

GIVING A VOICE TO ADOLESCENTS LIVING WITH A SIBLING WITH  
CHRONIC ILLNESS

by

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## DEDICATION PAGE

I would like to dedicate this thesis to the children and families living with chronic illness that I have had the privilege to care for. Your courage and dedication have been an inspiration.

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## Abstract

The purpose of this phenomenological enquiry was to gain a deeper understanding of what it means to be an adolescent living with a sibling who has a chronic illness.

Children's chronic illness has an impact on well siblings and research findings have been inconsistent as to what effect this has on them. Semi-structured interviews using photo-elicitation were conducted with eight adolescents who had siblings with a chronic illness.

Through the use of interpretive phenomenology, three themes emerged: *Making Sense over Time*, *Getting Away from It All*, and *Creating Common Ground with Siblings and Family*. The adolescents were able to make sense of chronic illness over time by asking parents questions about the illness and attending support groups. Siblings found normalcy in their lives by getting away to spend time alone or connecting with friends.

## **List of Abbreviations Used**

CBDHA	Cape Breton District Health Authority
CBRM	Cape Breton Regional Municipality
CF	cystic fibrosis
CHD	congenital heart disease
JIA	juvenile idiopathic arthritis
REB	Research Ethics Board
RMH	Ronald MacDonald House

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## **Chapter 1: Introduction**

Children diagnosed with chronic illness are living longer because of advances in health care and they are being cared for by their families at home (Bellin & Kovacs, 2006; Gallo, Breitmayer, Knafl, & Zoeller, 1992; Hollidge, 2001). The Canadian Paediatric Society Adolescent Health Committee (2013) estimates that between 14.8% and 18% of all youths living in North America have a chronic health condition or a special care condition. A chronic illness as defined by Gedaly-Duff, Heims, and Nielson (2005) is a health condition that is long term, not curable, and may affect a child's daily activities such as going to school. Many children with a chronic illness require daily management and assistance to maintain functioning.

Children's chronic illness can have a significant impact on all family members including the siblings of the chronically ill child. Much attention has been given to the psychosocial well-being of the well siblings. The research on the effect of the well siblings' psychosocial well-being is inconclusive and it would be beneficial to find out more about the effects that chronic illness places on it.

The literature has revealed that sibling relationships are important; however, researchers continue to examine these relationships. Dunn (2000) included three reasons for ongoing research: siblings have the ability to influence one another, finding out more about these relationships will help to understand how children relate to others, and finding out more about sibling relationships gives insights into how families may influence their development. Dunn (1988) explained:

The relationship between young siblings is distinctive in its emotional power and intimacy; its qualities of competitiveness, ambivalence, and of emotional understanding that can be used to provoke or to support. On common sense grounds these qualities, and the high frequency of interaction and limitation

between siblings, suggest that the relationship will be of developmental importance – both through the direct impact of siblings upon one another, and through the indirect effects of the siblings’ relationships with the parents. (p. 119)

Sibling relationships offer a complexity of experiences, not only because children with chronic illness are living longer, but also because of the potential to share the longest of all relationships, a relationship that begins in childhood and lasts throughout adulthood (Dunn, 2000). Therefore, because siblings share a mutual bond and the relationships have the potential to last many years it would be beneficial to find out more about the experiences of well siblings who are living with a brother or sister who has a chronic illness (Thibodeau, 1988). Dunn (1988) stated that when siblings live with a brother or sister who has an illness or disability, evidence has been inconclusive about exactly how this influences siblings and how it influences the parent-child relationship. What is known is that siblings influence each other’s well-being and this may be displayed by siblings expressing signs and symptoms of internal and external behavior problems.

In addition, another important consideration is that of adolescent siblings. Adolescence is part of one’s growth and development that is shaped by earlier experiences. Significant events that take place during adolescence include puberty in early adolescence, peer relationships, increased freedom, and increased independence in middle adolescence, and transition to adulthood in later adolescence (Dashiff, 2001). Adolescents experience many changes during the phase of adolescence. It is a time of rapid growth and development as well as change. “Change during adolescence occurs on multiple levels. On the individual level, changes include biological maturation, cognitive development, and psychological development. Change also occurs in the social contexts of adolescents’ families, peer groups, schools and workplaces” (Saewyc, 2007, p. 812).

Most adolescents go through this developmental stage with a minimal amount of emotional strain but some adolescents have difficulty coping when a lot of normal events happen at the same time and are combined with “nonnormative life events” (Saewyc, 2007, p. 835). Adolescent siblings of children with chronic illness have been classified as vulnerable because they have an ill sibling (Burton, 2010) and also vulnerable because of the developmental stage of adolescence (Waite-Jones & Madill, 2008). When adolescents engage in research it provides them with the opportunity to receive the benefits of health research that enhances overall physical health and well-being (Society for Adolescent Medicine, 2003). This research study is intended to give a voice to adolescents living with a sibling with chronic illness.

### **Purpose of the Study**

The purpose of this research is to gain a deeper understanding of what it means to be an adolescent living with a sibling who has a chronic illness. Therefore, the research question is **“What are the experiences of adolescents who live with a sibling who has a chronic illness?”** In order to answer this I asked the adolescents questions to develop an understanding of their experiences over the course of their siblings’ chronic illness. This was done through phenomenological enquiry. The methods involved photographs captured by the adolescents followed by photo-elicitation interviews. Photo-elicitation is a wonderful way to engage children and adolescents (Clark-Ibanez, 2004). The photos allow participants to discuss issues that otherwise may not have been brought up in a spoken conversation (Croghan, Griffin, Hunter, & Phoenix, 2008). Heideggerian hermeneutic phenomenology was deemed an appropriate methodology for researching

children and families to gain understanding of the meaning of their everyday experiences (Plager, 1994).

### **Reflection: Location of the Researcher**

I have worked for 25 years with children and families living with chronic illness. I have evolved from a novice nurse working with children who have cancer and those requiring bone marrow transplants, to an expert nurse working in an outpatient setting administering chemotherapy, reviewing the follow-up plan of care, and travelling to pick up bone marrow from matched unrelated donors. Now, as a nurse educator, I guide and mentor nursing students in a pediatric clinical setting where there are a variety of chronic conditions. I encourage nursing students not only to perform a physical assessment, research the pathophysiology of the disease process, and to develop an appropriate plan of care, but also to listen, witness, and see how illness has impacted the child and the whole family. I believe that I have developed a *connoisseurship* (Benner, 1984), a familiarity with working with children and families living with chronic illness.

Benner (1984) has described experience as a requisite for expertise. The Dreyfus Model of skill acquisition has been used by Benner (1984) as a tool to describe five levels of competency in clinical nursing practice: novice, advanced beginner, competent, proficient, and expert. This model takes into account the growth in performance of skills and education. It provides a basis for the development of clinical knowledge and the ongoing advancement in one's nursing career. By progressing through the stages of skill development I have developed a deeper understanding of how chronic illness impacts not only the child but the entire family.

Having worked in many family-centered care facilities I have seen siblings that struggle and appear to be lost and forgotten about and in contrast, siblings that take part in the whole process of diagnosis and treatment. Nursing care is holistic, providing care for the mind, body, and spirit. And because of this, Heideggerian hermeneutic phenomenology is an appropriate methodology to research lived experiences and the meaning of these experiences in the everyday lives of families living with chronic illnesses. The *connoisseurship* that I developed over time and through experience, my passion for this phenomenon and conducting this study have contributed to a growing understanding of these lived experiences.

## **Chapter 2: Literature Review**

The purpose of this review was to gain insights into what is already known about childhood chronic illness and the impact it has on family, and more specifically adolescent siblings. A literature search was conducted through various databases that included CINAHL, PSYCH INFO and PubMed since they are the largest databases of nursing literature on this topic. Key words included “chronic illness,” “childhood,” “teenagers,” “siblings,” “adolescence,” and “family.”

There has been much research done on how chronic illness affects a family and there is a growing interest in how the illness affects the well siblings. The research on sibling impact to date has been inconclusive; it is unclear what impact chronic illness has on the healthy sibling. I began by reviewing the literature related to chronic illness, families, and siblings to develop an understanding of the implications of chronic illness on these groups. Much of the research includes quantitative studies, largely involving mixed parent and sibling reports together, which is problematic because parents tend to voice more negative manifestations (Guite, Lobato, Kao, & Plante, 2004; Kao; Sharpe & Rossiter, 2002; Williams, Ridder, Liebergen, Piamjariyakul, & Williams, 2009). The remainder of the research has focused on impact on young children or children and adolescents mixed together and not specifically on adolescents. It is important to pay attention to adolescents because of their vulnerability to potential negative psychosocial effects during this developmental stage and also because they have an ill sibling.

### **Impact on the Family**

There is agreement in the literature that chronic illness has a considerable impact on all family members including siblings. There are inconsistencies on what the exact

impact is on the well siblings (Barlow & Ellard, 2006; Bellin & Kovacs, 2006; Dunn, 1988; Hollidge, 2001; Houtzager, Grootenhuis, & Last, 1999; O'Brien, Duffy, & Nicholl, 2009; Sharpe & Rossiter, 2002; Waite-Jones & Madill, 2008; Wennick & Hallstrom, 2006; Williams, 1997). Children with chronic illness require adjustments to household routine and this impacts the entire family (Looman, O'Conner-Van, & Lindeke, 2008). When there is a sick child in the family it can have varied effects on family relationships (Dunn, 1988). The consequences of chronic illness may have more profound effects than those imposed by the illness itself (Lavigne & Ryan, 1979).

There are many models and frameworks that have been presented in the literature to enable an understanding of the far-reaching effects that chronic illness places on the family and how the family evolves to manage it. Lewis and Prescott (2006) have explained the concept of the family system in relation to chronic illness, which is based on the systems theory:

The family is a system in which the sum is more than the total of the parts. Anything that affects the system as a whole will affect the individual members, while anything that affects the individual members will necessarily affect the system as a whole. Like all systems the family system struggles to gain control. (p. 156)

In the context of this research study it was difficult to isolate the well siblings and look at their experiences without considering that they are part of a family and being influenced by all family members. Systems theory is discussed here because it focuses on the family as a whole. Lewis and Prescott (2006) have proposed that this way of viewing the effects on family takes into consideration that family processes are always changing and considers social and psychological spheres of family members as well. This theory is applicable in the context of the impact of chronic illness on the family as it covers a

variety of experiences, the family is viewed within the context of a larger community that it is situated in and also includes the smaller subsystems or relationships, it involves interactions, and it looks at the family unit as a whole (M. M. Friedman, Bowden, & Jones, 2003).

Several studies have examined the challenges of chronic illness for parents. Melnyk, Feinstein, Moldenhouer, and Small (2001) described specific times in the course of chronic illness that parents encounter stressors. These stressors for parents can fluctuate but can be grouped as occurring during the following times: when the ill child is diagnosed, when the ill child transitions from one developmental stage to the next, when parents must keep up with the needs related to managing the illness, or during disease flare-ups and when the ill child is admitted to the hospital. In addition, Gibson (1986) found that the factors that presented the most challenges for parents were if they had a hard time accepting and adjusting to a new challenge imposed by the illness and facing the ongoing management of day-to-day care. Barlow and Ellard (2006) conducted an overview of the research evidence base on the psycho-social well-being of children with chronic disease, their parents and siblings. Only two out of the ten reviews located included parents. One of the reviews was related to timing of the stressors; the traditional review which related to parents of children with cancer, found that parents experienced an increase in distress at diagnosis and it decreased after one year. The second was a meta-analysis that found parents of children with sickle cell disease experienced no effect on their mental well-being compared with a control group. Barlow and Ellard (2006) concluded that the systematic reviews are helpful to confirm what is known in the



literature and to look further into the parental concerns within one specific chronic illness and compare to a variety of chronic illnesses.

Steele and Davies (2006) examined the process parents engaged in when a child is faced with a life-threatening illness using grounded theory methodology. The study findings revealed a process whereby parents were affected emotionally, physically, financially, and spiritually. The emotional impact included a variety of emotions such as “fear, uncertainty, and grief” (Steele & Davies, 2006, p. 577). Similar to Melnyk et al. (2001), Steele and Davies (2006) found these emotions were always there for these parents and would vary over time. As the child’s health status changed negatively, parents described a parallel increase in their experience of a variety of emotions.

Steele and Davies (2006) found that many parents responded in negative ways to stressors imposed by the illness, such as turning to alcohol and drugs. Due to limited financial resources parents who were clinically depressed were not able to benefit from counseling because of the cost. Many parents displayed physical symptoms such as migraines and physical and mental fatigue. The financial impact imposed by the chronic illness was felt by all families. This research shows the far-reaching effects imposed by chronic illness. If parents do not have the resources when living with a child with chronic illness this affects the whole family.

Hodgkinson and Lester (2002) conducted a qualitative study using a grounded theory approach. They identified the perceived causes of stress which were challenges for mothers caring for children with cystic fibrosis (CF). The mothers expressed they were often caught “in the middle” making decisions related to CF (p. 379); they felt the “burden of responsibility” from needing to keep family members up to date with what

was happening with the ill child, caring for the ill child and also involving well children in the CF routine (p. 380); and they felt that they had a “changed identity” as they made sacrifices, such as interrupting their work schedule, to care for the child with CF (p. 380).

Furthermore, many studies have examined coping strategies for parents. Social support influences coping in families living with chronic illness (Gibson, 1986; Hodgkinson & Lester, 2002; Melnyk et al., 2001; Nabors, Kichler, Brassell, & Thakkar, 2013; Tak & McCubbin, 2002). Hodgkinson and Lester (2002) identified coping strategies of mothers living with a child with CF: “problem-focused coping,” given that they were able to find appropriate supports; “appraisal-focused coping,” because they managed the problems and fit them into their lifestyle; and “emotion-focused coping” as they came to a point where they were able to accept the illness and had hope for the future (p. 381). Gibson (1986) conducted a quantitative research study looking at coping strategies utilized by parents of a child with CF. She found that for parents, social support, focusing on the positives, and strength from within were helpful factors in coping. The most important influence on how well the family was able to successfully navigate the challenges imposed by chronic illness and maintain healthy development was how the parents responded in these situations (Gibson, 1986).

Similarly, Tak and McCubbin (2002) found a positive relationship between perceived social support, coping and family resiliency. The researchers conducted a secondary analysis on a subset of a larger longitudinal study. The purpose of the study was to explore the connection between “family stress,” perceived social support,” and “coping” in families who have a child with a congenital heart disease (CHD), using the resiliency model of family stress, adjustment, and adaptation. Ninety-two families who

had a child under 12 years of age who was recently diagnosed with CHD participated. The researchers found that the mother's coping style had a large influence in encouraging family members to be worried, to be supportive of one another, and to have open communication with medical staff. Younger fathers found coping was related to sustaining social support and self-esteem and mental well-being. Overall, perceived social support was positively associated with both the mother's and father's coping ability and therefore was a contributing feature in family resiliency.

Positive coping has in turn been shown to influence family functioning. Nabors et al. (2013) conducted a mixed method study using standardized measures and grounded theory to examine the factors related to caregiver state anxiety and coping with a child's chronic illness. There were 95 primary caregivers and guardians of children with chronic illness who were living at a Ronald MacDonald House (RMH); 66% were mothers, 21% were fathers, and 13% were guardians. The findings identified four supports that helped the caregivers with coping: family and friend support, having RMH as a place to stay, help from the staff at the hospital where their ill child was being hospitalized, and faith. The factors identified that negatively affected coping included: the distance from home, concerns with their ill child's health, caregiver's emotional well-being and monetary concerns, the well child's lack of understanding related to their ill sibling's well-being, and the lack of ease with dealing with medical staff. Family functioning was identified as a resiliency factor that assisted to lessen caregiver anxiety.

The ability to normalize chronic illness is a way to maintain family functioning. Bluebond-Langner (1996) conducted research with families of children with CF, using an ethnographic methodology. She initially expected to find the children living with siblings

with CF to be different from children who had well siblings. One surprising finding was that there was not much of a difference and that the structure of family life influenced how well the siblings did. The well siblings had trouble with their thoughts and feelings but overall there was little difference when compared with families with well children. This was attributed to the fact that the families maintained a sense of control and normalcy and minimized disruptions caused by chronic illness until the terminal phase.

This concept of normalcy and sense of control is known as normalization.

Robinson (1993) conducted a qualitative study that used repeated in-depth interviews and analyzed the data using a constant-comparative method. She described normalization as the way that families and individuals living with chronic illness live “life as normal” (p. 6). It is “essentially normal persons leading normal family lives” (Robinson, 1993, p. 9). Robinson (1993) described it as a “shift in perspective” and compared it to viewing from a camera lens, in the sense that some parts are clearly visible and others are not well-focused. This “normalcy lens” views life as normal. When something does not fit with the normal view it is put “in the background” and what is seen as normal is focused on (p. 12).

Knafl and Deatrick (2002) defined normalization as a process that occurs when families who are faced with challenges related to chronic illness come to see both the child and their lives as normal. Deatrick, Knafl, and Murphy-Moore (1999) clarified the concept of normalization when they revised an earlier model presented by Knafl and Deatrick in 1986. The process of normalization will occur, in most situations, when a family does the following: “acknowledges the condition and its potential to threaten lifestyle,” “adopts a ‘normalcy lens’ for defining child and family,” “engages in parenting

behaviors and family routines that are consistent with a ‘normalcy lens’,” “develops a treatment regimen that is consistent with a ‘normalcy lens’,” and “interacts with others based on a view of child and family as normal” (Deatrick et al., 1999, p. 211). When families are able to normalize the chronic illness they are able to maintain family functioning (Deatrick et al., 1999). Knafl and Deatrick (2002) referred to normalization as a process, but it is not all or nothing. When normalization does not occur, parents focus on the illness and the differences, and often the illness can be viewed as a problem and cause conflict (Knafl & Deatrick, 2002). Normalization may prove to be more difficult for single parents or when there is more than one individual in the household with a chronic illness (Newton & Lamarche, 2012).

The role of fathers as caregivers for children with chronic illness has been given attention in recent findings in the literature (Schneider, Steel, Cadell, & Hemsworth, 2011; Swallow, Macfadyen, Santacroce, & Lambert, 2011) Schneider et al. (2011) conducted a secondary analysis of data obtained in a cross-sectional descriptive study to examine the differences on psychosocial outcomes between male and female caregivers of children with life-limiting illnesses and found that there are differences. The participants were 273 parents. The majority of caregivers in this study (224) were female. The researchers suggested that men are involved in care and professionals need to provide assistance so they can be more involved. There was not a major difference between males and females on self-esteem or spirituality. Other significant findings included: the men in the study were older; women struggled more in managing the financial issues connected with caregiving than men; women scored higher for “meaning in caregiving,” depression and burden but lower for optimism. The researchers

acknowledged the need to find ways to get fathers involved in research and suggested that a longitudinal study would better capture the caregivers' outcomes.

Swallow et al. (2011) conducted a narrative review of the literature to explore fathers' contributions to management of their child's long-term condition. The review included 7 countries and spanned over 13 years. Thirty-five papers that included 29 studies were included in the review. Twelve studies were qualitative, 15 were quantitative and 2 used mixed methods. An overall significant finding was that fathers' involvement in care may not be captured in the literature because they are seen less often by health care professionals. The researchers suggested resourceful ways that were noted in the review to get fathers involved that included health care professionals being available to connect in the evening and week-ends, having resources on the internet and the possibility of a group discussion, led by a male, on-line. Swallow et al. (2011) made recommendations for health care providers to provide "anticipatory guidance" to mothers on common responses from fathers when they seem unconcerned. They suggested mothers be given information on how to encourage fathers' participation in care and the benefits this would offer the family. Health care providers should also consider meeting with fathers alone or with the mother to allow expression of worries. Both of these studies acknowledged the need to have fathers more involved in research and in care of their ill child.

