic illness. Only if we listen to the stories of these children and adolescents can we understand how to help them cope.

Procedure:

Your son or daughter will be asked to talk about what it has been like to grow up with a brother or sister who has cystic fibrosis. She/he will be asked to help me draw diagrams showing who is in your family. I will use this information to describe the group of siblings in the study (e.g., 5 teens from families with two children). I will also invite your teens to use visual or other prompts (e.g. pictures, music) to help them tell their stories.

Your son or daughter will be interviewed at least once. She may be invited to participate in a second and third interview to clarify or expand their stories. The length of the interviews will depend on your son or daughter. The average interview will take about 1 to 2 hours. We will plan a time and a place for the interview that is best for your teen. Only your teen and I will be present during the interview. All interviews will be tape recorded and then typed word for word so that the information can be reviewed later.

Risks and Benefits:

There are no known risks to your son or daughter by taking part in this study. The study is not intended to benefit the teens in the study. However, some teens may appreciate the chance to tell their studies. Findings from this study may help nurses and other health care professionals to understand what it is like for teens to grow up with a brother or sister who has cystic fibrosis. This may help to improve care for teens and families of children with cystic fibrosis.

Voluntary Participation:

Your son or daughter does not have to be in this study if he or she does not want to be. She/he may withdraw from the study at any time by telling me or calling my supervisor. Your teen does not have to answer any questions or talk about a topic she/he does not want to. If your son or daughter becomes upset during the study, a counseling referral can be arranged. Your choice to take part or not will not affect your child's or family's care in any way.

Anonymity:

Neither your name nor your teen's name will appear in this study. A code number will replace your names on all the information. All information will be kept in a locked cabinet. I will destroy tapes and consent forms after seven years. If I receive approval from an ethics review committee, interview information may be used for other research in the future. Quotes from the interview may be used in study reports, but your teen's name or any material that may identify your teen or your family will not be used.

All information will be kept confidential except where professional codes require reporting.

Additional Contacts:

If you have any questions, you may call my supervisor or me. If you have any concerns about any aspect of this study, you may contact the Patient Concerns Office of the Capital Health Authority at 492-9790. This office has no affiliation with study investigators.

Capital Health

Appendix C

Healthier people in healthier communities

University of Alberta Hospital

8440 – 112 Street
Edmonton, Alberta
Canada T6G 2B7
Phone: (780) 407-8822

October 30, 2001

Dear CF Families,

Sylvie Larocque a Ph.D. student at the Faculty of Nursing, University of Alberta is interested in understanding the experience of teens living with a brother or sister who has cystic fibrosis. Sylvie will be recruiting her families from our clinic. The Cystic Fibrosis Team has looked at Sylvie's research proposal and has agreed to support her project because very few studies have asked teens to talk about their experience. The Team also feels that more information is needed to help develop programs for teens in order to help them cope.

We will be sending the Parents' Information Letter that describes the study in more detail to those families who have teens. If you do not receive this information and you have a teen, please call Joan or Josette at 407-6745 and we will send you the study's description.

Sincerely,

P. Zuberbuhler, M.D., F.R.C.P. (C)
Director
Pediatric CF Clinic

PZ/yl

10-05774

Appendix D

Recruitment for adolescent siblings' study
Telephone follow-up guide

I'm calling regarding the study on "Teens who have a brother or sister with CF"

Have you received our letter inviting you to participate? Y N
(You would have received it approximately 3-4 weeks ago)

Have you had a chance to talk to _____ (son/daughter) about participating in the research? Y N

Did you have any concerns or questions regarding the research?

Concerns/questions	Answer
Too far to travel	Sylvie will do the interview wherever it is convenient for your adolescent (home, etc.)
Not available during the day	Sylvie will do the interview whenever it is convenient for your adolescent (evenings, weekends, etc.)
Not a good time (e.g. Too close to the holidays)	The interviews can take place anytime that is convenient for you, before the holidays, after the holidays, in one week, one month, etc.
Not sure/ Have more questions	Forward name to Sylvie

If you have any other questions/concerns and if you agree, I can give your name to Sylvie and she can call you to answer any of your questions. Giving your name to Sylvie does not mean that you agree to participate in the study. After talking to Sylvie you can agree or not to participate. You can also withdraw at anytime.