Health care providers can offer support to families living with a child who has a chronic illness. Newton and Lamarche (2012) suggested that parents will try to get "normalcy" in their lives and identified ways to help support families: by keeping the relationship professional, working with parents on treatment plans for the ill child, having

compassion, being aware of supports, and becoming aware of “stressors” and alleviating them (p. E4).

In summary, chronic illness creates challenges for all family members including parents. Different events along the course of a child’s illness have been shown to cause more stress than others (Barlow & Ellard, 2006; Gibson, 1986; Melynk et al., 2001; Steele & Davies, 2006). Parents may respond in a negative way and chronic illness can cause a financial impact (Steele & Davies, 2006). Coping strategies have been identified (Hodgkinson & Lester, 2002; Tak & McCubbin, 2002). Social support influences coping in families living with chronic illness (Gibson, 1986; Hodgkinson & Lester, 2002; Melynk et al., 2001; Nabors et al., 2013; Tak & McCubbin, 2002). In addition social support has been linked to coping and family resiliency (Tak & McCubbin, 2002). Normalization is a way to maintain family functioning when living with chronic illness (Bluebond-Langner, 1996; Robinson, 1993; Knafl & Deatrick, 2002; Deatrick et al., 1999). Researchers have recognized the father’s role in caring for children with chronic illness and there is a need to keep them engaged and it may have implications for family functioning (Schneider et al., 2011; Swallow et al., 2011).

### **Impact on Siblings**

Many research studies including four reviews of the literature have revealed findings related to the psychosocial well-being of siblings living with chronic illness (Barlow & Ellard, 2006; Hollidge, 2001; Menke, 1987; O’Brien et al., 2009; Sharpe & Rossiter, 2002; Waite-Jones & Madill, 2008; Williams, 1997; Vermaes, Susante, Hedwig, van Bakel, & Oosterbeek, 2012). Four reviews were examined to provide insights into the contributing factors that have led to the inconsistencies in the literature.

Williams (1997) conducted a review of the literature with two main purposes. The first purpose was to identify effects of chronic illness on siblings being cared for at home. A second purpose was to look for variables related to adjustment of siblings with chronic illness. Williams reviewed 43 studies published between 1970 and 1995 relating to siblings and chronic illness. Most of the studies in Williams' (1997) review were quantitative in nature and most of the studies involved parents. Nine studies were done with the siblings alone. Only two were identified as qualitative studies; one focused on 6-12 year olds and the other included 6-16 year olds dealing with a sibling that has cancer.

The overall findings suggested that most studies reported an increased risk for negative psychological adjustment in siblings living with chronic illness. This included the following behaviors: "higher internalizing and externalizing behavior problems and lower social competence," "low self-esteem," "withdrawal or shyness," "somatic complaints," "multiple behavior problems," "poor peer relations or delinquency," "feelings of loneliness and isolation, anxiety, depression, vulnerability, anger; worry about ill child" and "school problems" (p. 318). The majority of studies, about 60%, revealed an increased risk for psychological adjustment for siblings. In 30% of the studies no risk was revealed for negative adjustment among well siblings. In 10% of the research studies there were both positive and negative effects of having a sibling with a chronic illness.

Positive findings were "enhanced family closeness," "very good sibling relations," "personal growth in siblings," "increased sensitivity/empathy," and maturity (p. 316). Williams (1997) identified variables related to positive sibling adjustment such as high levels of social support and resources, and positive communication between



parents and siblings about disease information. Williams (1997) also identified variables related to negative sibling adjustment such as maternal depression, lack of family cohesiveness, and numerous family stressors. Mothers who felt the healthy siblings were poorly adjusted also saw managing the chronic illness as a burden, did not feel control over the illness, and saw the chronic illness as being serious. Williams (1997) identified the characteristics of family, parent, illness, and siblings as being related and having an effect on the degree to which the well sibling adjusts to living with chronic illness.

In a more recent literature review of the impact of childhood chronic illness on siblings, O'Brien et al. (2009) included 17 quantitative research studies related to autism, cancer and Down Syndrome. The authors concluded that a sibling living with a child with Down Syndrome adapted well overall but found decreased time with parents and limited family activities. On the other hand, there was conflicting information on how well the siblings adapted to living with children with cancer and autism; some siblings were well adjusted and some siblings had behaviour problems, such as internalizing problems and difficulties with peers. Family support and sharing of responsibilities were variables that contributed to siblings adjusting well to autism. For siblings of children with cancer, hospital stays that meant parental separation were difficult. In this quantitative study variables such as socio-economic status and parental stress affected how well siblings managed. In conclusion there were many variables that were identified that contributed to sibling adjustment. The recommendation was that all siblings should be considered "at risk" for an adjustment difficulty until a full assessment is completed by a health care professional to assess each unique situation. This review supported Williams' (1997) review, in that both found there are many variables that have an effect on how the well

sibling deals with living with chronic illness. This review highlighted research findings from quantitative methodologies and emphasized the inconsistencies in the literature in that some siblings did well and others had negative effects – overall it was inconclusive. Both of these reviews showed the majority of studies involved reports from parents and siblings. These two reviews revealed the need for more qualitative research that focuses on the experiences of the well child.

Sharpe and Rossiter (2002) conducted a meta-analysis on siblings of children with a chronic illness. They reviewed 51 published studies between 1976 and 2000. They found parents' reports were more negative than the child reports. This is significant as it demonstrated that it made a difference in who was reporting. This research validated that it is important to hear about the experiences of the adolescents who are living with the ill siblings and give them a voice. Sharpe and Rossiter (2002) stated that “the sibling relationship is paradoxical, incorporating both conflict and companionship” (p. 706). They also concluded that although there may be complications in the relationship there can be a resiliency factor that is brought out in the context of disability. Sharpe and Rossiter (2002) found that overall there was a negative effect of living with a sibling with a chronic illness. This was consistent with other noted reviews including those by Williams (1997) and Williams et al. (2009). Sharpe and Rossiter (2002) stated that this meta-analysis highlighted the need for more research in this area of psychological well-being of siblings of children with chronic illness including qualitative studies. In addition, they reported the mean age as 10.8 years; the youngest siblings were 2 and the oldest were 20. Fewer studies have been conducted with adolescent siblings compared with younger children.

Barlow and Ellard (2006) conducted an overview of the research evidence base on the psycho-social well-being of children with chronic disease, their parents and siblings. This review included five reviews on the psycho-social well-being of the ill child, one that combined the psycho-social well-being of an ill child and parent, one on parents alone and two on the well siblings. The findings that pertained to the well siblings included those from Sharpe and Rossiter (2002) which were already described in this review and the findings from a second review by Houtzager, Grootenhuis, and Last (1999) which showed mixed findings. Some siblings had substantial behavioural issues, emotional grief and positive effects. The extent of these findings was uncertain because of the conflicting reports in that some studies reported increased levels of “anxiety and post-traumatic stress” in a percentage of siblings while other studies reported lower levels of “anxiety and depression” (p. 28). Barlow and Ellard (2006) concluded that there are many differences between studies and limitations that include “paucity of longitudinal data, small sample sizes preventing exploration of the effects of factors such as gender and age, lack of systematic research on situational coping strategies, and failure to include standardized measures” (p. 29). The findings from this review again speak to the inconsistencies in the literature pertaining to the effects of chronic illness on well siblings.

The fourth and most recent review by Vermaes et al. (2012) is a meta-analysis that was done on the psychological functioning of siblings in families of children with chronic health conditions. It included 56 research reports, 52 of them being studies. The studies in the meta-analysis started in the 1970s and there were 10 done since 2000. The studies in the meta-analysis included a mixture of reports from parents and children; they

also used control groups and normative data. The findings revealed an overall substantial small negative effect on well siblings that implies this is a vulnerable group. It showed that siblings are at risk for internalizing negative behaviours. Younger siblings appeared to be less at risk than older siblings in relation to their “self-attributes”; however, the researchers felt that parent reporting was a variable in this finding. The study also found that siblings of children who had a life-threatening illness have an increased risk for psychological troubles. One suggestion was that future studies should focus on “moderating effects” of certain variables such as support and coping (p. 173). Alderfer et al. (2010) conducted a systematic review to explore psychosocial adjustment of siblings of children with cancer, and similar to Vermaes et al. (2012) found that adolescent siblings appeared to have more adjustment challenges than other groups such as preschool-aged siblings, school-aged siblings and adults. Overall well siblings seem to have less difficulty over time.

In addition, in a quantitative study conducted by Havermans et al. (2010) that examined quality of life and impact of illness on siblings of children with CF, they also found that siblings who were older than the age of the child with CF reported a higher impact of CF than younger siblings. The well siblings completed the questionnaires themselves. A finding that was different than they hypothesized was that the CF siblings reported a better quality of life compared to their peers with healthy siblings.

Despite the inconsistencies in the literature related to the effects of chronic illness on well siblings there was a consensus that chronic illness has an overall negative effect on the psychosocial well-being of the well sibling.

Parental perceptions on sibling adjustment is found in much research related to chronic illness and impact on siblings (Cordaro, Veneroni, Massimino, & Clerici, 2012; Guite et al., 2004; Kao, Plante, & Lobato, 2009; Menke, 1987; O'Haver et al., 2010; Sharpe & Rossiter, 2002; Waite-Jones & Madill, 2008; Williams et al., 2009). Parents' voices on pediatric chronic illness were highlighted in a study that was a secondary analysis of data provided in a random control trial by Williams et al. (2009). The majority of findings were negative manifestations for the well sibling. The average age of the well sibling was between 10.9-11.5 years. The mother was the voice in the research in 96% of the couples. Five overall themes identified negative findings in the well siblings that included "jealousy/envy," "upset/anger/resentment," "fear/worry/anxiety," "negative behaviors," and other problems such as "guilt" and "school problems" (p. 101). All five themes indicated negative parental perceptions. Up to one third of the parents' voices reflected positive effects for the well siblings that included an increase in "family closeness," "sibling sensitivity to the ill child and caregiving," and "sibling personal growth and maturation" (p. 105). Guite et al. (2004) found differences in perceptions between sibling (ages 8-13 years) and parent reports on a questionnaire. Typically parents reported having higher levels of concerns for the siblings than the siblings did. As well, Cordaro et al. (2012) conducted a mixed method study with parents to assess the psychological adjustment in siblings of children with cancer and found that the older siblings had more visible difficulties than younger siblings. The researchers suggested that support programs that had a focus on the healthy siblings would help parents to be attentive to the requirements of healthy siblings.

In the research findings noted above by Guite et al. (2004) and Williams et al. (2009), the parental reports included younger aged children. Menke (1987) interviewed children with chronically ill siblings between the ages of 6-12 years and their parents. Many worries and concerns were identified related to siblings. The children were not able to identify as many changes in themselves compared to their parents; 64% felt that their parents had changed. The children thought they noticed their parents were more worried and more tired, and had more fights yet also reported that the parents got along better, and spent increased time with the ill sibling. The types of worries seemed to vary depending on the age of the child and the diagnosis of the ill child. This data suggested that there may be differences in worries depending on age and diagnosis.

A qualitative study of siblings living with chronic illness, Waite-Jones and Madill's (2008) study explored the lived experiences of families living with juvenile idiopathic arthritis (JIA). Eight families were interviewed including eight well siblings and eight siblings with JIA. Eight mothers were interviewed as well as seven fathers and one grandmother. The age range for well siblings was 9-24 years. The transcripts were analyzed using grounded theory methods and the results of the study revealed five categories. The first was "comparing with a norm" (p. 483). The well siblings compared their family life with that of their peers. The second was "social contagion" (p. 484). The siblings felt self-conscious that others were aware of the visible differences in their siblings and drew negative attention. The third was "emotional contagion" (p. 485). The well siblings were aware of their emotions as well as their family members'; there were a variety of emotions, including fear, uncertainty, unpredictability, anger, and frustration. The fourth was "amplified ambivalence" (p. 486). Often the siblings experienced

ambivalent feelings about the child living with JIA. On one hand the well siblings displayed concern for their sibling and on the other they competed for attention from parents. The fifth category was “social and emotional adjustment” (p. 42). Extended family support helped to reduce some of the negative consequences of living with a sibling with JIA. This study explored the experiences of siblings living with chronic illness and suggested that adolescence is a time of increased sensitivity for siblings and increased support would be helpful in dealing with some of the negative consequences associated with having a sibling who has JIA. Researchers used the traditional interview method and some of the siblings interviewed may have felt a power difference between themselves and the researcher conducting the interviews.

In a more recent qualitative study, Wennick and Huus (2012) interviewed siblings between the ages of 10 and 17 years who lived with siblings who were newly diagnosed with type 1 diabetes. The interviews were analyzed using content analysis and three categories were developed: “living differently” – the researchers found that the siblings made adjustments for living a more regimented routine and were more perceptive of the emotions of their sibling and parents and became more patient, understanding, and empathetic; “being concerned” – the siblings found that it was difficult learning about issues related to diagnosis, and they had worries and fears related to the well-being of their siblings; and “participating in care for the affected child” – the siblings had more responsibilities and chores at home and they often helped out with diabetes management. The researchers found that the siblings needed more information and support from the healthcare team and more so at the time of diagnosis.

Support that the well siblings receive in the form of support groups and family functioning is connected to positive sibling mental well-being (Houtzager, Grootenhaus, & Last, 2001; Incledon et al., 2013). Incledon et al. (2013) conducted a review of the literature on factors associated with mental health in siblings of children with chronic illness. They reviewed 17 studies that were a mixture of intervention, randomized controlled trial, longitudinal, and cross-sectional studies. Several factors were identified that were associated with sibling mental health “Group programs and social support,” “informational support,” “emotional support,” “coping strategies,” and “family functioning” (pp. 3, 7-8). Mental well-being was associated with “camp attendance, perceived parent/peer support, illness education, and enhancing control through cognitive support strategies and routine” (p. 1) Parental emotional support was found to be a safeguard for sibling mental health. Siblings who had a positive outlook were found to adjust more positively than those who did not. The researchers suggested that parents play a significant role in providing support for the sibling’s mental health well-being and it is important that they assume responsibility for their own mental well-being by initiating appropriate supports as needed.

Houtzager et al. (2001) conducted a quantitative study to assess the effectiveness of support groups for siblings of children with cancer. The well siblings were between the ages of 7-18 years old and nine were males and 15 were females. The researchers found that support groups were beneficial to reduce anxiety. During the sessions the siblings had the opportunity to learn new strategies to deal with changes brought on by their brother’s or sister’s illness. The group sessions provided an opportunity to understand emotions and family relations as well as information about the sibling’s illness.



In summary, psychological adjustment of siblings when living with chronic illness has received much attention, mainly through quantitative methodologies and many including mixed parent and sibling reports. Negative psychosocial adjustment for siblings was noted in the literature (Alderfer et al., 2010; Barlow & Ellard, 2006; Cardaro et al., 2012; Guite et al., 2004; Havermans et al., 2010; Menke, 1987; Sharpe & Rossiter, 2002; Vermaes et al., 2012; Waite-Jones & Madill, 2008; Wennick & Huus, 2012; William, 1997; Williams, 2009). Positive psychosocial behaviours for siblings were identified in the literature (Barlow & Ellard, 2006; Houtzager et al., 1999; O'Brien et al., 2009; Sharpe & Rossiter, 2002; William, 1997). Parental perceptions on sibling adjustment were often found to be more negative (Guite et al., 2004, Menke, 1987; Sharpe & Rossiter, 2002; Williams, 2009). Some researchers identified that older siblings were more at risk for negative psychosocial behaviours (Alderfer et al., 2010; Cardaro et al., 2012; Vermaes et al., 2012). Havermans et al. (2010) found well siblings of siblings with CF rated a higher quality of life compared to peers with healthy siblings but also found children who were older than their sibling with CF reported a higher impact. Support that contributed to sibling adjustment was identified by Houtzager (2001), Waite-Jones & Madill (2008), O'Brien et al. (2009), Cardaro et al. (2012), and Incedon et al. (2013). In addition many variables have been identified that affect how siblings adjust suggesting why some children adjust better than others.

Although much research has been done looking at the implications that chronic illness places on well siblings there remains a gap in the literature related to adolescent siblings' lived experiences. There have been qualitative studies done using the traditional interview style, not taking into account that more child-friendly interview styles may

elicit more in-depth accounts about their lived experiences. More research is needed to explore the lived experiences of adolescents living with siblings with chronic illness and with this in mind this interpretive phenomenology study has been conducted so the voices of these adolescents may be heard.

### **Chapter 3: Methodology: Interpretive Phenomenology**

A qualitative approach was chosen for this research study, specifically interpretive phenomenology. Qualitative research approaches offer a beneficial way to research the “lived experiences” of youth (Drew, Duncan, & Sawyer, 2010, p. 1677).

Creswell (2007) has shared his insights:

Qualitative research begins with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is inductive and establishes patterns and themes. The final written report or presentation includes the voices of participants, the reflexivity of the researcher, and a complex description and interpretation of the problem, and it extends the literature or signals a call for action. (p. 37)

Interpretive phenomenology was selected to find out more about the lived experiences of adolescents living with siblings who have a chronic illness. Interpretive phenomenology has been developed as part of a philosophical movement to understand phenomena and has very early origins that date back to Plato, Socrates, and Aristotle (Fochtman, 2008). This philosophy has evolved over time to reflect beliefs of various philosophers. The intent in this research study was to focus on the phenomenology of Heidegger, interpretive phenomenology, because its goal is to develop a deeper understanding of the nature of meaning of our everyday experiences (van Manen, 2007).

Martin Heidegger (1889-1976) was born in Germany and his philosophy focused on the human experience as lived (Dowling, 2007). He was a student of Husserl (1859-1938), a German Philosopher who made significant contributions to phenomenology, but they had differences of opinions and he challenged some of Husserl’s beliefs on how the lived experience is explored. Husserl’s phenomenology was founded on Cartesian

traditions, meaning the phenomenon could be studied through consciousness and how the subjects described the experience (Dowling, 2007; Lopez & Willis, 2004). Husserl also believed that the researcher should put aside their prior knowledge on the subject being researched so they could gain an insightful understanding of the lived experiences (Lopez & Willis, 2004). Heidegger believed that the hermeneutic tradition was interpretive; that meaning is not always apparent to the participants in the research study but it becomes known from interpreting the narrative (Lopez & Willis, 2004). In addition to this, the “fore-structure is what is understood or known in advance of the interpretation. It is prior awareness” (Mackey, 2005, p. 182). The researcher makes this known as part of the research process. In this interpretive process the researcher goes back and forth between the fore-structure and what is being revealed by the participant to make meaning and develop a better understanding of the topic being researched. This has been called the “hermeneutic circle,” moving back and forth through parts and whole narratives to bring out hidden meaning (Koch, 1996, p. 176; Mackey, 2005).