Would you like us to forward your name and phone number to Sylvie?

Health Research Ethics Board biomedical research health research

2J2.27 Walter Mackenzie Centre
University of Alberta, Edmonton, Alberta T6G 2R7
p.780.492.9724 f.780.492.7303
ethics@med.ualberta.ca

3-48 Corbett Hall, University of Alberta
Edmonton, Alberta T6G 2C4
p.780.492.0839 f.780.492.1626
ethics@www.rehabmed.ualberta.ca

Appendix E

UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES, CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP

HEALTH RESEARCH ETHICS APPROVAL

Date:	October 2001
Name of Applicant:	Ms. Sylvie Larocque
Organization:	University of Alberta
Department:	Graduate Studies; Nursing
Name of Supervisor:	Dr. Margaret Harrison & Dr. Lynne Ray
Organization:	University of Alberta
Department:	Nursing
Project Title:	Adolescents Living with and Managing the Demands of Their Siblings

The Health Research Ethics Board has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information material and consent form (if applicable).

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval.

for Dr. Sharon Warren
Chair of the Health Research Ethics Board (B: Health Research)

File number: B-090901-NSG

Appendix F

(On Letterhead)

Adolescents' Information about the Study

Project Title: Adolescents Living with a Sibling who has Cystic Fibrosis.

Investigator:
Sylvie Larocque, RN, MN

Faculty of Nursing
University of Alberta
Research Phone: (780) 492-3032

Supervisors:
Dr. Lynne Ray and
Dr. Margaret Harrison
Faculty of Nursing
University of Alberta
Office Phone: (780) 492-7558

Why I'd like to talk to you:

My name is Sylvie Larocque. I am a nurse who works with children, teens and their families. I am also a student who's interested in knowing what it's like to grow up with a brother or sister who has cystic fibrosis. I think it would help if nurses and other health care professionals knew more about what brothers and sisters are thinking and feeling.

What we'll do:

I would like you to tell me what it's like to grow up with a brother or sister who has cystic fibrosis. If you like, you can share with me any pictures or other things that may help you tell your story. I will also ask you to draw diagrams of your family. I may need to talk to you more than once to make sure I understood everything. The amount of time we spend talking will depend on you. You and I will be alone during our talks. We will plan a time and a place to talk that is best for you. I would like to tape what we say so I don't forget anything.

Will it be helpful or not?

Sharing your story with me should not be a negative experience. It is also not meant to help you but some teens may like telling their stories. The information from your stories may help nurses and other health care professionals know what it is like for teens to grow up with a brother or sister who has cystic fibrosis. This may help to improve the care teens and families receive.

If there is something you don't like:

You do not have to be in this study if you don't want to be. If you don't want to answer my questions, you don't have to. You can change your mind about talking to me. It is your choice. Your choice to talk to me or not won't affect your brother/sister's or your family's care in any way. I have told your parents that too. If you become upset during our talk, I can arrange for you to talk to someone about your feelings.

Other things:

What you say will not be shared with anyone. Your name will not be on any of my papers it will be replaced by a code number so no one can tell what you said. If you tell me about a problem that no one knows, I will need to tell someone that can help.

Call us:

If you have any questions about the study, you may call my supervisor or me.

Appendix G: Informed Consent Form (On Letterhead)

Part 1: Research Information

Title of Project: Adolescents Living with a Sibling who has Cystic Fibrosis.

Principal Investigator: Sylvie Larocque, RN, MN
Faculty of Nursing
University of Alberta
Research Phone: (780) 492-3032

Supervisor: Dr. Lynne Ray and Dr. Margaret Harrison
Faculty of Nursing
University of Alberta
Office Phone: (780) 492-7558

Part 2: Consent of Participant

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to the information you share?	Yes	No

This study was explained to me by: _____

I agree to take part in this study.

_____	_____	_____
Signature of Research Participant	Date	Witness (if available)
_____		_____
Printed Name		Printed Name
_____	_____	_____
Parental Signature	Date	Witness (if available)
_____		_____
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____	_____
Signature of Investigator or Designee	Date

Appendix H

Hermeneutic Interview Guide

As you know, I am here to find out what it's like to grow up with a brother or sister who has cystic fibrosis. So, tell me what it's like to live in your family.