Lopez and Willis (2004) have outlined two central tenets of Heidegger: “*lifeworld*” and “*being-in-the world*” (p. 729). Lifeworld means that all individuals’ realities are influenced by the world that they live in. Being-in-the world means that individuals are very much a part of the world that they live in. These two tenets are the focus of an interpretive or hermeneutic inquiry. Heidegger’s objective is to deepen our understanding of what it means to be. In order to do this, first a question must be developed and then the search follows. Heidegger (1962) stated,

Inquiry, as a kind of seeking, must be guided beforehand by what is sought. So the meaning of Being must already be available to us in some way. As we have intimated, we always conduct our activities in an understanding of Being. Out of

this understanding arise both the explicit questions of the meaning of Being and the tendency that leads us towards its conception. (p. 25)

There are several ways that someone or something can be and this is related to being human. Dreyfus (1992) stated, “Dasein in colloquial German can mean ‘everyday human existence,’ and so Heidegger uses the term to refer to human being. But we are not to think of Dasein as a conscious subject” (p. 13).

van Manen (2007) suggested there are four fundamental existential elements that are present in the lived world that give meaning to interpretive phenomenology: “spatiality,” “corporeality,” “temporality” and “relationality”; these elements helped to add meaning and guide reflection in relation to the lived experiences of the participants in this research study.

Spatiality does not refer to a concrete measurement of distance such as a kilometer, but refers to a feeling evoked by the space. van Manen (2007) said, “lived space (spatiality) is felt space” (p. 102). An example might be the feeling of freedom from being on top of a mountain or a feeling of comfort evoked from being home. Space gives meaning to what is important to the person (Mackey, 2005). van Manen (2007) said, “...lived space is a category for inquiring into the ways we experience the affairs of our day to day existence; in addition it helps to uncover more fundamental meaning dimensions of life” (p. 103). The participants’ descriptions of their everyday realities gave meaning to what is close to them; for one it was finding freedom outdoors and for others it was a feeling of being close to family members.

Time is fundamental to the lifeworld and it gives context to our understanding. Heidegger considered one to be temporally situated in the world, meaning that past, present, and future is acknowledged (Mackey, 2005; van Manen, 2007).

Lived time (temporality) is subjective time as opposed to clock time or objective time. Lived time is the time that appears to speed up when we enjoy ourselves, or slow down when we feel bored during an uninteresting lecture or when we are anxious, as in the dentist's chair. (van Manen , 2007, p. 104)

An understanding of time helped to situate participants in their everyday reality and gave meaning to their day-to-day routines (Mackey, 2005).

“Lived body (corporeality) refers to the phenomenological fact that we are always bodily in the world” (van Manen, 2007, p. 103). It means to be physically present in the world and how we act in various situations. It could be how a research participant responds when they are scared or threatened and wanting to flee. In this research study it was an adolescent moving around in his seat and fidgeting with his hands but once reassured he appeared more comfortable and these actions stopped. Another adolescent was laughing and smiling as happy memories were evoked by the photographs that she described.

“Lived other (relationality) is the lived relation we maintain with others in the interpersonal space that we share with them” (van Manen, 2007, p. 104). Relationality refers to our response to others in our interpersonal space. van Manen (2007) further stated, “In a larger existential sense human beings have searched in this experience of the other, the communal, the social for a sense of purpose in life, meaningfulness, grounds for living, as in the religious experience of the absolute Other, God” (p. 105).

Relationality was demonstrated by an adolescent in this research study who questioned where God was when his sister developed cancer. He stated, “Sometimes I don't understand how things work, like how can a two year old get cancer, like where's God in that situation?”

All of these existential elements are present in the lifeworld and one is not independent of the other; rather, they are interwoven and add layer upon layer of meaning to the lived experience. An understanding of these existential elements helped me to develop a deeper understanding into the lived experiences of adolescents who live with siblings with chronic illness. These elements guided my reflection and thematic analysis in relation to their lived experiences.

According to Creswell (2007) paradigms are a set of assumptions or beliefs that help researchers to guide their research question. He has stated that interpretive phenomenology is in the “constructivist paradigm” where the individual seeks to understand the world that they are in. Creswell (2007) added,

The goal of research then is to rely as much as possible on the participants’ views of the situation. Often these subjective meanings are negotiated socially and historically. In other words they are not simply imprinted on individuals but are formed through interactions with others (hence social constructivism) and through historical and cultural norms that operate in individuals’ lives. (p. 21)

When choosing to conduct qualitative research, researchers make assumptions. In ontological assumptions the question is “What is the nature of reality?” In epistemological assumptions the question is “What is the relationship between the researcher and what is being researched?” (Creswell, 2007, p. 17). Heidegger’s beliefs were different from Husserl whose belief was epistemological (Dowling, 2007; Mackey, 2005). Heidegger’s goal was to gain a deeper understanding of presence in the world through asking the question, “What does it mean to be?” Heidegger (1962) stated,

ontological research itself, when properly understood, gives to the question of Being an ontological priority which goes beyond mere resumption of a venerable tradition and advancement with a problem that has hitherto been opaque. But this objectively scientific priority is not the only one. (p. 31)

Heidegger's efforts were ontological (Dowling, 2007) and when the researcher selects a Heideggerian method, the researcher is dedicated to an ontological approach (Mackey, 2005). In the analysis of my study findings I developed themes supported by quotes from the adolescent participants. I focused on the meaning of what it was "to be" from the voices of the adolescents to develop a deeper understanding of the experiences of adolescent siblings of children with chronic illness.

### **Photo-Elicitation Interviewing**

In this study I used photo-elicitation interviewing as a method to elicit in-depth discussions so adolescents were able to share their experience of what it was like to be a sibling to someone with a chronic illness. Photo-elicitation interviews involved introducing photographs into the interview (Clark-Ibanez, 2004; Collier & Collier, 1986; Harper, 2002; Wells, Ritchie, & McPherson, 2013). Photo-elicitation methods are gaining in popularity in the social sciences (Croghan et al., 2008). Clark (1999) called using photos as the focus of discussion an "autodriven interview" (p. 39). The goal through using photo-elicitation in this research was to incorporate photographs as a means of collecting rich voiced descriptions of the adolescents' lived experiences. The stories that were told by the participants were analyzed using thematic analysis.

Photo-elicitation interviewing has many advantages when conducting research with children and adolescents. It is a child-friendly method that helps to engage children and can "ease rapport" between the participant and researcher (Clark-Ibanez, 2004, p. 1512). The adolescents in this research study were engaged during the interviews and they seemed to enjoy telling me stories about their photos. When they finished describing what each photo meant to them it was helpful for the flow of the interview to have



another photograph to refer to. The photos were helpful to elicit the participants' memories as they described different events in the course of their siblings' chronic illness. Sometimes looking at photos will bring about a memory and start a discussion based on the photo (Clark-Ibanez, 2004). Croghan et al. (2008) added that these methods help to gain a deeper perspective of the participants' self concept. This type of interview also gives the adolescents control as to what they want to include in the photos (Wells et al., 2013). In addition, during the interview, the photograph can serve as a point of reference for more discussion (Collier & Collier, 1986). Collier and Collier (1986) found that in photo-elicitation, "The images invited people to take the lead on inquiry, making full use of their expertise" (p. 105). In this research study, the photographs elicited a meaningful response from the participants as they evoked memories and caused the adolescents to reflect and articulate their experiences. All of the adolescents appeared comfortable as they referred to their photos and shared their stories.

### **Sampling and Recruitment**

In this phenomenological research study that incorporated photo-elicitation as a research method, there were eight participants. Their pseudonyms are: Kalel, Joe, Anthony, Jonathan, Zoe, Kosmo, Marie and Mats. The participants were recruited based on being between the ages of 11-17 years, residing within the Cape Breton Regional Municipality (CBRM) and having siblings diagnosed with chronic illnesses that primarily include diabetes mellitus, cancer, asthma, rheumatoid arthritis, cystic fibrosis, and chronic genetic disorders. These chronic illnesses share attributes that include the need for daily treatment regimens and daily interventions and have periods of stability mixed with periods of exacerbations. The participants' siblings ranged in age from 7-15 years

who had ongoing health issues that included diabetes, cancer, congenital heart disease and Down Syndrome. Four of the participants had siblings with diabetes and two of the participants had siblings with Down Syndrome, one had a sibling with cancer, and one had a sibling with congenital heart disease. Two siblings from one family were interviewed who had an older brother with an ongoing health issue; another sibling had two younger brothers with an ongoing health issue. Overall five participants had younger siblings and three participants had older siblings.

Purposeful sampling was used to select the participants for the study meaning that the individuals were selected based on their experience of the topic being studied. (Patton, 2002). In phenomenology the sample size is small to enable the researcher to explore the topic in depth (Ray, 1994). “The important point is to describe the meaning of the phenomenon for a small number of individuals who have experienced it” (Creswell, 2007, p. 131). I purposefully sampled 8 siblings for this study.

I contacted six local pediatricians and four Diabetic Educators and met with the Pediatric Unit Clinical Leader and Pediatric Ambulatory Care Nurse to inform them of my study and discuss the possibility of meeting and potentially recruiting participants through their offices and clinics at Cape Breton District Health Authority (CBDHA) (see Appendix A for Letter of Introduction to Health Care Professionals). The role of the health care professional was to give pamphlets that I provided (see Appendix B) to families who met the criteria and ask the families to contact me if they were interested or if they had questions. The pamphlets highlighted the study and directed the adolescent participants/families to contact me.

Recruitment was slow and after recruiting six participants I realized that I needed to increase my potential to meet more possible participants, so I also placed a poster (see Appendix C) that had similar content to the pamphlet in local community agencies, family practice settings and other community settings that may be visited by this population. I also incorporated the snowball sampling recruitment strategy so that families and participants who were aware and informed of the research study could pass along by word-of-mouth to others they knew who shared the same characteristics that may be potentially interested (Patton, 2002). When the participants contacted me I verified that they were eligible to participate in the study.

### **Data Collection**

Research methods include ways that the researcher and participants were able to engage in order to reduce the gap between the participant, researcher and the unknown (Hansen-Ketchum & Myrick, 2008). “The lifeworld, the world of lived experience, is both the source and object of phenomenological research” (van Manen, 2007, p. 53). As participants agreed to participate in this study I scheduled a time and a place to meet to explain the study, obtain consent, provide them with a camera and instructions, and to schedule a follow-up photo-elicitation interview. Data collection involved interrelated activities, participants taking photos and then describing what they meant to them in the photo-elicitation interviews that were set out to answer the research question, “What are the experiences of adolescents living with siblings with chronic illness?”

Because these were photo-elicitation interviews, the photos that the participants took guided the semi-structured interview. I considered using digital versus disposable cameras and they both have pros and cons. Plunkett, Leipert, and Ray (2012) have

suggested that digital cameras are readily available and could be re-used between the participants, and photos can be sent easily between participant and researcher, but participants also have the ability to delete photos. With disposable cameras photos cannot be deleted and I anticipated that much thought would be put into what photo to take hence adding for a deep discussion. A negative side was the cost associated with photo development and cost of all the cameras. After a discussion with my Supervisory committee I decided to proceed with the disposable cameras with the idea that the participants would put more thought into their photos and not be able to delete the photos. Overall the disposable cameras were well received by the adolescents in this study. There were a few noted concerns. One participant's camera broke so their parent bought a new one. A few others voiced some displeasure on the quality of the photographs; they felt the photos were blurry or out of focus. One participant had a couple of photos that did not turn out so I gave him the opportunity to describe, title and explain them during the interview.

At the time of consent (see Appendix D for Letter of Introduction and Consent Form to Participants and Appendix E for Parent/Guardian Consent) each participant was given a 27 exposure disposable camera along with a sheet, Instructions for Camera Use (see Appendix F). The participant was asked to take 8-10 photos of things or places that helped to show what it was like to be a brother or a sister to someone living with an ongoing health issue. They were told that some examples may include photos of things they liked to do with their brother/sister, or things they liked to do alone. It could include photos of places that they may like to go or maybe not like to go. It was reinforced that

they were the experts. For privacy reasons the participants were asked not to take pictures of people.

In the steps that were outlined on the Instructions for Camera Use, the first step was for the participants to write down a name on a piece of paper that they could be identified by in the research study; it was not to be their real name but a pseudonym. Each participant was identified by a pseudonym that they chose; this assisted to maintain confidentiality and privacy. As done by Smith, Gidlow, and Steel (2012), the participants were instructed to take a photo of the pseudonym that they had written on a piece of paper; this step helped them to get familiar with the camera. The participants were then instructed to take pictures of things or places to help tell their story. It was reinforced that they were the experts because they were the people in the study, between the ages of 11-17 years, sharing their experiences of living with a sibling with an ongoing health issue within the defined area. I gave the participants a call after week one with the camera to follow up on their progress and to see if they had any identified concerns or questions to ask. I gave a second call after the participants had the camera for two weeks, again, to see if they had any questions or any identified concerns. This step also assisted in developing a rapport with each participant. The conversation would start out with me asking how they were doing and what they were up to followed by a brief discussion on how they were getting along with the camera. If a parent answered the phone I would always ask to speak with the participants. Texting was the preferred communication with a couple of participants; the conversation that flowed through texting was the same as verbal conversations on the telephone. During this call or text we picked a time that I could pick

up the camera and have the pictures developed and we also arranged an interview time and location.

After the photographs were developed each participant was the first to see them and they had the opportunity to take out any photos they did not want to talk about or remove any photos that may reveal their identity. During the photo-elicitation interviews, the photos guided the semi-structured interview format. The participants were asked to give each of the photos a title, to add meaning to the photo. The participants placed the photos in the order that they wanted to talk about them and let me know when they were ready to begin the discussion. Semi-structured interviews allowed the children to engage in conversation and gave them control over what photograph that they wanted to start with first. I followed an interview protocol with probes (see Appendix G). This provided me with a set of questions with probes as a guide for the conversation (Petty, Thomson, & Stew, 2012). Collier and Collier (1986) found that the use of structured probes helped to elicit a deeper discussion.

During the interview I listened closely to the stories that I was told by the adolescents. I was relaxed, warm and respectful. It was a privilege to hear their stories. Building a rapport was easy with all of the participants; it was helpful to have made contact at least three times before the interview – during the consent signing and the two telephone follow ups to see how they were progressing with taking pictures with the camera. We engaged in everyday small talk about school, their part time jobs or sports leading up to the interviews. This allowed them to become familiar and comfortable with me as I set up the audio-recorders in the conference room or in a room in their home.

### **Setting**

The participants were given a choice to have the photo-elicitation interviews conducted in a private conference room on the Pediatric Unit at the Cape Breton Regional Hospital or in their home, with the provision that the family could make available a private room in their home for the interview. Three of the participants chose their homes and five participants chose the conference room on the pediatric floor. When the interviews occurred in the family homes the families were very accommodating. Two interviews took place in the downstairs family room when other family members were upstairs and the other took place in the family dining room while family members did some errands. The adolescents were able to share their stories in private.

### **Timeline**

Data collection was conducted over a 5-month period from the time of the first participant interview to the completion of the eighth participant interview. Data analysis began after the first interview, and writing took a total of seven months.

### **Thematic Analysis**

Data analysis began after the first interview. I transcribed each of the audio-recorded interviews myself and this allowed me to become very familiar with the narrative. It was a time-consuming process but it allowed me to return to the original interview as often as I wanted. I made comments in a different color font along the way as I transcribed, notes to myself and what I was thinking, things that stood out as being important. Audio-recording the interviews also enabled me to incorporate exact quotations into my final written work.

van Manen (2007) explained the process of hermeneutical phenomenological writing:

Writing creates the reflective cognitive stance that generally characterizes the theoretic attitude in the social sciences. The object of human science research is essentially a linguistic project: to make some aspect of our lived world, of our lived experience, reflectively understandable. (p. 125)

As Benner (1994) suggested, I moved back and forth between parts of the text and pieces of the analysis. This shifting between texts and parts and wholes enabled me to develop new interpretive questions. Thematic analysis is not a “rule bound process but a free acting of ‘seeing’ meaning” (van Manen, 2007, p. 79).

In the process of thematic analysis, as Mackey (2005) suggested, I reflected on the participants’ experiences as described with the philosophical tenets in mind. I remained open to the process, as Smythe, Ironside, Sims, Swenson, and Spence (2008) found was key to teasing out the hidden meanings. What was revealed were characteristics of the described experiences of what it was like to be an adolescent living with a sibling with chronic illness. I pieced together these characteristics to develop a set of themes that illustrate what having a sibling with a chronic illness meant for this study’s participants.

### **Trustworthiness**

Rigor in qualitative research is expressed as Trustworthiness, and is achieved by accurately representing the study participants’ experiences (Streubert Speziale & Carpenter, 2003). Lincoln and Guba (1985) have identified terms to refer to techniques that support rigor of the research work: “credibility,” “dependability,” “confirmability” and “transferability.”



Credibility includes activities that will increase the chances that credible findings will be produced in the research (Lincoln & Guba, 1985). “Prolonged engagement” with the subject matter is one of the best ways to establish credibility (Lincoln & Guba, 1985, p. 303). I attended to credibility through meetings with the adolescents. I met them first for consent signing during which time I gave out the cameras. I often met the adolescents along with their parent(s) at their homes which gave me an opportunity to see them in their natural setting and begin to develop a rapport. I then gave the adolescents two follow-up telephone calls during which time I asked how it was going with the photo taking and asked if they had any questions. During these calls I engaged in informal conversation to find out more about the participants: how their day was, how school was and finding out more about their part-time jobs if they were working. A couple of the participants preferred texting as a means of communication as opposed to verbal conversations; the conversations followed the same patterns. Through the photo-elicitation interviewing, the participants described their photos and what they meant to them, and provided a title for them and this helped to deepen the understanding of their situation. Petty et al. (2012) stated that documents such as photographs enrich the understanding of the context. Dependability is met when credibility has been demonstrated (Streubert Speziale & Carpenter, 2003). It is important to acknowledge that throughout the thematic analysis my supervisor and I had much correspondence via e-mail to ensure that my interpretation of all the findings was consistent with her interpretation given that she had more experience in this area.

Confirmability is the process used throughout the study that documents the findings (Lincoln & Guba, 1985). One way to achieve confirmability is to leave an “*audit*

*trail*” (Streubert Speziale & Carpenter, 2003, p. 38). I kept a reflective journal during the research study. My thought processes are made clearly visible in this research through the margin notes and the highlighted words/themes in the transcribed interviews. In the reflective journal, I made notes immediately following all of the interviews on the back of the Interview Protocol to capture my immediate thoughts and informal observations. The notes were kept in a reflective journal and I engaged in active reflection through writing and keeping track of new ideas, often in a table format, and reflective insights as time progressed.

In qualitative research the findings are specific to that study (Petty et al., 2012). However, Streubert Speziale and Carpenter (2003) stated, “transferability refers to the probability that the study findings have meaning to others in similar situations” (p. 39). To contribute to the transferability of the findings of this study attention has been paid to fully explaining methodology and methods so that those reading the findings will be able to make a decision about the transferability of these findings to other settings.