1) What are some of the struggles/challenges you (and your family) have lived with because you have a brother/sister that has CF? How does that make you feel? **Probe:** Can you describe to me an experience that you have found difficult (eg. hospitalization)

2) Do you have any concerns about your brother's illness (how it affects the family, the future, ...).

3) How do you feel about having a brother/sister who has CF? **Probe:** How would you describe to a friend what it's like to have a brother/sister with CF? How would you describe it to another sibling?

4) What are some of rewards (joys, hopes) of having a brother/sister who has CF? How does that make you feel? **Probe:** Can you describe an experience that you have found rewarding?

5) What have you found helpful in dealing with the challenges of your brother's /sister's illness? **Probe:** Other teens have used the following strategies to deal with the challenges of their brother/sister's illness. Have you used the following? Why, why not? Talk about it to someone, Try to think about the positive things in my life, Spend time with my friends, Get angry and yell at someone, Work hard in my school work or other activities, Try to deal with it on my own, Get away from the situation, Spend as much time as I can with my brother/sister, Help with the treatment, etc...., Get as much information as I can about the illness, **Other things that may be helpful?**

6) What have you found not so helpful in dealing with the challenges of your brother's/sister's illness?

7) Who has helped you to deal with the challenges of your brother's/sister's illness? (family, contacts outside the family, self,...)

Appendix I

Evaluation of the process: Pilot exercise

1. Picture activity:

What did you think of this exercise? How did you find the questions? What did you think of the length of the process? What did you like the most? What did you like the least?

Pilot $_1$: Easy to talk about pictures; did not feel it was a long process; easy to show what you mean and what your talking about when showing pictures.

Pilot $_2$: Good way to connect with memories; no problem with questions and the length of the activity; enjoyed the activity.

2. Things I think about ("Think cloud") activity:

What did you think of this exercise? What did you like the most of this exercise? What did you like the least? What did you think of the length of the exercise? What did you think of the cartoon character used?

Pilot $_1$: Fun activity; Had no problem competing the activity. Everything OK.

Pilot $_2$: The exercise was OK; Wanting to put the preoccupations on top of each other (after given the permission to do so no problem completing the activity).

3. Card sort activity:

What did you think about the exercise? Evaluating of the comprehension of each statement (see cards).

Pilot $_1$: Suggestion to change one of the statement (see card). Other statements were found easy to comprehend. Fun exercise.

Pilot $_2$: The exercise was OK; interactive process enjoyable. Comments about statements written directly on cards.

Appendix J: Second interviews with adolescents

Note taking for picture activity **Code:**

Can you describe the picture to me? Who/what is in the picture? What did you hope the picture would tell (show) about what it's like for you to have a brother/sister who has CF? What were you thinking when you took this picture? What were you feeling when you took this picture? What were you hoping I would think or see when I looked at this picture? What are you seeing/thinking now when you look at the picture? What are you feeling now when you look at the picture?

Picture 1 **What it is:** **Meaning:**	**Picture 2** **What it is:** **Meaning:**
Picture 3 **What it is:** **Meaning:**	**Picture 4** **What it is:** **Meaning:**

Etc...

Appendix K

Permission from my family members to use their pictures in my thesis

I agree to have my picture(s) appear in Sylvie Larocque's Doctoral Thesis entitled:

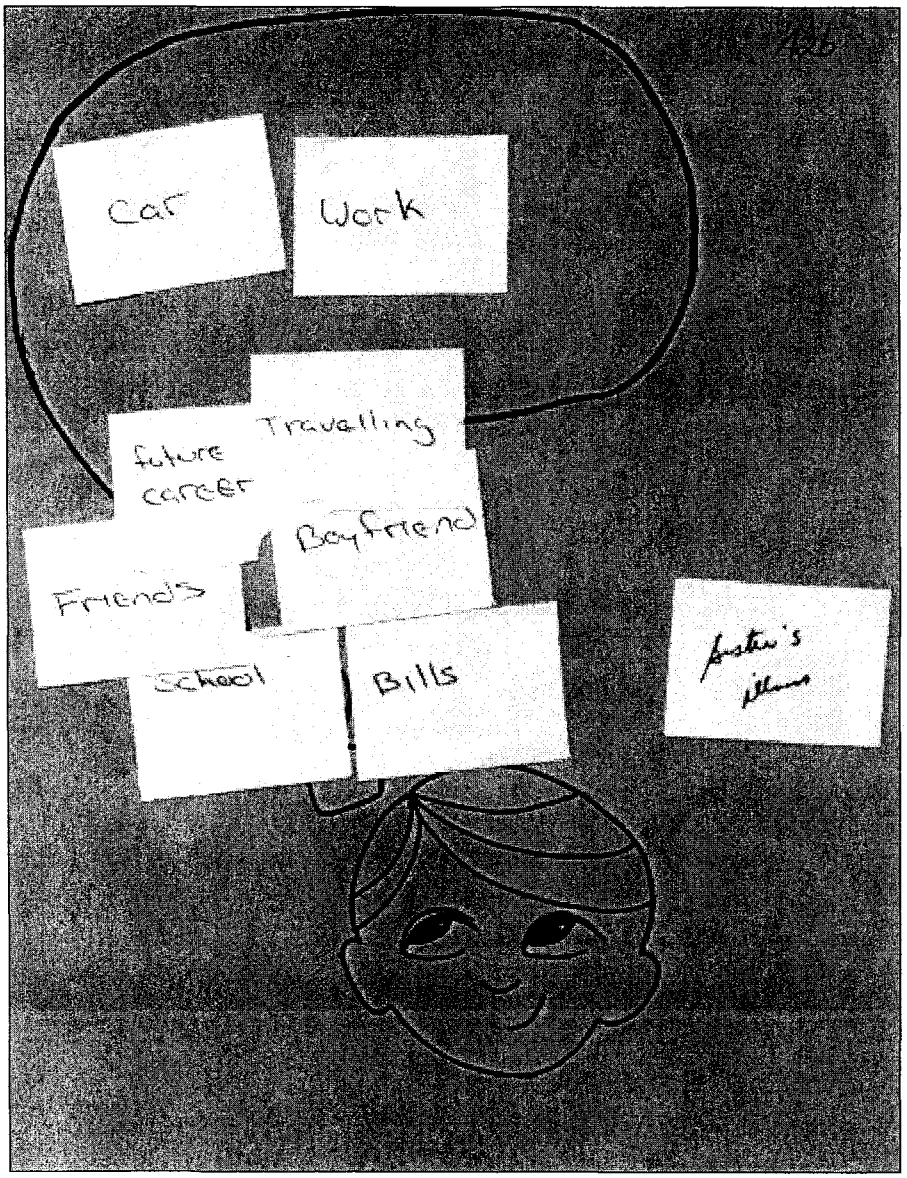
Breaking the Silence: Adolescents' Experience of Living with a Sibling who has Cystic Fibrosis.

Print Name	Signature	Date	Witness
CAROL LAROCQUE	C Larocque	JAN. 26/06	S Larocque
MIQUEL LAROCQUE	Miquel Larocque	JAN 26/06	S Larocque
JACINTHE LAROCQUE	Jacinthe Larocque	JAN 26/06	Sylvie Larocque
ALAIN LAROCQUE	A Larocque	JAN 26/06	Fernand Larocque
Nicolas Doucette	Nicolas Doucette	Feb 13/2006	S Larocque
Sylvie Larocque	S Larocque	Feb 10/2006	Jean Gilbert

NB: When a family member was younger then 18 years of age, written permission from a parent was also obtained.

Appendix L

Example of a completed think cloud



Appendix M

"Things I think about"

Instructions for the adolescents:

1) I would like you to write down things that you can't stop thinking about. For example, you may spend a lot of time thinking about school because you are having difficulty with math and you have to do a lot of extra work. Or, you may find yourself thinking about your boyfriend/girlfriend a lot or sports because you like it so much. It could be not so good thoughts (exams, someone's poor health) or good thoughts (spending time with friends).

2) Write one thing per card. Example, one card may have school written on it and the other card may have boyfriend/girlfriend written on it.