### **Ethical Considerations**

Ethical approval was obtained from Dalhousie University’s Research Ethics Board (REB) and from the CBDHA REB. During the meeting with the participant and parent(s)/guardian, I took two copies of the consent so that they could follow along with me as I reviewed and explained the purpose of the research. It was important that the letters and consents that I prepared for the adolescent and parent(s)/guardian be written in a clear, concise manner that was easy to read, so I used the The Flesch-Kincaid Grade Level 6-8 as a guide to written materials. Informed consent, permission to audio-record the interviews and future presentation of my research findings was obtained at the initial

meeting with the participants and their parent(s)/guardian. I also included the fact that I had passed a recent criminal record check. Highlights of the consent document were again reviewed prior to the photo-elicitation interview, to confirm participants' consent. I explained to the participants and families that I would accommodate them as best as I could to make this as easy as possible for them. The final time commitment for the research study was estimated to be 1 hour and 45 minutes.

Following the interview process, I obtained Participant/Parent Photograph Consent (see Appendix H). Participants and parent(s)/guardian had the opportunity to see the photos and remove any photos that they did not want used or that may identify the family in any way. I used the example that if they lived in a round house and there was a photo of this that the photo could be removed so the family would not be identified. The signed consent meant that the photos could be used in presentation findings.

The possibility existed that probing into the participants' feelings and experience may have a negative emotional effect. I considered that this reflective process may affect the participants and cause some unsettled feelings that they were not aware of. After consultation with a few local pediatricians it was decided the best follow-up, if necessary, could be provided through the care of the family physician, the pediatrician, or through the emergency department. Adolescent mental health services were contacted to see if direct referrals were a possibility but due to reduced services in the area, it was not an option. By establishing a referral process I was prepared in the event that the adolescent was distressed; this could be shown by crying or comments of thoughts of self-harm or threatening harm to others. If this had happened I was prepared to inform parents and involve them in the referral process. If an adolescent voiced concerns of anxiety or

depression, or if I suspected this, I also planned to involve the parents. If the adolescent was just upset I allowed them to discuss this, and asked if they felt comfortable talking with their parent(s)/guardian about the issue or let them know how they could get help as noted above, for more follow up. On the Participant Consent Form, I explained to the participants that if they informed me of ways they were being harmed by anyone, may it be abuse or neglect, I had a duty to report this to the Children's Aid Society for the adolescent's protection.

The participants were also advised that they did not have to answer any questions that made them feel uncomfortable or that they preferred not to answer. I informed them that they could end the interview at any time. I let the participants know that if they needed a break during the interview that I could turn off the audio-recorder to allow for a break. There were no direct benefits from study participation. There was the opportunity that the participants could benefit indirectly by talking to someone about their feelings, thoughts and experiences of living with a sibling with an ongoing health issue. The use of photographs may have been an empowering opportunity and resulted in personal growth (Drew et al., 2010). As a token of appreciation a \$20 movie card was given to all participants following the interview or at the time of the withdrawal from the study. There was one potential participant who withdrew from the study after signing the consent because she decided afterwards that she was not interested in participating in this research study.

Participant anonymity was not a possibility as I met all of the participants face-to-face. In order to maintain confidentiality, not reporting some details such as age and gender was carried out. For example if there was only one sibling with a specific disorder

two identifiers were not used together. All personal information and data related to the research is being kept in a locked filing cabinet. Pseudonyms are attached to all of the data which includes audio-recordings on saved DVDs, papers, transcripts and computer files. All of the original identifying information was linked to a pseudonym and stored separately from the audio-recordings and consents. I transcribed all of the eight interviews myself. All data pertaining to this study will be kept in my locked office at Cape Breton University for 5 years after the study is completed and published. After this period of time, all information pertaining to the study will be destroyed, including all audio-recorded DVDs, all papers, files and photographs. E-files will be deleted and hard copies will be shredded.

## Chapter 4: Findings: Making Sense over Time

I conducted this interpretive phenomenology study and identified three themes central to the meaning of the lived experiences of the participants. These themes are: *Making Sense over Time*, *Getting Away from it all*, and *Creating Common Ground with Siblings and Family*. The theme *Making Sense over Time* was coined to capture participants' accounts of the emotions they experienced surrounding significant events in the course of their siblings' chronic illness and making sense of these emotions over time. *Getting Away from it all* represents my interpretation of participants' actions as they responded to events in their siblings' chronic illness. Theme three, *Creating Common Ground with Siblings and Family* was identified to portray what family means to the participants and that having a family and family support makes everything better. The adolescents also described support from family members that helped them along the way.

Central to the experiences of the study participants was making sense of their siblings' chronic illness. Participants in this study provided many examples of how they felt and thought about their siblings' illness and how it affected them and their family. They talked about and reflected upon how they experienced a wide range of emotions and how these emotions changed over time. The examples they gave were connected to significant events in the course of their siblings' illness. Some examples related to the early stages of the illness (*In the Beginning*) and others to the passage of time (*As Time Goes On*). The early examples included the time after diagnosis followed by the passage of time which included significant events such as hospitalizations, day-to-day ongoing management and relapse. They all described how their siblings' illness impacted them and how difficult it was for them at various times in their siblings' illness. Although they

each described their journey in their own unique way, they all expressed how their understanding of their siblings' chronic illness evolved and how the illness affected them personally as well as their relationships with their sibling. For many, it became easier to deal with the illness over time and this was interpreted as *Making sense* of this significant family health issue.

There were eight participants in this research study and they will all be introduced in this chapter. In *In the Beginning*, Marie, Joe, Kosmo, and Mats will be introduced followed by Zoe, Jonathan, Anthony, and Kalel in *As Time Goes on*. There were five males and three females varying in ages from 11 to 17 years. Four of the adolescents had siblings with diabetes, two adolescents had siblings with Down Syndrome, one adolescent had a sibling with cancer and one adolescent had a sibling with congenital heart disease. The siblings with chronic illness varied in age from 5-15 years and seven were male and two female.

### **In The Beginning**

Four of the adolescents shared their stories as they remembered back to the time their siblings were diagnosed. They reflected that the chronic illness caused a variety of emotions, uncertainties and worries. The chronic illness imposed limitations, created disruptions in family life, and left them struggling to understand both the disease as well as the change in their lives. As time went by the adolescents found that various forms of support made a difference such as explanations from a parent and information from a health care professional and from a support group. Over time the adolescents saw that the limitations that were imposed by the chronic illness seemed fewer and that they were able to feel balance returning.

Marie is a fifteen-year-old female with a younger brother who has Down Syndrome. Marie shared her experience of what it was like around the time that her younger brother was diagnosed when she was four years old. Her experiences unfolded as she introduced her first photo, *The Teddy Bear* (Figure 1).



*Figure 1. The teddy bear.*

Marie told me that for the first five or six months after her brother was born he was unwell and had to be flown by helicopter to the provincial pediatric hospital, which is over 400 km away. Marie stated:

It kinda represents the oldest thing here. It's when he was younger, um, he always had to get, well not always, but he had open heart surgeries and bowel surgeries so he was always back and forth from the hospital all the time and he had the breathing tubes and the feeding tubes and everything. I remember one time in particular, I was really upset about. I was all ready to go to the Teddy Bear Picnic and um, then my parents were like, "Oh no, we can't go because..." um they just found out they had to go to Halifax right away with brother's name and I had to go with my grandparents and I missed the Teddy Bear Picnic. So the picture is of a bear that he got from the paramedics.

Marie added, "I was scared a bit because I really didn't know what was going on. My parents were just, 'Ok, we have to go with brother's name.' I knew that wasn't good



because they were sending me to my grandparents. I never understood why I couldn't go with them.”

This disruption had a big impact on Marie and her family. Marie was disappointed and upset that she missed the picnic that she wanted to go to. Her parents never explained why they were leaving, only that they had to go. She stated they would say, “‘Oh, we’re just going for a ride.’ Actually they took the plane a few times too.” Her parents minimized the urgency to travel by plane and just called it “a ride”; perhaps this was done to lessen Marie’s worries about separation but rather what this did was intensify her worries because of her lack of understanding. Marie’s worries and uncertainties may have been reduced had everything been explained to her; this would have helped her to make sense of the situation. Consequently what Marie understood from this situation was that she would be staying with her grandparents and there was a big disruption in family life.

Marie told me another story surrounding the time soon after her brother was diagnosed:

Yeah, the first year and I remember um, just sitting on my parents’ bed and my dad would be putting a feeding tube down him and I didn’t understand what he was doing and I was asking, I said “well why can’t he just eat food through his mouth, like he has a mouth!” I didn’t understand at all.

In this example Marie was not able make sense of this situation on her own; she could not understand why her brother could not eat from his mouth and why he needed a feeding tube. Her parents did what they needed to do in caring for her brother but they did not explain it to her so she could understand in her terms. Marie was only four years old at the time and at this age she was a concrete thinker; she needed more information from her parents so that she could make sense of what was going on.

In the beginning, the way that Marie made sense of what was happening was to ask her parents questions. Initially her parents minimized their explanations but this only served to enhance her worries and uncertainties. Over time, as she grew older, her understanding developed more and she told me that her mother explained things to her and it helped her to make sense of her brother's chronic illness and the care that he needed. Marie said that the teddy bear is still around and she sees it when she goes down to the basement. The teddy bear is a reminder of past experiences, a reminder that chronic illness is in the background but still present.

One way that families and individuals have been able to manage living with chronic illness is through the process of normalization. When families and individuals are able to live "life as normal" they are able to manage living with a chronic condition (Robinson, 1993, p. 6). One strategy that has been identified as being part of this process is compared to looking through a camera lens; certain aspects are in clear focus while others are not as visible (Robinson, 1993). Furthermore, Robinson (1993) added, "events that do not fit with the evolving story are placed in the background where they do not intrude on the dominant story" (p. 12). Thus, the teddy bear serves as a reminder for Marie but is not in the foreground of everyday living.

Joe is 17 years old and has a sister who was diagnosed with cancer when Joe was four years of age. His sister was two years old at the time of diagnosis. After many years in remission, Joe's sister's cancer returned a few years ago. Joe chose to have the interview take place at the hospital on the day his sister was receiving treatment. I met him in his sister's hospital room where she was receiving chemotherapy on that day. The whole family was in the room together; the mother and father were having a conversation

about the day's events and the two siblings were smiling and laughing as they watched a country music video. It was an informal, relaxed environment with some light-hearted laughing as we left the room and went down the hallway to get settled in the interview room.

Joe, like Marie, went back to a time soon after his sister was diagnosed with cancer for the first time. The story evolved as he told me about how much he loved freedom and getting away on his ATV. I asked him if there was anything about his sister's chronic illness that made him want to get away. He described:

Um, not so much now, but when I was younger, cause like my sister was like really sick, throwing up and stuff, walking around, it was like really sad seeing her big pole with her medicine on it. I forget what they call it, she has to roll around with it in the house, it has to feed her liquids and stuff. It sucked seeing that. She couldn't go outside and stuff like that.

This memory was from many years ago, but Joe remembered his sister's restrictions: needing a feeding tube and being more limited in her activity because of her feeding tube pole. The limitations imposed by the chronic illness in the beginning were more memorable to him because of his love for nature, the outdoors and freedom. As time went by Joe believed that the chronic illness had less restrictions as he stated, "...I don't find, like it doesn't hold her back, like she's independent, she's a super strong girl..." It got easier for him to make sense of and handle living with a sister with chronic illness when the reminders were moved to the "background" (Robinson, 1993, p. 13). That being said, when his sister went back to the hospital to receive her chemo, he was reminded of her limitations and he captured this as he stated, "Ah, it's just sad to come to the hospital, to know she has to go through sitting in a chair and get chemo pumped in her and stuff. Like I just think it's not fair..." Joe's sister's chronic illness was brought

into “clear focus” when she came to the hospital for treatment; it was a reminder that she was ill and this stressor was hard for Joe (Robinson, 1993, p. 13).

Both Joe and Marie were much younger when their siblings were diagnosed with chronic illness and their understanding evolved and grew. When Marie was younger she asked her parents many questions and Marie stated that it helped to have things explained to her. Joe recognized that his sister’s illness placed many restrictions on her and as time went on he was able to see that there were less restrictions but he was still reminded of her chronic illness when she went to the hospital for her chemo treatments.

Kosmo is a 13-year-old boy with a 15-year-old brother who was diagnosed with diabetes three years ago. Kosmo remembered the unknown around diagnosis. He stated, “...because when he [his brother] first became a diabetic I didn’t really even know anything. Like I knew kinda what it was but I never knew, so I didn’t really know much.” Kosmo told me that the diabetic education classes that he attended at the hospital, along with his parents and brother, helped him learn more. He told me, “I think my parents did, like my brother went to some but most were for my brother and parents. My brother went to a support group a couple of times. I only went to a couple of them.” I asked him if they helped and he said, “It was ok I guess.” When asked if he would go to more he stated, “Well now that we know more, I don’t think we would. It’s more when you’re just starting I guess it helped.”

At the time of his brother’s diagnosis, Kosmo felt like he knew nothing and as time went on his understanding grew, and as he got “used to it.” The diabetic educational classes and the support groups were beneficial at the time of diagnosis. Over time, he and his family became more informed of supports and knowledgeable about the chronic

illness. Interestingly, a few of the photographs that Kosmo captured and described were related to information that he sought out on his own through the internet, healthy cooking shows on TV, and information from a book that his grandfather gave the family on diabetes. One example was a photo of a garden that he and his mom planted, titled *Healthy Eating*. They planted stevia, a natural sweetener that he stated was a substitute for sugar. They planted this because they felt it would be a better alternative than sugar for all family members.

The supports that Kosmo received from the diabetic education classes and diabetic support group were helpful in the beginning. As time went on, Kosmo was able to access information on his own from the internet and other sources which continued to enhance his understanding of healthy living which had positive effects on diabetes. Through doing so, Kosmo was able to help with his brother's chronic illness management.

Marie, Joe, and Kosmo all reflected back to a time, at the beginning, when their siblings were diagnosed and shared their feelings from that time. There was a variety of emotions expressed but what they all had in common were their uncertainties and lack of understanding of what was going on at the time with their siblings' chronic illness. Similar to these findings, Hollidge (2001) reported that when a sibling is diagnosed with chronic illness the well siblings might experience a mixture of emotions and have difficulty adapting because of sibling and parent challenges brought on by the illness. This interpretive phenomenology research study revealed that explanations and understanding over time improved the adolescents' ability to handle living with a sibling with chronic illness. Wennick and Huus (2012) found that well siblings need information

about the chronic illness that their ill sibling has and they need support from the health care team to give them a feeling of hope for their ill sibling's future. Similarly, in this research study I found that adolescents benefitted from information and support at diagnosis and that this helped to reduce their worries about the chronic illness. In addition, age specific knowledge appropriate to each developmental level is important so the siblings can understand the chronic illness. Barlow and Ellard (2004) stated, "psycho-educational interventions for children and their families need to take account of developmental age as well as disease progression" (p. 642). In this interpretive phenomenology research study, the adolescents described having more uncertainties and worries when their ill sibling was diagnosed, and as time went on, they were able to make sense of what was happening because their understanding increased.

In addition to the above descriptions, Mats also remembered his sister's diagnosis but for him, it had a slightly different meaning. Mats is a seventeen-year-old male with a sister who is three years younger than him who was born with Down Syndrome. He remembered when his sister was born and recalled that she had to have surgeries to fix her eyes and there were "just a lot of trips to the IWK the first few years." He added, "Well after a while you just kinda get used to it and it started becoming, not just like ah, a quick trip to Halifax, but we kinda made it a week-end trip and went to some stores and stuff." When Mats described his past experiences of trips in the first years they were also connected with other things in order to "not make it all negative and stuff."

Mats and his family made the necessary trips to the provincial pediatric center, yet they also coordinated other activities for the trips so the primary focus was not on their chronically ill child. Robinson (1993) referred to this as "selective focusing of attention"

(p. 14), which is part of normalization. In this way, the family was able to reduce the significance of their trip and “look on the bright side” (Robinson, 1993, p. 14) of things and balance it with other activities.

Joe, Marie, Kosmo and Mats chose to share moments about their siblings’ chronic illness that had a significant emotional impact on them. The picture that Marie shared of the teddy bear was a visual reminder of the past. These past significant moments were all part of meaning making that brought the adolescents to a point of “normalization” in their day to day world. Deatrck et al. (1999) stated that normalization begins after the period of uncertainty that follows the diagnosis has settled. The adolescents shared their stories that followed their siblings’ diagnosis of chronic illness and demonstrated normalization strategies that they used in living with chronic illness. As Robinson (1993) stated,

The story acts as a guiding light or beacon that can be shone to illuminate the past, present, or future. Thus the past is given meaning in relation to normalization and is judged in terms of its contribution to the story. (p. 15)

Joe, Marie, Kosmo and Mats shared their stories which worked like beacons, illuminating the past and giving meaning for normalization.

### **As Time Goes On**

Zoe, Jonathan, Kalel, and Anthony did not share memories as far back as the diagnosis, but rather shared stories about more recent memorable events. All of the adolescents in the study described different events throughout the course of their siblings’ chronic illness such as hospitalization, day-to-day management and relapse. This included sharing their emotions and expressing what was difficult about living with a sibling with a chronic illness. All of the adolescents described how they were able to make sense of their siblings’ chronic illness and how they handled different memorable

situations. Family support, communication with their ill sibling when separated, and participation in disease management were all seen to be helpful to them. For a few who experienced increased responsibility, it meant something different to each of them and led to feelings of unfairness, frustration, or empowerment. Independence was not seen as a positive effect but rather something that was taken on reluctantly because of perceived preferred treatment to a sibling living with a chronic illness.

Zoe is a thirteen-year-old female with an older brother who has diabetes. She told me about a time when he was hospitalized: “Ah, last year he was in the hospital. I think it was aci-do-sis or something that he had. He was in the hospital for a while. I don’t know if his sugar was too low or too high, but he was in there for a while.” She described her emotions around this time as she admitted, “I was nervous for him. I was hoping he’d be okay.” It appeared that her worries were related to the unknowns and uncertainties of how long he would be in the hospital and if he would be okay. She told me that she was able to carry on with her normal routine of school and activities because extended family members were available to provide family support. Zoe told me that one parent usually stayed with her brother in the hospital and the other parent came home. Family support from aunts, uncles, cousins and grandparents made this difficult time easier for her to handle.

Jonathan is an eleven-year-old boy who is a younger brother to Zoe described above. He told me that his brother was in the hospital twice in the last year for a couple of days each time. He told me it was “sort of hard” because “you couldn’t see him.” He said that he was able to keep up with his activities including school and sports because many extended family members were around to help out. Having many extended family



members around their home was a normal occurrence and they were a tight-knit family who routinely helped the children get to their activities. Jonathan found that being physically separated from his brother was hard but being able to text his brother when he was in the hospital made a difference because he could communicate with him and find out how he was doing. Similar to Zoe, Jonathan found family support helped as well as being able to connect with his brother.

Marie told me that her biggest worry was when her family was “away” at the provincial pediatric centre. Marie spoke about how the distance that separated her from her parents and younger brother caused her to feel concerned. She told me “...yeah, I wasn’t concerned, well I was concerned, but not as concerned when they were in the hospital here because then I would be up visiting all the time.” Marie was jealous of the attention that her brother received and she enjoyed the attention the nurses gave her when she visited. They gave her popsicles and made her feel special. Although it was a worry that her brother was in the hospital, it was comforting for her to be able to visit and spend time with him.

Three of the adolescents described periods of hospitalization to be a stressor for them and they described having worries and uncertainties about if their sibling was going to be okay. Family support made the difficulties easier to deal with. One adolescent expressed feelings of jealousy because of the attention that her brother received in the hospital. Attention from the nurses made her feel special and being able to visit her ill sibling in the hospital provided a comfort. For another adolescent, it was difficult not being able to visit his brother in the hospital but communication via texting made a

difference, as well as being part of a tight-knit extended family that were able to provide help, thus enabling him to continue on with day-to-day activities.

In addition to stressors related to hospitalizations, many of the adolescents described day-to-day challenges that they faced and the emotions that these events stirred. In their stories they explained that it was not always easy. Routines, meal scheduling, and limitations imposed by chronic illness often created uncertain feelings for the adolescents.

Kalel is a twelve-year-old girl and she had two younger brothers ages seven and ten who both have diabetes. Kalel shared her experiences surrounding the insulin pump set changes. In her home, her two brothers' insulin set changes occurred about every 3 days. During this time, she usually liked to work on schoolwork at the computer or play a game because it made her feel relaxed. She said, "...they're crying because it hurts, which is sad, it's the one place where I can relax and I like to express myself cause I like to write stories which I am really good at."

It appeared that insulin pump set changes were hard for Kalel; she found it a stressful time. She is the older sister and she felt helpless when both brothers were upset about this but she knew that it needed to be done. During this time she found that she needed to relax and she found it helpful to use distraction strategies to keep herself busy. Kalel also told me that "nothing" is easy about her brothers' chronic illness because "It changes so much." She told me:

Well it's just sort of like, my brothers went from like getting needles three times a day or two times a day, and them getting like really sad but then they get...like extra dessert or something or they get like a new DS game or something and now it's evolved since then, and they have a pump, and it's on, and it's sort of like hard for my parents because my little, my youngest brother, who was actually diagnosed with diabetes first, forgets to bolus for what he eats a lot and that sort

of makes it hard on my parents cause his sugars are crazy and they're like ok, well you need to eat this and bolus for this, and give me your DS because you weren't listening and you didn't bolus.

Kalel described numerous challenges of day-to-day chronic illness management that clearly showed this was difficult for her. It appeared that she recognized the uncertainties and instability of the disease and the fact that things were always changing. It appeared that she felt a loss of control at times because as she described her experiences her ideas flowed quickly from one topic to the next, almost in exasperation. First of all, her brothers' insulin management changed from insulin injections to the insulin pump. Secondly, she described feelings of ambivalence and jealousy because on one hand, her brothers were sad and she understood this, but yet on the other hand, they got "extras" such as dessert or a new game. She also recognized that it was hard for her parents to manage her youngest brother's diabetes and it was not well controlled. Kalel was frustrated by this example of the day-to-day management and she handled these situations by acknowledging them as being difficult and engaging in other activities as a form of distraction at that time.

In another story that Kalel shared, she described a time when she volunteered to help out by giving her brother his insulin at school. She told me the story with some humour added:

...and my brother, a couple of, like last month I think, he was playing with his pump. Well he had his pump on in the snow, his pump, his battery like froze over, and so my mom was like freaking out and she was like well you're going to have to do your insulin needles at school and then I was like well, you could give me the stuff and I could give it to him in school and then we practiced it on brother's name and I sort of gave him the needle and he didn't like it because he didn't trust me with a sharp object. [*laugh*]

She added, “I think I was pretty good at it.” This example showed how Kalel was closely involved in her brother’s care. She responded not only to the physical dilemma of providing injections but she also responded to her mother’s frustration and non-idealistic solution (in her opinion) to have her brother give himself his own insulin injection. It appeared that Kalel was willing to help out as she was the one who came up with the idea and offered to give the injection. Her saying that she was pretty good at it was also evidence that she was proud of herself. Clearly, this was an empowering moment for her and an example of how adolescents with siblings with a chronic illness deal positively with challenges.

Other participants also spoke about dealing with challenging situations related to their siblings’ chronic illness. Kosmo, like Kalel, described the challenges associated with ongoing management of chronic illness. Kosmo talked about unfairness with the meal scheduling at home. Meals were on a set schedule and the structure frustrated him. He says, “...cause when we’re with him we always have to eat around 5 so it’s not like we can just go somewhere and just eat when we get home or wait ‘til we get to a place to eat like ya have to eat around certain times.” In addition Kosmo appeared to be jealous when he added, “I guess cause if we were eating, they’d always get him food first, it’s kinda like they wait on him I guess.” He said it was not that bad and he would get his own food. In Kosmo’s eyes his brother was given preferred treatment at mealtimes because of his diabetes and as a result of this Kosmo had become reluctantly more independent.

Kosmo shared a photo of his phone as he told me his parents used it as a way of contacting him so he would check on his brother. It appeared that they were keeping a watchful eye on his brother when they were not at home and he said that he was annoyed

and frustrated with their expectations that he check on his brother. His older brother had been experiencing frequent high and low blood sugars and their parents would phone Kosmo to make sure his brother was awake and had checked his blood sugar. Kosmo said, “After a while it gets annoying because like if he wouldn’t, sometimes he doesn’t charge his phone or it’s off or if he’s not responding so I guess it gets frustrating.” Kosmo stated that his brother would get up after he woke him and then it was his brother’s responsibility to contact his parents. Kosmo was affected by his brother’s diabetes in a few ways: the instability of the diabetes was a worry for Kosmo and his parents and he was also frustrated by his brother’s lack of responsibility towards his diabetes management and the increased responsibility, which he reluctantly tended to.

Marie also shared a story with mixed emotions of jealousy, understanding, and pride:

Yes, um, I used to be jealous a lot because people would always be coming to the house and it would be like, “brother’s name this and brother’s name that, he’s so cute, he’s so good at this and that” and um and then I’m saying “I was better than him at that when I was his age.” That was when I was younger that I would say things like that because I still didn’t exactly understand and my mom would explain to me...um just that you know, brother’s name, it’s just more impressive, I guess because a lot of kids with Down Syndrome can’t do things like that. Like a lot of them can’t speak as well as he can, can’t write as well as he can. You know so. I don’t know he just seems pretty good I guess.

Marie’s mom explained things to her and because of this her understanding grew and developed over time. Marie’s negative feelings of jealousy changed over time with explanations and this made a difference in her relationship with her brother; it evolved into one of acceptance and pride.

Kosmo, Kalel, and Marie all described feelings of jealousy and unfairness mixed with feelings of helplessness, loss of control and being frustrated as they told stories

about the day-to-day challenges of living with siblings with chronic illness. Kalel and Kosmo responded by taking on more responsibility with the care of their sibling but in different ways. Kalel willingly took on the increased responsibility and this led to a sense of empowerment for her; however, Kosmo reluctantly took on the increased responsibility and this left him frustrated and annoyed. Marie's initial jealousy over the attention her brother received went away as her understanding increased over time.

Anthony is a fourteen-year-old male with a younger brother who was born with congenital heart disease, and following complications after his last heart surgery his brother was sent home to receive palliative care for a life-limiting illness six years ago. He said, "it's pretty much done and over with now." His brother had complications post-surgery that interfered with his activities of daily living. One of Anthony's photos was of a lawnmower. He expressed a lot of frustration and dislike about mowing the lawn. He expressed that it was unfair that he had to do more at a younger age. He said "Sometimes it makes me angry" and reported "I had a lot more stuff to do when I was eight than he does now." Anthony, like the others, felt that this was unfair treatment and what happened in the past to him was inconsistent with what was happening with his brother at the same age. Anthony was not happy to have increased responsibility.

Mats stated that more recently, his sister had some ongoing health concerns related to a newer diagnosis of celiac disease and consequently this resulted in variable mood changes on a day-to-day basis. He said that the effects of the mood changes are very hard for him to deal with. He told me "...most of the time she's not in the best mood so when she's in the pool it's good to see that she's happy." He added, "Well it seems like she's on her 'lady time' all the time," and further added, "...if she's in a mood and

you try to switch her channel, or try to use the iPad or something [*he makes a motion with his hand spinning next to his head – like the sign for escalating*]. No you just can't do that. That's why I'm in the basement most of the time, just because she dominates the television.”

This example showed that Mats has defined the situation with his sister's spiraling moods as being annoying and frustrating. He felt a loss of control and found it easier to manage by leaving the situation and getting away to another room. Deatruck et al. (1999) stated “normalization has been conceptualized as both a cognitive (defining) process and a behavioral (managing) strategy for parents” (p. 212). This research study confirmed the work of Deatruck et al. (1999) for the adolescents and this is how Mats normalized his situation; he was cognitively aware and he understood how his sister was acting so he chose to manage the situation by leaving. Robinson (1993) stated that “chronic conditions were associated with particularly intrusive experiences that were contradictory to the story of ‘life as normal’ but were difficult to minimize” (p. 14). One way to deal with this that Robinson (1993) identified was by “reconstructing the reference point” (p. 14). Mats did this when he saw his sister's behaviour as being variable and moody and adjusted his routine to avoid his sister and spend time in other areas of their home. MacDonald and Gibson (2010) found that parents of children who required complex care described the need to “escape” the weight of care-giving as opposed to the ill children (p. 249). This break away was reported as a way the parents could feel “normal” and was described as being part of normalization for the parents. In this research study, Kalel used distraction and Mats removed himself from the situation as a way of handling living with a sibling with chronic illness and feeling normal.

Joe is the only participant who experienced living with a sibling who relapsed.

When he told me about his sister's relapse he shared this:

Ah, that was the most difficult for me, because I was older right. When I was younger I knew what was going on but I didn't like...when she was 5, I was 8 and I knew what was going on but I was still young and I didn't fully understand everything. From when I was 5-8, for 3 years, I knew I would go to the hospital for sister's name like every day because she pretty well lived in the hospital and we would go back and forth to Halifax. That was like, I guess I was so young I just got accustomed to it, I was just so used to it, like you think that everyone does the same thing, but it's not. I guess I think that's why it's so normal for sister's name because that's what I'm used to. I don't think of her any different than anyone else...I mean I still pick on her, she throws stuff at me, we still fight, just like a normal brother-sister relationship.

Looking back, Joe recognized what a difficult time relapse was. It was difficult because he was older and understood more. He compared it to what he thought when he was younger and as he said he knew what was going on at that time but he didn't "fully understand everything." Joe's understanding developed as time went on. At this time Joe and his family normalized the chronic illness by making visits to the hospital part of their routine. Normalization is a process that is put in place to minimize the disturbances caused by chronic illness (Lehna, 2010). As time goes on, the end result of the strategies that families put in place is "the perception of living a normal family life despite a member's chronic illness" (Knafl & Gilliss, 2002, p. 184). However, relapse had a significant emotional impact which he articulated so well: "I called Mom and asked what was going on and how was the check up and she just started crying and said it's back and stuff. I almost dropped to my knees, it was so sad." He further explained what happened later that night when he was out with friends:

...I told my buddy who comes with me, his older brother is my good buddy too and he was at the party and it was pouring rain outside and we were outside. Well first, a girl told me, she was like ah... "I heard the news and stuff, I'm so sorry" and then I was like getting upset so I went outside and I was trying to get over it



and then he came over and asked what was wrong. I told him, and we both started just bawling and ran to under a tree, we both just started bawling, it was sad.

It felt good to release his emotions and have the support of his friend at this time. He also said, “but I mean I couldn’t believe how many years it was since it was gone and just [*snaps fingers*] it came back one day. It was sad.” The emotional impact of relapse was evident; it caused a profound sadness for Joe and he suddenly had an awareness of the fragility of life and how fast things could change. At this time, illness was brought back into focus once again and it was not possible for it to be put in the background. This reflects the delicate nature of normalization, the fact that this process is not a constant but has the potential to change. Knafle and Deatruck (2002) stated that there are obstacles in the process of normalization and this often occurs when there is reason to have to refocus on the illness such as a disease exacerbation or a developmental transition that relates to accommodating the illness. Joe’s sister’s relapse after many years of treatment was cause for the family to refocus on her illness, thus disrupting the process of normalization at that point in time.

In this research study all of the adolescents experienced memorable events during the course of their siblings’ chronic illness that impacted the way they responded to and felt about themselves, their sibling and other family members. Some participants asked parents questions to enhance their understanding; some recognized limitations imposed by the chronic illness but also acknowledged that this changed over time and was a balancing act. Some adolescents took on more responsibility and this meant different things to each of them; for one it meant unfairness, for another it caused frustration, and for another, increased responsibility led to empowerment. Independence was not seen as a positive effect for one adolescent but rather it was the result of preferred treatment for a

sibling with chronic illness. Many of the participants incorporated normalization strategies as a way of living with and giving meaning to a chronic condition, thus enabling them to put chronic illness in the “background” and focus on living “life as normal” (Robinson, 1993, p. 12). Over time this process has also helped the adolescents to make sense of living with chronic illness.

## **Chapter 5: Findings: Getting Away from It All**

The second overarching theme that emerged in this research study was how all the adolescents responded to the far-reaching effects of chronic illness by getting away from it all. All of the adolescents expressed their own ways that they handled living with the stressors imposed by chronic illness. They expressed a need to get away from a variety of factors: parental expectations, a loss of control and feeling overwhelmed by the effects of chronic illness. The need to get away provided a break and freedom to think and reflect; it offered an opportunity to find a balance in their lives from the effects of chronic illness. All of the adolescents described unique ways that they were able to get away. Some expressed an urgency to escape and be on their own, while others were able to get away and connect with their faith, friends or support groups. Many adolescents expressed that they found comfort in their pets and realized the mediating effects that pets provided in their home.

### **Escaping**

Many of the adolescents in this research study described the need to escape. They described feeling helpless, annoyed, and frustrated with effects of chronic illness. Escaping provided an opportunity to have a break and relax; it was a way to deal with chronic illness and expectations placed on them. Some escaped by themselves and some escaped with friends to a place where they did not have to worry about their ill sibling.

Kalel shared a couple of stories of how she responded to parental expectations shortly after her youngest brother was diagnosed with diabetes:

Well we're sort of all close as a family and we know what my brothers have gone through and when my little brother first got diabetes my dad sat us all down at the dining room table and he said "ok, your youngest brother is diabetic and he's only 26 months and he's really scared about having to test his sugar" and

then he looked at me and said, “can you please, can I just prick your finger with the little needle that it gives you and test your sugar and show your little brother how easy this is and how it didn’t hurt?” I was only 7 at that time. I did not like having my sugar tested. I like...I was screaming and crying, I was like “no, I don’t want to do this” and my dad was like “you have to do this, it will make your little brother feel better.” And so, I really liked unicorns at that point, and so I had this like, giant unicorn I had got for my birthday and I sat at the dining room table like, holding my unicorn for dear life, sticking out my finger and then the needle went in, I didn’t even know because I was too busy panicking.

In this example Kalel reluctantly provided help at her father’s request to have her blood sugar taken. It was a difficult situation for her because on one hand, she was afraid but on the other hand, as her father stated, it would make her brother “feel better.” Kalel was able to find comfort in her unicorn. After it was done she realized that the greater fear was in the unknown as opposed to the needle.

Kalel told me another story related to her parents’ expectations that she locate supplies even though she found the names long and difficult to remember. She said it was not easy:

No because I am the one that it’s like “ok, well they are doing their set changes, like go get this bottle of this stuff out of the fridge and you gotta take it and you have to get it ready.” And I’m like “what?” And they’re giving me this big long name and I can’t even remember any of them but it’s, and then it’s just really hard for me to think of the names and then open it up and find the right one...

Kalel found it challenging to be put in this situation where she was expected to pick out the right insulin and she was worried that she may make a mistake. She felt the burden, the pressure of the responsibility placed on her at that time. It was not something that she willingly wanted to provide.

In addition to parental expectations, Kalel recognized the difficulty that came with insulin pump set changes. She realized that she needed to either remove herself from the

situation or find a distraction such as music. She told me a story as she described a photo called *Paradise* (Figure 2).

...my brothers were getting their set changes and I said if I go downstairs and go on the computer, I'm going to have to put my headphones on and crank the volume because of this screaming and crying cause they really don't like getting their sets changed. I just sort of sat up in my room and it took me like an hour and a half just drawing and coloring it with crayons.

The photo was of a picture of a "tribal princess" that she coloured upstairs in her room.



*Figure 2. Paradise.*

She stated:

It's just sort of another way that I relax and I get away from it all. And I just sort of like hide and I go into my own little world and then I like almost feel like when I'm relaxing like this bubble appears over me and I just hide from everyone else and I'm by myself.

Kalel's brothers had not adjusted to getting their insulin pump sets changed and this happened frequently, every three days. She found this hard and how she handled it was through escaping – either by listening to music or by hiding up in her room. When she went up to her room she felt protected and was able to relax when she was by herself.

Living with two siblings who had chronic illness combined with parental expectations to help was overwhelming at times and it was important for her to be able to get away and

relax. This was a way for her to get away and be “normal,” to minimize the impact imposed by chronic illness.

Similar to Kalel, Mats also told me of a need to escape. He described a photo of a hockey net outside of his home at the top of his street that he titled *Relaxation-nation* (Figure 3).



*Figure 3. Relaxation-nation.*

He stated, “That is the time in which I can escape my house and either being outside with my friend next door or just going outside to get some exercise, get some fresh air and relax.” He further added that it was “ah mainly relaxation, but if I just feel like a couch potato all day I go out there just to get some fresh air but if my sister’s in a bad mood or something I just bolt it outside.” To add to his frustration, Mats told me that his sister did not listen to him; she did not turn the TV channel if he requested it and she had taken over the upstairs TV room, resulting in him watching TV downstairs. He felt annoyed and frustrated that his sister would not listen to him and he said that she listened best to his mom because she had “more authority.” I asked him what authority meant and he said that authority meant, “To direct her attention and give her orders and her following the orders.” There were times when his sister would not listen to her mom and the result was

“...like sometimes if she’s flippin and sometimes she’s gotta let her scream it out, just let her do it.” The result was that Mats wanted to remove himself from the situation. He stated, “...escape, I find you can compare it the best way to, once you have ignited the fire, let it die down, don’t try and put more gas onto it. Don’t fuel it more.” Mats identified *Relaxation-nation* as his favorite photo,

cause going outside and getting the exercise is good for mental health and physical health. You also get to relax, like the sound of the wind is very calming and just un-stresses your mind, I’m not even sure if that’s a word, but it de-stresses your mind.

Mats needed to escape his sister’s mood and the fact that he had no control over the situation; he felt helpless, annoyed, and frustrated and recognized the benefits of going outside to “escape.” Mats demonstrated a maturity, an awareness, that if his mother could not resolve a difficult situation with his sister that sometimes his sister needed to “scream it out” and he removed himself instead of adding more fuel.

Mats presented another photograph titled *Man Cave* (Figure 4).



*Figure 4. Man cave.*

He told me he took it

because it’s very similar to my hockey net, just like, playing, just hanging out with my friends, those are two places where they’re mostly mine and where I can mostly just hang out and not have to worry about, I don’t know my sister.

Mats described that spending time away from his sister and with his friends was another way that he was able to relax.

Kalel and Mats both identified the need to escape and relax. They both found their situations very overwhelming at times and lacking control. As Mats said, his mother had “more authority” than he did. When they escaped they went into their own space and felt protected. Mats also found spending time with friends was relaxing. Escaping was a way for Mats and Kalel to be “normal” and to do what they wanted to do. Similarly, MacDonald and Gibson (2010) noted that parents of children who required complex care at home required a break away so they could feel normal. It was an “escape” from the worry of care-giving, not the ill child (p. 249).