3) This is a picture of you and your "think cloud." What I would like you to do is to place the things that you think about the most closer to you in the "think cloud." Those things that you think about less often place them far away from you in your "think cloud."

4) Can you tell me about each one of these things that you can't stop thinking about? Can you tell me why you can't stop thinking about them? Can you tell me why you have placed it there in your "think cloud"?

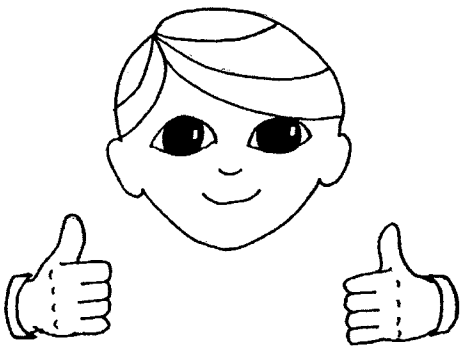
5) If the adolescent **has** chosen to put his sibling's illness as one of the things that he or she thinks about a lot, I will ask the adolescent: Why did you choose your sib's illness as something you think about a lot. Why did you place it where you did in the "think cloud"? When (i.e., hospitalizations) does it get closer to you in the "think cloud" (vice versa)? How do you feel when it gets closer? What do you do when it's in your thoughts a lot? Is there anything that could be helpful for you when you're having those thoughts?

6) If the adolescent **hasn't** chosen their sibling's illness as one of their preoccupation, I will ask them why? I will also ask them: Does it ever become something you think about a lot? (When?) How do you feel when it does become something you think about a lot? What do you do when in it's your thoughts a lot? Is there anything that could be helpful for you when you think about your sib's illness?

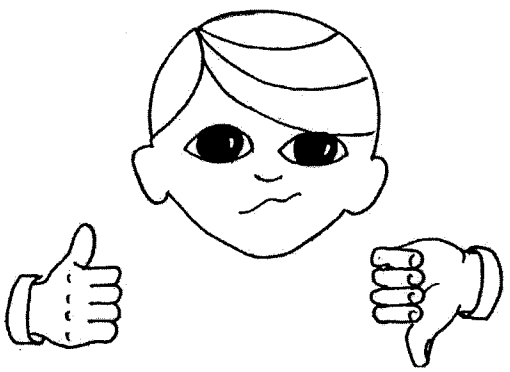
Appendix N

Cartoon characters "Always like me", "Sometimes like me", "Never like me"

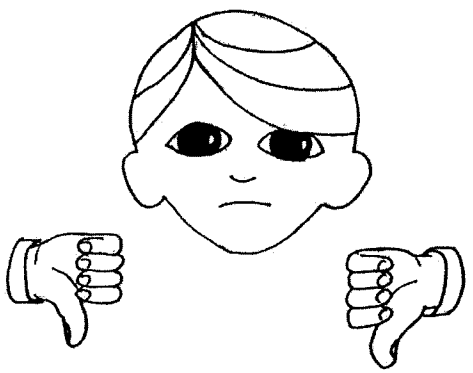
Always like me



Sometimes like me



Never like me



Appendix O

Card sort exercise
(Adolescents' experience based on key statements from the first interviews)

Instructions: I have chosen sentences from the first interviews that adolescents have shared with me when describing what it's like to have a brother or sister who has CF. I would like you to read each sentence and decide if it's like that for you ALWAYS, SOMETIMES, or NEVER. Make one pile with the sentences that are "Always like me", a second pile for the sentences that are "Sometimes like me", and a third pile with the sentences that are "Never like me."

After the piles have been made, I will go through every phrase in the ALWAYS and SOMETIMES pile and ask them why they have chose that phrase, what it means for them. For example, if they chose the following phrase:

My family is normal. We are not different from any other family.

> I will ask them to describe for me: Why have you chosen this sentence as being part of what it's been like for you/or what it's sometimes like for you? What does a normal family look like?...act like?...do? What makes your family "normal"? How do you think others perceive you family? Lets say someone comes up to you and says, I don't think your family is normal, what would you say to this person to convince them you were? Why is it important for you to be part of a normal family?

I will also ask them if there is anything they wanted to say about the sentences in the NEVER pile.