Similar to Kalel and Mats, Joe found that it helped to escape. Joe introduced many photographs of nature and the outdoors. He presented a photo of his ATV and called it *Freedom* (Figure 5). He told me of his need to get away and have time to think about things. He said that he thought about everything that was going on in his life when he had time on his own. He thought about friends, family, school and his sister. He said, “Just cause it’s nice to get a break from everything and just relax, be able to think there, sit on the grass and look at the mountain and see nothing but trees and water, it’s peaceful.”



*Figure 5. Freedom.*



Another one of his photos was a group of trees that he has called *A Fence* (Figure 6). He said, “When I see those trees I think of it as a fence. As a tree it is blocking everything that I don’t want out, and keeping everything good in. The trees don’t let the negativity go inside. I could see that as a fence.”



*Figure 6. A fence.*

Joe expressed his feelings very well as he described living with a sibling who had a chronic illness. An underlying theme emerged of his need to get away to nature and seek freedom to think. He shared,

As I was saying earlier, I go in the woods because it’s so peaceful and quiet and you can just appreciate all the little things, I mean, everything just, think of everything that makes you happy and how you appreciate everything and how you have to appreciate more.....like how grateful you are for everything. Like my sister is sick but I’m still grateful that she’s even here. I mean stuff happens. There’s a kid in my school whose little brother had the same thing as my sister and he died last year. I couldn’t deal with that, losing my little sister would not be good. So I just block everything out, time for yourself.

Like Kalel and Mats, Joe found that seeking time for himself was important. It offered a time for him to think and reflect on life’s events and also practice gratitude. He recognized the fragility of life when someone at his school lost their younger brother to cancer and this hit close to home for him because of the similarity of the situations.

Kalel, Mats, and Joe identified stressors such as parental expectations, siblings not adjusted to routines of chronic illness management and other effects of chronic illness that were present in their day-to-day life that made them need to escape. The terms that they used may indicate their intensity to escape in these situations: “my own little world,” “bubble,” “hide from everyone,” “bolt it outside,” “escape,” “freedom,” “break from everything and relax.” They said that when they escaped, either by themselves or with friends, what they wanted to do was “relax.”

Other adolescents talked about spending time on their own. Anthony spoke about spending a lot of time in his room upstairs watching TV and playing PlayStation. When he spoke about himself and his brother he stated, “We’re in the same house all day but I stay in my room.” He also stated that they fight a lot. I asked him what they fought over and he said, “We just bicker.” Anthony’s room was a safe spot where he could relax and do the activities that he wanted to do on his own. This was a way that Anthony normalized the impact of chronic illness; he was doing “normal” activities up in his room. He told me his brother did not spend any time up in his room with him.

In contrast, a few of the adolescents described spending time on their own or up in their room but they did not express a need to escape. Zoe said that she enjoyed spending time in her room, playing on her iPod and listening to music. I asked her how listening to music helped and she stated, “I don’t know, music sometimes just calms you down. I think it depends on what type of music you listen to, like soft music or loud music.” Zoe told me that she did not really need to get away and “that your family is always going to be there.” Jonathan told me that there was nothing he needed to take a break from but he enjoyed playing with his iPod for thirty minutes before bed. Marie told me that her

brother frustrated her sometimes, “Just when he messes with me [*laugh*]. If he finds something that frustrates me he’ll just do it all the time, like just certain things he’ll say to tease me.” She told me that sometimes her younger brother and mother pick on her in fun together. She added, that she would say:

Um, I’m just “oh my gosh just stop it!” He starts laughing and they keep going. I go up in my room and close the door and they come down and 10 minutes later they come up and they’re just at the door, they’ll open it a crack and they’ll start to laugh.

These adolescents enjoyed time away but there was no urgency expressed in terms of getting away. When they went to their rooms they enjoyed listening to music or playing games on their electronic devices; these were routine normal activities.

### **Connecting with Supports**

Some of the adolescents found other ways of dealing with chronic illness. One adolescent described a strong faith that provided comfort; others spoke about friends, support groups and also the positive influence of having pets in their home in relation to their siblings with chronic illness.

Joe talked about a strong faith and he showed me the cross and chain that he wore around his neck. His faith had provided a lot of strength in dealing with his sister living with chronic illness. He said:

That’s just, well my grandma gave me that. I guess I pray a lot and it means a lot to me. Whenever I’m down I pray for whatever I’m sad or thinking, just down, say a prayer for my sister or whatever, say a prayer for people who don’t even need prayers, just say prayers for people.

He told me that he had lost a few crosses and chains over time but they were always replaced. He said he had hope, “maybe because you’re just praying, hoping and praying that everything goes perfectly fine, that everything goes away and never comes back.”

Lee and Rempel (2011) conducted a study that described the process of normalization in parents who had children with hypoplastic left heart syndrome. One of their findings was that parents often look for a deeper meaning in their experiences and they expressed gratitude for what they had. They reframed their difficulties and viewed them through a positive lens. This research study had a similar finding. Joe found strength in his religion and he expressed much hope and gratitude for his sister living with chronic illness. In addition, Joe talked about his involvement with his church and the relationship that he had with his priest: “It’s nice to talk to him, it feels really, really, really good to talk to my Priest.” He added:

...So you can say anything to your Priest, right...I mean you can’t get into trouble talking to your Priest. It’s pretty much like being in the woods by yourself thinking and you just say what you think and he talks about it with you.

Joe found strength and comfort in religion. The cross that he wore around his neck was a constant reminder of his faith and hope that his sister would be okay. He compared the comfort and openness that he got from the freedom in the woods and his priest. He felt free to say what was on his mind and this freedom and openness provided a way of dealing with a sister who had a chronic illness.

Friends were discussed in all of the interviews and for a few of the participants, friends were considered to be like family. Joe confided in his “best friend” and was supported by him in a couple of ways. His friend had accompanied Joe and his sister to the hospital for her chemo treatments and had shown emotional support. When asked how friends helped in the context of living with a sister who has a chronic illness he said,

Ah, like my best friend, he only lives down the road from me but they’re like really involved with my family too and they know everything that is going on with my family too. I talk with him about anything and he knows pretty much, but it’s almost like he’s a brother. It’s kinda like he feels it too like his sister is like a

sister to him too. It's all the same deal. We're both brothers actually, there's two of them and they're really close to the family.

When Joe found out that his sister relapsed, his parents and sister were out of town at the provincial pediatric centre for children, which was over 400 kilometers away. His friend provided support to him by just being there, listening to him, sharing in his tears and acknowledging the difficult time of relapse. "That was nice. It was nice crying with my friend. I mean letting it all out, everything. That was good...." He described the tight bond between him and his friend when he compared him to be like a brother.

Kalel, similar to Joe above, described how friends helped when her second brother was diagnosed with diabetes. She felt that her brothers were receiving more attention than her at that time. Kalel said,

Yeah, because I think it was when my other brother got diabetes and he was in grade primary, I was only in grade 2 and I think like a couple of months after he was diagnosed with diabetes I had no clue what was going on and my parents were directing all their attention towards them because they didn't know and they were like "Ok you have to eat this and this and this, well I don't know, I don't know what's that there so I'm going to go call." My friend had her birthday party a couple months after that and I think just going to that and being with my friends was, just made me more relaxed, and got me sort of used to the fact that I'm going to have to live with this until I'm older.

In Kalel's situation, there were two brothers at home living with diabetes and her parents spent much time and energy focusing on the boys. Kalel recognized that it was hard for her parents to juggle what the boys were eating with their insulin. The time that Kalel spent with her friends was an opportunity to maintain normal activities. It was like a break away that provided an opportunity for her to reflect and realize that she needed to accept living with chronic illness.

Zoe and her brothers were involved in many activities and she told me that their friends were often around their home, especially around their pool in the summer.

“Mmm, yeah, we’re always together as a family, sports and everything, and friends in there too.” I asked her to tell me more about friends and she added, “They’re like family too, they’re always there to help you get through things.” Her friends, like family, provided a support network.

The adolescents in this study described their friends as providing a means of support, safety, and comfort. The adolescents confided in their friends and for one participant, they helped her to acknowledge and accept that she needed to live with her brothers’ chronic illness for the rest of her life.

Many of the adolescents participated in some type of support group during their siblings’ chronic illness and found it was beneficial. It provided reassurance that others understood and were living in similar situations. Two of the adolescents found that some of their friends did not understand what it was like to have a sibling with a chronic illness because they were not in a similar situation; these adolescents found it helpful to be involved in the support groups.

The two adolescents who had siblings with Down Syndrome felt that the Down Syndrome support groups had been a positive experience for them; they enjoyed the interactions with teens the same age and sometimes they talked about Down Syndrome and sometimes they just talked about regular day-to-day activities. Marie described the benefit of the Down Syndrome support group:

Just because it’s someone else that understands cause all my friends, you know, their brothers or sisters are going out to soccer games and stuff and they’re doing everything, or some of them are older and they’re driving them places and I just think, you know, I don’t know if brother’s name is going to be able to drive me places anytime...but...just someone else that understands.

Marie identified that she was aware that her brother was different. She realized that he would not be able to do everything that her friends' well siblings could do and she found understanding and support from the group. Mats, like Marie, felt that most of his friends did not understand what it is like living with a sibling with Down Syndrome. He said, "Mostly just to make their lives easier I try to just bolt downstairs with them." And he added,

yeah just because ah, I don't know some people aren't comfortable, like some of my other friends, like ah, I have a friend whose known her for years and years and years and is comfortable with her and he can be upstairs with her but most of my friends, they aren't comfortable with her and he can be upstairs with her but most of my friends, they aren't used to it so I just take them downstairs.

Mats had one long-time friend that he felt was comfortable with his sister's chronic illness so it was okay for him to remain upstairs with her in the family room where she spent most of her time watching TV. However, he felt the need to avoid his sister when some of his friends were around, in order to protect them because they were not comfortable around her. By doing this, Mats was also minimizing the differences between himself and his friends that were not familiar with his sister.

Joe, like Mats and Marie, enjoyed being in a group with common interests. Joe had a strong faith, and told how he participated in a religious "holy" weekend. He travelled to a convent along with a group of adolescent males, and found it to be a very supportive experience to be part of and also share similar stories. He said:

Oh yeah, really positive, super positive, super, super, super positive. They have like speakers and everyone tells their story, their sad stories and people who are going through pretty much the same stuff as I am. Everyone pretty much talks about everything...

Joe had a strong faith and this has helped him to make meaning in his life, living with a sister who has chronic illness. The support group provided an opportunity to share stories and through this experience Joe realized that others have similar heartbreaking stories.

Zoe has participated in a Diabetes Awareness Walk and along with family members, she made a t-shirt to show support for her brother. The photo of the t-shirt was one of the photos that she presented, called *Team Attack* (Figure 7). By being involved in this group she realized that there are many people living with diabetes.



*Figure 7. Team attack.*

Kosmo described being in a diabetes support group after his brother was diagnosed with chronic illness and found it a means of support around the time of diagnosis.

Support groups offer an opportunity for adolescents to meet other children, adolescents, and families in similar situations. The adolescents in this research study found that support groups offered socialization and provided an opportunity to talk about common relevant issues related to living with siblings with chronic illness. It helped them because they were able to talk with others who understood. The support groups provided an opportunity for the adolescents to minimize their differences with others who had similar lives. Support groups provided an opportunity for the adolescents in this study to



normalize their experiences. Likewise, Houtzager, Grootenhaus, and Last (2001) found that siblings of children with cancer benefited from attending a support group; their knowledge about diagnosis and effects on family relations increased, their anxiety decreased and they learned strategies to deal with living with chronic illness.

Six out of the eight participants had a family pet. All of them were dogs, and all of the pets were seen as having a beneficial relationship with the sibling with chronic illness and the adolescents. Mats explained that his dog contributed to family harmony.

He said:

This is a picture of my dog. I have to say we couldn't have gotten a better dog considering my sister's situation. I'll put it like this – when he was very, very young, I don't know, but she tried to stick her arm down his throat and he just let her. Like he gets it [*emphasized*] and he never barks unless it's like the mailman, like any other dog. He's a very, very calm, loving dog. Very funny too.

He added, "...he just kinda helps the mood in the house, like stay stable sometimes." Mats appreciated the calmness in his home as he explained that his sister's behaviour was stressful for him. His pet offered a balance to living with the stressors imposed by chronic illness. Mats shared with me that he enjoyed walking the dog outside. He said:

taking my dog for walks is relaxing. I started to realize that walking my dog is a chance to also escape so I take him for longer walks than I used to. I walk him down, almost more than two thirds down the street.

Anthony talked about the benefit of his dog. He said, "cause, she's just always there." Anthony made the connection to his brother who has an ongoing health issue when he stated, "she's pretty well....a lot of people say they have the best dog in the world but that one is. She wouldn't, if brother's name hops on her, or picks, or pokes she doesn't move." Anthony found comfort in his pet and acknowledged that she was a positive influence around his brother.

Kosmo had two Shiatsu dogs that were able to detect when his brother's blood sugar was low. He explained:

Well when my brother is like low, he will, like my dog and the other dog, will like cry. Pebbles will go downstairs and walk around his bed when he's low. We realized that the first time she did it. We didn't know that they did that but doctor's name which is my brother's doctor, told us that, especially the Shiatus....

Kosmo explained that one of the dogs was particularly connected to him and spent a lot of time with him. So not only was there a connection between the sibling with chronic illness and the pet but Kosmo enjoyed having the attention that the dog gave him and this offered some balance to the effects of chronic illness.

Three other participants included photos of their dogs and warmly talked about them as being a significant part of family relationships. In this research study family pets had a balancing effect with chronic illness as the participants described above; they acknowledged the benefits that the pet contributed to living with a sibling with chronic illness. Similarly, E. Friedman and Thomas (1985) reviewed the research literature to gain an understanding of the health benefits of pets and found that the list is long. The view that "pets are good for you" has been supported. They found that the companionship that a pet offers led to a reduction in loneliness and consequently to improved "psychological and physiological status" (p. 198). Caring for pets can contribute to an increase in self-esteem and a decrease in anxiety and depression, offer companionship for healthy activity such as walks, and increase responsibility through care (E. Friedman & Thomas, 1985, p. 192).

All of the adolescents in this research study needed to get away from living with chronic illness. For some there was an urgency attached to it "bolting outside" and for some there was a protective measure – going into their "own little world" and being in a

“bubble.” Some escaped to freedom, to get a break away, to reflect and to relax. Getting away for others meant that they connected with a supportive network that included religion, friends, support groups and/or family pets. The family pets often had a calming effect in the home and balanced some of the stressors imposed by chronic illness. Getting away from it all appeared to be an opportunity for the adolescents to find balance and understanding; it was a strategy they used to deal with living with chronic illness.

## **Chapter 6: Findings: Creating Common Ground with Siblings and Family**

The third overarching theme experienced by all of the adolescents in this research study was a description of how they created ‘common’ ground with their siblings and family. For the adolescents in this study ‘common ground’ meant more than simply finding common activities to do together. The meaning shifted to include an interpretation of the activity as “every day” or normal, something that would put the chronic illness into the “background.” Many of the adolescents identified common activities and interests that they shared with their sibling with chronic illness.

Normalization is a process that occurs when families who are faced with challenges related to chronic illness come to see both the child and their lives as normal (Knafl & Deatrick, 2002). The adolescents also identified common activities and routines that they engaged in with family members and by doing this, lived “life as normal.” Some of the adolescents identified a ‘common ground’ that was created between the siblings because of common interests and activities; however, there were times when chronic illness placed a stressor on their relationship as it clearly came into the focus and was no longer in the “background” of daily living. ‘Common ground’ was also identified as important with both immediate and extended family members.

### **Identifying a Way to Relate to Each Other**

The adolescents in this research study described different ways that they were able to relate to their siblings with chronic illness. Through sharing similar interests and engaging in a variety of activities, many realized that chronic illness had not changed their brother or sister and they described them as normal. Some of the adolescents were

more aware of ways that the chronic illness made their siblings different and they described ways that chronic illness influenced their relationship with their sibling.

Jonathan believed it was important to create a common bond between himself and his brother. By doing so, this brought the normal, routine day-to-day activities into clear focus and put chronic illness in the “background.” Robinson (1993) supported this as a strategy in normalization (p. 12). It was significant to Jonathan as he described many common interests that he and his brother shared: games, music, sports activities such as soccer and hockey, and school subjects such as science and math to a varying degree. He said, “We both like the same subjects I guess. I like science, he sort of likes science. I like math and he kinda likes math.” Jonathan said it was important to have common interests because “that way we can relate to each other. Like we can sort of talk and have a bond between us.” He added, “What’s the point of having a brother if you don’t like them?” I asked him if there was anything about his brother’s chronic illness that interfered with the bond or made it hard and Jonathan replied “no.” While Jonathan discussed one of his photos titled *Art* (Figure 8) he said that nothing has really changed since his brother was diagnosed and “he’s still normal.”



*Figure 8. Art.*

When asked what he meant by normal he said, “You don’t even think about it” and “Well it’s been happening since I was a little kid so I don’t remember.” Jonathan and his family have normalized living with chronic illness; the management has become a normal part of their routine, being assimilated into their lifestyle. Carrying through with normal things is important in the accomplishment of normalization (Robinson, 1993).

Zoe, like Jonathan, spoke about the activities and interests that she shared with her brother who has a chronic illness. Zoe was able to bring the common interests into focus and put chronic illness in the background. *Outside Soccer* (Figure 9) is a photograph of an outside soccer net, cleats and a soccer ball. She said, “We are always outside kicking the ball, playing sports. He [*her brother with chronic illness*] always wants to shoot on me but I don’t want to get in nets.”



*Figure 9. Outside soccer.*

When they were younger, they played on the same soccer team together. “I liked being on his team but I don’t know if he liked me being on the team though [*laugh*].” As Zoe described a photo called *The Pool* she said, “Him and his friends are always out there, listening to music and swimming, pushing me in the pool [*laugh*].” She has an understanding of her brother’s insulin pump: “his pump is waterproof but he takes it off, just in case. He’s allowed to have it off for 2 hours I think, but then he has to run insulin

through it again and then he can take it off again.” Zoe recognized that there were limitations with her brother’s activities but they were minimized and this was part of the “balancing act” of normalizing living with chronic illness. In this process abilities are highlighted and deficits are played down (Robinson, 1993, p. 14).

Kalel shared three photos of activities that she engaged in with her brothers. She has spent time with her brothers playing Xbox, Legos and games on the computer. I asked her how these pictures reminded her of her brothers with chronic illness and she said, “Well it doesn’t like really affect them because it’s just like normal kids like normal kids draw pictures, and play Legos and play the Xbox so....” Kalel, like the other adolescents described above, focused on the common activities she shared with her brothers, thus focusing on the normal activities and putting chronic illness in the background. They are “essentially normal persons leading normal family lives” (Robinson, 1993, p. 9). Similar to this research study, Lehna (2010) explored sibling experiences following a major childhood burn and found that the activities the children engaged in following the burn were very similar as those prior. In this interpretive phenomenology study it appeared that doing activities that all of the siblings enjoyed was important. It was an opportunity for them to play together and have fun.

Joe shared a story about his sister driving a four-wheeler, an activity that they both enjoyed. He laughed as he described why *Freedom* (Figure 5, above) is his favourite:

I probably like this one because me and my sister both love four-wheeling. It’s something we have in common. She, like right down there, she has a four-wheeler, she doesn’t use it much, she uses, drives this one because the other is too slow she says. This one could have the flag flying in the wind behind it, it’s that quick. She doesn’t go fast on it. She’ll go down there and tear up the grass and do donuts and stuff. I remember one time I was teaching her how to do a donut on

the four-wheeler, like she was spinning around in a circle, and she flipped her four-wheeler and fell off. I was taking a video and I just started laughing cause I knew she was alright. She got back up and jumped on it again and kept going. And like, she made me take a video of her down there on the four-wheeler in the mud. She just hops off the four-wheeler and starts running and does belly slides in the mud, sliding across.

As Joe described the fun that he shared with his sister in this photo there were no limitations with her activity. Like the other adolescents described above, Joe was able to focus on his sister's abilities, what she could do and not what she could not do because of her cancer. Joe told me that chronic illness has not affected his relationship with his sister:

No, other than the fact that I gotta come here (to the hospital) and stuff, but other than that she's as normal as can be...I couldn't wish for her to be any different, other than the fact of her not having that and her being one hundred percent okay but other than that I love her the way she is. But if, of course, if that could just go away, oh yeah, I'd want it to go away and her to be the exact same. I just love her.

Joe, like the other adolescents above, described a close relationship with his sibling. They have all normalized chronic illness into their life and described common everyday activities that they have enjoyed and engaged in with their siblings. Robinson (1993) stated, "Doing normal things was critical to the performance of the story of normalization" (p. 17). However, when chronic illness is brought into focus it has potential to jeopardize normalization if it is not balanced. Over time, Joe has gotten used to his sister's diagnosis with chronic illness and stated, "you just don't think about it," and "that's just the way it is. It's her."

All of the adolescents described above saw their siblings as being normal. They emphasized what they were able to do. They were able to put the chronic illness in the "background" of their day-to-day life and focus on the normal routine activities, thus living life "as normal." A couple of them identified some situations that brought the



chronic illness into the foreground, such as going to the hospital and as Zoe described, limitations related to her brother's insulin pump, but did not dwell on these limitations, therefore enabling the process of normalization to be carried on.

In contrast to the adolescents above, some of the adolescents described how their siblings were limited by their chronic illness and how this influenced their relationships. Although they shared common ground and identified common interests or activities, the siblings were aware that the chronic illness was more visible in different ways. A couple of the adolescents were able to minimize the limitations and normalize them into their life, but for others, it was a tricky process and this emphasized the variability in normalization. Similarly, Knafl and Deatruck (2002) described parents that had altered experiences of normalization between two data collection points and stated that these different experiences “highlight the fragile nature of normalization and how changes in the disease are linked to normalization efforts” (p. 50).

Marie told me that she babysat her brother a lot; she had more of a nurturing role with her younger brother with Down Syndrome. He looked up to her and enjoyed doing the same activities as she did but she was aware of the limitations caused by chronic illness, such as some developmental delay and mobility issues with his gait that she explained. Marie described spending time with her brother doing activities such as playing on the iPad and watching movies that were mainly centered around him and what he liked as opposed to their common interests. Marie and her mom were both avid runners and her brother ran as well but he had some limitations related to his chronic illness. Marie stated:

...I'm not sure how to describe this, like when he runs it's not like ah, ....I'm not exactly sure...he doesn't have a good stride. It looks like he's kinda having a hard time bouncing along. He's getting a lot better but....

Her brother's mobility issues are visible but Marie and her family have minimized the limitations thus allowing for normalization to occur because they are not focused on. Marie also told me her brother was one of her biggest supporters as she explained:

He always likes to come and watch and he's always at the finish line and hollering for me. He'll try and come out a little bit from the finish line and run the last couple of meters with me. But there's kids races too sometimes that he loves to do and he always says that he's going to win. He always says that he does win, even if he didn't really. We don't like it when he runs the whole thing, we won't let him cause we're nervous of his heart.

It was a balancing act for Marie and her family as they acknowledged what her brother could do and minimized what he could not do. It appeared this family thought it was important to try and normalize chronic illness. Normalization was important because it allowed the family to acknowledge the chronic illness and move forward incorporating the limitations of chronic illness into their lives without a major disruption.

Normalization is a "reference point" for parents whereby they can evaluate the effectiveness of their attempts to look after their child's chronic illness (Knafl, Darney, Gallo, & Angst, 2010, p. 88). Knafl et al. (2010) found that for a group of parents who were able to normalize living with a chronic genetic condition, it meant they were managing effectively in a way that added to the overall value of their family life. As a result of minimizing her brother's limitations, it appeared Marie's family had balanced the effects of living with chronic illness.

Kosmo explained that his brother had more recently been having trouble regulating his blood sugars and this had brought chronic illness into clear focus because

of the hard time managing it. This was a threat to living life as normal. Kosmo showed me many photos, one that revealed that he and his brother both shared the same interest in basketball and have played on the same team in the past, and others that he had taken that showed his independence and his interest in seeking information and health awareness. Even though he was two years younger than his brother he made some lifestyle choices that he hoped would have a positive impact on his brother. He said his decision to eat healthier, such as cutting out pop and reducing his intake of junk food, may have a positive effect on his brother because there would be less junk food in their home. "Cause then I guess if I didn't eat as much there wouldn't be as much in the house and then I guess he wouldn't eat as much." I asked him how this made him feel that he had done something to help out his brother. He replied, "Good, I guess so that way his sugars aren't as high or low." Kosmo was concerned about the unpredictability of the highs and lows with his brother's blood sugars and the fact that his diabetes was not well controlled, and he made some choices in his life that he hoped would have an influence on his brother's chronic illness. He also explained about his parents' vigilant behaviour; they kept a close eye on his brother indirectly by phoning Kosmo from work to ensure his brother was awake to check his sugars. This placed Kosmo in a care-giver role to oversee his brother. Similarly, Waite-Jones and Madill (2008) found in their study with siblings who had JIA that sometimes there could be reversed roles whereby younger siblings looked after older siblings and there was unevenness in power between siblings.

A couple of the adolescents described their sibling relationships in a broader context together with their family. Anthony enjoyed spending time outdoors with his grandfather and sometimes they engaged in activities closer to home to accommodate his

brother's limitations. He said, "Yeah, the odd time we take him fishing and we'll just go down to the creek or we'll just go somewhere where he is guaranteed to catch a fish or something." Like Anthony, Mats shared a common interest with his sister. They both enjoyed music and have attended concerts together but Mats was also aware of his sister's developmental limitations and her more recent mood swings that were related to her recent diagnosis of celiac. These two adolescents identified common ground between themselves and their sibling with chronic illness but they were aware of the differences caused by the chronic illness. Mats said that his sister's mood had improved since his family had started to remove the gluten from her diet; however, her moodiness was still pronounced at times. During these times it was more difficult for him to balance normalization because her irritability was a source of stress and frustration for Mats. There are barriers to normalizing chronic illness in families. Two identified barriers noted by Knafle and Deatruck (2002) that relate to this research study are when illness becomes the focal point and when it is a source of tension in the family (p. 50). Normalization is a process and there can be varying degrees at different times during the chronic illness when the family is faced with challenges to living "life as normal."

All of the adolescents shared common interests or activities with their ill sibling and some saw their siblings as "normal." By doing this the adolescents were able to acknowledge many of the things that their siblings were able to do and downplay or minimize the effects of chronic illness in their lives. However, for some, the limitations imposed by the chronic illness were more visible at times and it was somewhat of a struggle to continue on with "life as normal." This meant that the balance in "everyday"

normal had shifted and chronic illness became the focus for the family and family members until a point of normalization was achieved.

### **Engaging with Family**

All of the adolescents described the importance of engaging with family and they all described unique activities, routines and relationships that were significant to them. For some, family activities were described as a way the family came together to relax and have fun, and it was an opportunity for the siblings with chronic illness to be “normal.” A few spoke about family activities that were influenced by the effects of chronic illness and how they managed them. Some of the adolescents described special relationships that they had with a parent or a grandparent that allowed them to participate in activities without their ill sibling. All of the adolescents described ways that extended family provided support while living with chronic illness.

Kalel described spending time with family members; it was a time when most of the family connected. She said:

Well we usually all play like Mine Craft on the Xbox, or we play like family games, and we have the Connect, so we play a lot of like active games and it's sort of a way that we all come together on the weekends to just relax and have fun.

She described the closeness in her family and how all members had a sense of what her brothers have gone through. The family activities provided an opportunity to be free of the limitations imposed by chronic illness. The photo that Kalel presented of the Xbox was her favourite. She stated:

Because, I think it's my overall favorite, because it's just sort of a way that we can all connect and we help each other out when playing games and it's just sort of a way that my brothers can feel like they're normal, like kids in grade 4 and grade 2 and they just, I think just sort of like, zones them out of the fact they have to get needles every 3 days, and they have to test their sugars and they are not

allowed to eat certain things. I think it's just a way that they make themselves feel normal and we all join together as a family.

Kalel had described earlier how her brothers had difficulty adjusting to their insulin pump set changes. She felt helpless during those times and felt the need to get away or use distraction so she could not hear their crying. During family time, she was able to help her brothers when they were playing games and this made her feel good. This was a time when her brothers were able to forget about their treatment regimen and just be normal kids. This was an opportunity for Kalel and her family to put chronic illness in the “background” and family activities that are normal were focused on. This is a successful strategy for normalizing chronic illness.

Kalel told me that her whole family used the computer. The computer was set up in the dining room, in the center of their home on the main floor where they gathered to watch movies, play games and do homework. As she talked about her photo of the computer, *Digital Fun* (Figure 10), she said,

Well it is the family computer that everyone uses. And I think I took this because we spend a lot of time on the computer. Like our dad downloads movies and then we usually all sit there in the dining room with all kinds of pillows and blankets and we watch a movie...and we play, like there is still Mine Craft on the computer and there's all kinds of stuff and I usually spend a lot of time usually when my brothers are getting their set changes, or testing their sugar and I usually just work on something for school or play a game.



*Figure 10. Digital Fun.*

Family activities were focused on in her home. This is another way this family was able to put routine activities into focus and live “life as normal.” As Kalel described the photo *Lego Land* (Figure 11), she told me of the evolution of the formal dining area in their home:

.....then we started like getting Lego sets, my brothers got them when they were little and I got some. And then it slowly sort of, what evolved from a formal dining room, to a baby changing room, to a Thomas the Train room, to a Lego room, and it’s like that now and basically it’s where we keep all the Legos.



*Figure 11. Lego land.*

Knafel, Deatrick, and Kirby (2001) stated that there are many challenges for families and family members when living with a child who has a chronic condition. It is anticipated that parents will adapt a new complicated treatment plan and then incorporate

this into their everyday life so that it does not dictate the family or child's life. Two attributes in the normalization process as identified by Deatrack, Knafl, and Murphy-Moore (1999) that Kalel's family has demonstrated are "adopts 'normalcy lens' for defining child and family" and "engages in parenting behaviors and family routines that are consistent with 'normalcy lens'" (p. 211).

Zoe, like Kalel, described family activities, but she described them as being part of a family routine on Sundays that made her feel good. Zoe presented three photos as she explained the importance of the routine. The photos were *Sunday Morning* (Figure 12), *Summer* (Figure 13), and *Grandma's Flowers*. She explained the routine starting with *Sunday Morning*.



*Figure 12. Sunday morning.*

She said, "we just go to church and spend time as a family." The next photo, *Summer*, captured time at the beach.





*Figure 13. Summer.*

Every Sunday in the summer after church, she and her family drove to the lighthouse to watch the ocean. The picture evoked happy memories. “We’re always together as a family, sports and everything, and friends in there too.” When Zoe and her family finished at the lighthouse they stopped to get some treats and then had a visit with her grandmother.

Zoe described the importance of a family routine that has meaning for her and her family. This routine did not put chronic illness at the forefront but rather captured the significance of a normal family routine that is not interrupted by diabetes management.

Jonathan, like Kalel and Zoe, talked about family activities. Our interview took place in the family room of his home. He presented many photos that helped him describe family. Jonathan explained that family was important to him: “blood is thicker than water,” “family is better than friends” and “you can change your friends but you can’t change your family.” Jonathan told me how much he enjoyed visiting relatives in the summer, “because we always go on little road trips around places, to our family, my cousins, their bungalow.” He added, “Sometimes cause we need to take his insulin and

that.” He said that it was both his brother’s and his father’s responsibility to remember the insulin on road trips and that they have never forgotten to take it along. He realized the importance of remembering the insulin when living with a brother who has diabetes, “cause without it he couldn’t like, if he had a high blood sugar, we wouldn’t have anything for him.” Jonathan told me that he sometimes helped out with diabetes management by travelling with his father to the drugstore for supplies. He told me that he and his brother did not really talk about his brother’s diabetes because his brother was able to manage it by himself and sometimes with the help of his parents when he was not feeling well. Jonathan described his immediate and extended family as being very close. The road trip description put normal family routines into focus; there was an awareness that supplies and medication needed to be remembered for the trip but it was not the focus of the trip.

Jonathan told me that his brother had been in the hospital twice during the last year and extended family helped a lot: “so like my aunts, uncles and cousins were all over at my house.” Extended family members have spent much time at his home and have often taken the children to activities. Because of this type of family support Jonathan and his siblings were able to maintain their usual schedule of activities and their routine despite his brother’s hospitalization.

Marie presented photos related to activities she did with all of her family members together. *Hanging Out* (Figure 14) was a photo of her living room and it showed the area where her family spent time together.

The next picture is just, actually he [her brother] took this picture, but I want to keep it. It’s of the couch and the chair and the living room because we’re just relaxing. He likes to relax. He tells everybody to relax, he can tell if someone’s worked up about something. He comes over and says, “hey relax” and then he’ll

sit there and puts his hand behind his head and puts his feet up but he loves just sitting home. He always wants to watch movies with us. Like every night he's um, "want to watch a movie tonight and make popcorn and go in the basement and watch a movie?" He loves to go in my parents' bed sometimes before bed.



*Figure 14. Hanging out.*

Family relaxation time was valued and it allowed everyone to forget about the restrictions imposed by chronic illness. There was much humour shared in the family.

Marie added:

Yeah, even if we're not watching TV, like a lot of times, I'll come home from doing something and him and my dad and my mom might be sitting on my parents' bed just, I don't know, maybe my parents are on their phones and he's on the iPad or something and I'll just come in and just sit there with them and somehow all the phones and stuff go away and then we're just there laughing about something. He likes that.

Marie described ways that her family spent time together: travelling, hiking, running, outside water activities in the summer and relaxing together. Marie laughed often as she shared stories and discussed the photos during the interview. She shared a photo of race bibs or race numbers that she had collected from various races, entitled, *The Winner* (Figure 15). She and her mother had an upcoming half marathon planned. The whole family has engaged in running at various levels as she explained:

Um there was a race this past weekend and me and my mom ran the 10K and brother's name and dad did the kids race which I think might have been a mile.

So, me and my mom went over and watched brother's name and my dad do that and then me and my mom had to do the race right after that so then, you know, we're all kinda out there doing something together.



*Figure 15. The winner.*

As Marie explained, her brother had limitations related to his chronic illness:

Yeah because he can't, like I was saying earlier, when he runs, he doesn't have the stride, like when he walks, it's not graceful and he's just not that fast and he'll get tired quicker so we're trying to go through the airport as fast as we can because we're late for a flight. Also what I was talking about earlier and he's just, my dad has to put him on his shoulders, and my dad gets really hot and tired out. That's frustrating sometimes.

Marie added that her younger brother helped out in these times: "Even if we only have 3 suitcases so I can take one and my parents can take one, he'll want to take one, a big huge one." Marie was aware of the differences in her brother's mobility but the family was easily able to make adjustments in their daily living to accommodate his mobility issues. Marie acknowledged a benefit related to travelling and her brother's disability. She explained:

and we go to Disney, but when we go to Disney we always get the um, it's like a disability pass and it will get you to the front of every line; so we love that and he loves that cause I know he wouldn't be able to handle waiting in lines for 2 hours or so. So that's good.

She further explained that when she wanted to do something by herself, the pass also got her to the front of the line so her family was not stuck waiting for her to be done. In this way, Marie was able to “look on the bright side” through focusing on the good and playing down the limitations (Robinson, 1993, p. 14).

Similar to the others, Anthony described family activity as “just family stuff we do together” and this was time that he spent with his family including his brother where limitations from chronic illness were not focused on. One of his photos, titled *The Fire* (Figure 16), captured an activity that he enjoyed doing with his father but also evoked memories from the past when the whole family camped together in their trailer.



*Figure 16. The fire.*

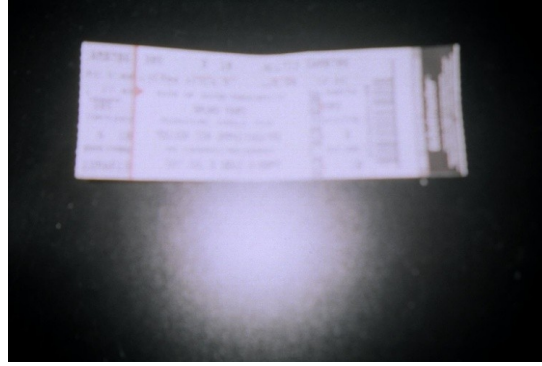
Anthony fondly talked about the relationships between himself and his father and himself and his grandfather. A picture that he captured of his golf clubs titled *Something I Like To Do But Don't Get To Do Very Often* (Figure 17) represented the activity of golfing that both he and his dad enjoyed.



*Figure 17. Something I like to do but don't get to do very often [Golfing].*

He further clarified that what he enjoyed was “just outside, spending time with dad, me and dad. Most times it’s me and him.” This was a time when he and his father were able to do normal things that they enjoyed. “Doing normal things was critical to the performance of the story of normalization” (Robinson, 1993, p. 17). Anthony told me that he and his grandfather often went fishing together and sometimes his brother with chronic illness would go along but they needed to accommodate his brother’s limitations so they went to places that were closer to home for shorter periods of time. This worked out well for all three and Anthony did not mind making the accommodation for his brother and was “happy” with it.

Mats, like Anthony, described enjoying the time he spent with his father. In a photo titled *Guy Retreat* (Figure 18), Mats described a concert that he and his father attended.



*Figure 18. Guy retreat.*

He sounded pleased as he talked about their time together, “Just guy time, not having to worry about my sister, ah we can just relax.” He also valued time spent with his mother as they drove in the car and talked. I asked him what they talked about and he laughed as he said, “I think this goes for any teenager, you can talk about a lot but you can’t talk about everything.” These normal activities seemed to be an effective way of dealing with living with chronic illness so that the illness was not always focused on.

I asked Mats if he spent time with his family and he stated, “Most of the time, it’s mostly when my sister’s gone to bed and we’re watching TV in the family room, that’s mostly when we’re happy.” He added, “Well we’re in the family room watching TV that we like to watch in the night and we enjoy watching it and joke around when we watch it.” Mats had already described his sister’s irritability and moodiness to be limitations in dealing with celiac. He had stated that his sister spent most of her time watching TV in the family room. It was important for him to be able to spend this time with his parents in the family room but his sister’s chronic illness and subsequent moodiness was a threat to normalization when it became the focus and caused tension with the family.

Similar to the others, Kosmo and Joe told stories about time spent with family members. Kosmo shared a story about spending time with his mother; they planted a garden in wooden pallets together. He spoke about his grandparents and described how his grandfather was supportive of the family by giving them books to gain a better understanding of diabetes management. Joe described happy stories about spending family time at the beach. He gave credit to his grandparents for having a role in his strong faith. His religious practice was developed at a very early age when he started attending church with his grandparents. He stated:

Um, well cause I have been going to church as long as I can remember. Since I was quiet enough to sit in church without screaming and yelling, my grandparents would take me to church. I mean I was involved for a while.

This was significant because Joe's spirituality was a source of strength in dealing with his sister's chronic illness.

The adolescents described how extended family members provided support for them and how it positively influenced family functioning. Zoe and Jonathan talked about how extended family took them to their activities on a regular basis and they were also available to help out when their brother was hospitalized. Due to this support, the children were able to continue with their regular set schedules. Extended family provided support for Kaleb's family while her parents went away for short periods. She said:

...there have been times that my parents would go away....like, one of our family members, our aunt actually stays with us a lot and like usually a couple of nights before she'll come over and then my Mom will show her how to give insulin just in case the pumps aren't working, how to do a set change on the pumps and just sort of like show her what they can't eat and what they can eat.

Extended family provided support in many ways for the adolescents in this study. Some noted that extended family provided support so that family life could continue as normal;



the adolescents maintained their activities during periods of time when their ill siblings were hospitalized or when parents went away. Another noted that extended family provided written materials so the family was able to gain a better understanding of the chronic illness and for many, extended family influenced well-being; one adolescent acknowledged his grandparents as being an influence in his spirituality.

The adolescents described activities and routines that captured ways that they spent time, relaxed and had fun with their families. This was part of the process of normalization and a way that the adolescents dealt with living with chronic illness. Through engaging in these routines and often everyday activities, the children and families were able to feel normal. The visible limitations, medications, and routines were minimized but not forgotten. In some cases it was more of a challenge to manage the limitations but the adolescents described ways that they successfully managed. When adolescents and their ill siblings were able to create a common ground they were able to relate to one another and accommodate one another and this made them happy; it brought out good feelings between family members. Extended family members provided support and had a positive influence on all families.

## **Chapter 7: Discussion**

The purpose of this interpretive phenomenology study was to gain a deeper understanding of what it means to be an adolescent living with a sibling who has a chronic illness. The research question, “What are the experiences of adolescents who live with a sibling who has a chronic illness?” was answered through conducting eight photo-elicitation interviews with adolescents between the ages of 11 and 17 who had siblings living with chronic illness that included diabetes, cancer, congenital heart disease and Down Syndrome. Three predominant themes emerged that gave meaning to their lived experiences: *Making Sense over Time*, *Getting Away from It All*, and *Creating Common Ground with Siblings and Family*.

### **Making Sense over Time**

The first theme, *Making Sense over Time*, captured the adolescents’ descriptions of emotions that they experienced surrounding significant events in the course of their siblings’ chronic illness and how they were able to make sense of these emotions over time. The adolescents talked about and reflected upon a wide range of emotions that were related to early stages of the illness (In the beginning) and others to the passage of time (As time goes on). The adolescents described unique ways that they responded to the chronic illness and felt about themselves, their sibling and other family members. Some adolescents gained an understanding of their situation by asking parents questions and other adolescents recognized the limitations imposed by the chronic illness but realized that it changed over time and it was a balancing act. Some of the adolescents described ways that they took on more responsibility because of the chronic illness and each of them viewed responsibility with a different lens; one felt it was unfair, another expressed

frustration with the responsibility and yet another described the increased responsibility as empowering. Becoming more independent was described by one adolescent, as the result of his brother with chronic illness receiving preferred treatment at home. Many of the adolescents incorporated normalization strategies into their day-to-day living, thus enabling them to manage living with chronic illness. Support from parents in the form of explanations and communication strategies that enabled the children to understand in the beginning and over time helped them to make sense of living with chronic illness. Family support, which included support from extended family members, and supports from education classes (diabetic) and support groups helped the adolescents make sense of their siblings' diagnosis.

### **Emotions**

In this interpretive phenomenology study the photographs that the adolescents took and the titles that they gave their photos assisted them in reflecting upon and bringing a deeper understanding to their everyday lived experiences. The photos served as triggers to their memory and helped them to identify and describe their emotions. The adolescents interviewed described a variety of emotions and responses to living with a sibling with a chronic illness. In the beginning some were “scared” and “sad,” they felt chronic illness “sucked” and “it’s not fair.” One participant stated, “... I didn’t really even know anything...” Some stated they “never understood” what was going on. It also appeared that they were upset, found it hard, and had worries, uncertainties and disappointments. As one adolescent reflected back he stated, “...after a while you just kinda get used to it...” As time went on, hospitalizations evoked feelings of concern and worry. The adolescents described being “nervous” for their hospitalized sibling and

“hoping” they would be okay; some found it “sort of hard.” In addition, it appeared they had worries and uncertainties, and one was jealous of the attention her ill sibling received in the hospital. The day-to-day challenges caused a variety of emotions and feelings as the adolescents verbalized “it changes so much” and “nothing” was easy. Some adolescents described the day-to-day issues as “annoying” and “frustrating.” One adolescent found it made him “angry” and felt it was unfair that he had more responsibility than his brother with chronic illness had when he was the same age. It appeared another adolescent felt a lack of control over behaviour issues that he had no influence over and adjusted his routine accordingly. One adolescent expressed profound sadness when his sister relapsed and releasing his emotions and crying with a friend was a positive outlet in addition to expressing hope and seeking support in his religion. These findings were similar to the findings of other researchers who noted negative manifestations. Hollidge (2001) found the semi-structured interview revealed emotions of “responsibility, unhappiness, jealousy, competition, negativity, shame and guilt” (p. 19). Williams et al. (2009) reported parents’ perceptions revealed negative manifestations: “jealousy/envy,” “upset/anger/resentment,” fear/worry/anxiety,” “negative behaviors,” and other problems such as “guilt” and “school problems” (p. 101).

Nurses working with adolescent siblings of children with chronic illness need to be attentive to their emotions because there is a consensus in the literature that they are at risk for developing negative psychological effects. Williams (1997) found that 60% of the studies she reviewed showed that siblings of children with chronic illness were at an increased risk for mental health problems. The work of Hollidge (2001) also supported the negative manifestations found in siblings of children with chronic illness as he stated,

“studies suggest that well siblings may suffer from emotional distress and adaptive challenges because of complicated sibling negotiations and parental demands from the illness” (p. 16). When nurses are able to work with adolescent siblings and emotional concerns are identified strategies and supports can be put into place to decrease further negative impact.

The adolescents openly discussed their feelings during the photo-elicitation interviews. They articulated in detail how they felt at different times during the course of their siblings’ chronic illness. It appeared that although some of the adolescents identified the same emotion as other adolescents in the study, each adolescent’s emotion had a different meaning because of his or her individual experiences with his or her family in unique circumstances. Similarly, the emotions expressed by the adolescents in this research study support previous researchers’ findings of emotions experienced by well siblings of children with chronic illness; however, it is important to listen to the voice of each adolescent to develop an understanding of their unique experiences.

In this research study, responsibility had different meanings when interpreted in the context of each situation. One adolescent was closely involved in her brother’s care and offered to help out by suggesting that she give her brother’s insulin injection at school when the insulin pump was problematic. The adolescent came up with the idea on her own and stated she was “pretty good at it.” She was proud of herself and it proved to be an empowering moment for her as she accepted this responsibility. On the other hand, another adolescent was given the responsibility to keep a watchful eye on his brother while his parents were at work. His brother with diabetes had been experiencing frequent high and low blood sugars, was sleeping later in the morning and not answering phone

calls from parents either because his phone was not charged or he just did not respond. The adolescent found it annoying and frustrating and reluctantly tended to the increased responsibility. In yet another example, an adolescent in this study felt it was unfair that he had to do more at the same age of his brother with chronic illness. He felt that this was unfair treatment and he was not happy to have the increased responsibility. All three of these adolescents had different perceptions of responsibility and it was revealed as they shared their stories. This speaks to the importance of the nurse speaking with each adolescent sibling to develop an understanding of their expressed emotions. In a similar fashion, other researchers have identified responsibility as a finding. Hollidge (2001) found that responsibility was the result of “internal expectations on being protectors and caregivers towards their ill brothers and sisters” (p. 20). Wennick and Huus (2012) conducted a qualitative study using content analysis. Siblings that ranged in age from 10-17 years, of children with newly diagnosed type 1 diabetes were interviewed. They found that the well siblings had increased responsibility at home; they helped out with chores and assisted with management of the illness. All family members helped with looking after the ill child and this resulted in the well siblings feeling that all family members had become more tight-knit.

Feeling responsible was identified as a shared emotion amongst a few participants. However, the experience of responsibility meant something different to each of them. Other researchers found additional meanings and this shows the potential for diverse findings and therefore individualized approaches are needed. This research finding speaks to the importance of family health nurses taking the time to meet with adolescents to foster a rapport so they can develop an in-depth understanding of

adolescents' experiences and how they feel about them. It is important to go beyond assumptions and to find out more detail and meaning so family health nurses can attend to these issues and provide the appropriate supports.

The adolescents in this research study described worries about the unknowns with their siblings' illness. They described worries about separation from them and their parents while the ill child was hospitalized because they did not know what was going on. One adolescent remembered when she was younger that her parents minimized their urgency to travel by plane and called it "a ride"; perhaps this was done to lessen worries but it actually intensified her worries because of a lack of understanding. The adolescents told me that communication with their ill sibling in the hospital helped and that understanding over time made a difference. It is important for the nurse to talk with the adolescents so they can describe and identify what their worries are about so the appropriate supports are put in place. Nurses can provide guidance and support to parents so they can talk to family members and provide the information that they need that is developmentally appropriate. Worries may vary for adolescents and in the same way there may be different meanings reported amongst researchers. Hollidge (2001) also found that the siblings interviewed discussed worries; they were worried about their ill sibling's health and frequently worried about them dying. Some well siblings expressed worries about their own health. Menke (1987) interviewed school aged children who had siblings with chronic illness and found that most of the children had worries about their ill sibling. The sibling worries were related to their time spent in hospital, the medications they received, their diagnosis and how they were doing. Others had worries about themselves and their parents. Wennick and Huus (2012) reported that siblings that had a

brother or sister that was newly diagnosed with type 1 diabetes had a hard time learning about their sibling's diagnosis, in that they did not know much about the diagnosis, and they had fears that it would damage their sibling's life. They also had concerns and worries that needle punctures hurt. These findings were similar to the findings of this research study except that the adolescents in this study did not express fears about the illness damaging their sibling's life.

The adolescents in this interpretive phenomenology study described ways that they were able to make sense of what was happening with their sibling who had a chronic illness. As they developed the ability to make sense of what was happening this alleviated their fears and worries. One adolescent described how she asked her parents questions and felt supported in the form of parental explanations that helped enhance her understanding. In addition, the adolescents found that education from health care providers and support from relevant groups, such as diabetic support groups made a difference by increasing their understanding about the chronic illness. Support from parents, support from health care providers who provided education, and support from support groups were identified by adolescents as ways to help develop an understanding. Similar results were found in the literature. Wennick and Huus (2012) noted that lack of information about the illness led to fear and when children asked questions about their ill siblings' health it helped to reduce the fears. Similar to this interpretive phenomenology study, Wennick and Huus (2012) found that support for the well siblings is important. They felt the well siblings required information about the illness and needed a chance to be involved in educational opportunities with the pediatric team so they could increase their knowledge about the illness and also help out with the management of the illness.



Although the adolescents in my study described a variety of negative emotions, they were reflective and the passage of time made a difference as they described ways that they handled living with a sibling with chronic illness. In support of this statement, Alderfer et al. (2010) conducted a systematic review of psychosocial adjustment of siblings of children with cancer and found there was a reduction in distress over time from the time of diagnosis. However, Alderfer et al. (2010) also stated that adolescent siblings displayed the least favourable adjustment in comparison with other groups such as preschoolers, school-aged children and adults. In this interpretive phenomenology study the adolescents described ways that they managed living with chronic illness through various supports that helped them make sense over time.

In this research study, an interesting finding was that many of the adolescents' siblings were diagnosed when they were younger, varying in ages from three to six years at the time of diagnosis. One adolescent was ten when his sibling was diagnosed more recently, three years ago. This passage of time allowed the adolescents an opportunity to reflect back and consequently describe how things made sense to them over time. Parental support, educational support and support groups (diabetic) were described by the adolescents as ways that enhanced their understanding.

In this study, the adolescents themselves described how they made sense of their siblings' chronic illness over time. In contrast, other studies have not reflected views of the well siblings and have only included negative manifestations that well siblings experienced. Sharpe and Rossiter (2002) found the parents' reports to be more negative than those of the well children. In addition, a review on the psychosocial well-being of children with chronic illness and their siblings and parents conducted by Barlow and

Ellard (2006) found that the reports of psychosocial well-being varied depending on who was reporting the status. Parents always had the most negative reports; this speaks to the importance of attending to the adolescents, letting them express themselves and listening to what they have to say. This study gave a voice to the adolescent siblings of children with chronic illness and they described their emotions but they also expressed an increase in understanding over time and articulated what enabled the process.

*Making Sense over Time* described ways that the adolescents were able to gain an understanding of their situation by asking parents questions, and support received through support groups and educational support all contributed to making a difference. Some of the adolescents recognized limitations imposed by chronic illness and developed normalization strategies that helped them deal with it. As the adolescents developed the ability to make sense of what was happening, this alleviated their fears and worries. Nurses working with adolescents need to listen to their voices and attend to their worries and concerns so they can meet the challenges of living with siblings with chronic illness.

### **Getting Away from It All**

The second theme, *Getting Away from It All*, represented my interpretation of the adolescents' actions as they responded to events in their siblings' chronic illness. The adolescents expressed their own ways of handling stressors related to the chronic illness such as parental expectations, feeling overwhelmed and a loss of control. Getting away provided an opportunity for a break, to relax, and a time to reflect. Some adolescents felt an urgency to get away and described it as "escaping" and "bolting" outside and others described getting away as going into their "own little world," to be protected in a "bubble." Getting away for others provided an opportunity to connect with a supportive

network, such as support groups, friends, and religion. Many of the participants had family pets and described the positive influence that they provided in their homes. Overall, getting away was an opportunity to find balance from the effects of living with chronic illness.

### **Finding a Balance**

The adolescents in this study described ways to balance the effects of living with a sibling with chronic illness. It was an opportunity to feel normal, focus on other things, and as many identified, a time to relax. MacDonald and Gibson (2010) noted that parents who cared for a child with complex care needs at home required a break away so they could feel “normal” and referred to it as an “escape” from the worry of care giving. There are far reaching effects of living with siblings with chronic illness and the balance enabled them to put chronic illness in the “background” and focus on themselves.

Some adolescents described getting away as an opportunity to connect with a supportive network, such as support groups, friends, and religion. Adolescents in this research study described their participation in support groups as being positive. This opportunity provided socialization, education, understanding, and an awareness that others were living with similar challenges and thus a realization that they were not alone. An adolescent who was involved in a support group through his church went away for a weekend with a group of adolescent males and found it to be very supportive; he stated “Oh yeah, really positive....they have like speakers and everyone tells their story...” The adolescents in this research study found the support groups beneficial. Similarly, Houtzager et al. (2001) found that siblings of children with chronic illness benefited from attending a support group. Having an opportunity to share stories and reveal emotions in

a group was believed to contribute to decreasing anxiety in the siblings. The support groups offered an opportunity to increase the well siblings' knowledge and understanding of the illness and the impact that this had on family relationships and emotions. It provided an opportunity to resolve misunderstandings (Houtzager et al., 2001). In recognizing the implications for support, Hollidge (2001) identified well siblings who accompanied families to the clinic as "auxiliary helpers" (p.24) because the ill child places many responsibilities on parents and the well siblings are seen as accommodating family members and relieving some of their parents' pressure. Hollidge (2001) noted that although well siblings may be "auxiliary helpers" and this may increase their sense of ability, it does not attend to their negative feelings. Many initiatives could be put in place to serve families and well siblings. Psychoeducational groups for parents and group programs for well siblings would be beneficial (Hollidge, 2001).

An interesting finding in this study was that pets were valued for their contributions to family life. Many of the participants took photographs of their family pets and described the positive influence that their pets provided in their homes. One adolescent stated the value his dog added to his home, "...He just kinda helps the mood in the house, like stay stable sometimes." It appeared many of the pets were like family members. Another adolescent described how his dog was able to detect when his brother's blood sugar was low by giving a cry and going to his brother's room. E. Friedman and Thomas (1985) reviewed the literature and found that pets offer many health benefits. Some of the benefits include: companionship; decreased loneliness, anxiety and depression; enhanced well-being; and increased self-esteem (E. Friedman & Thomas, 1985). *Getting Away from It All* described how the adolescents found balance

which appeared to be a normalization strategy that enabled them to handle living with a sibling with a chronic illness

Nurses are in a position to provide support and refer the adolescent and family to additional supports in the community so that they have an opportunity to be connected with others in similar situations. The adolescents in this study described unique ways to find a balance that nurses may promote: connecting with peers, support groups, pets, and the use of electronic devices. The electronic devices that the adolescents used in this study to relax were iPods and phones that provided games and music, ipads for TV, games and connecting with social media and Play Station and Xbox. Support offers an opportunity to balance the negative effects of chronic illness and provides an opportunity to be connected so adolescents can enhance their understanding the effects of chronic illness.

*Getting Away from It All* represented my interpretation of the adolescents' responses to events in their siblings' chronic illness. All of the adolescents described ways they balanced the effects of living with a sibling with chronic illness. Some of the adolescents described the need to get away and either spend time alone or with friends. Support groups, pets, friends and religion were identified as ways to help provide balance. The adolescents' ability to find a balance was a normalization strategy that enabled them to put chronic illness in the background and focus on what was important to them.

### **Creating Common Ground with Siblings and Family**

Theme three, *Creating Common Ground with Siblings and Family*, was identified not only as a way that the adolescents found "common ground" with their siblings but

also as a way they were able to put chronic illness in the background and to live “life as normal”, by doing routine day-to-day activities that they enjoyed and made them happy. The adolescents described many interests and activities that they shared with their siblings that focused on their abilities and not the limitations related to chronic illness. The routines and activities represented a way that chronic illness had been normalized into their lives. Some of the adolescents described ways that chronic illness infringed on their lives but they also told how they dealt with it. Some dealt with it by doing the same activity with their ill sibling but for shorter amounts of time to accommodate the limitations imposed by chronic illness, and others dealt with it by recognizing the illness when it was time for treatment but putting it out of focus at other times.

### **Limitations and Recommendations for Further Studies**

This research study used a small sample size that allowed for an in-depth interpretive analysis of adolescents’ experiences of living with siblings with chronic illness. The participants in this research study represented an homogenous group of adolescents with two-parent families, and therefore it may be beneficial for future research to look at other types of families. This sample size may not be representative of all families living with children with chronic illness. The study took place in one geographical area and findings cannot be generalized.

### **Nursing Implications**

The adolescents in this research study identified many strengths that made it easier to deal with living with siblings with chronic illness. Throughout this paper I used the term “deal with” or “handle” when referring to how the adolescents successfully managed living with chronic illness. Using an interpretive lens, this could also be viewed

as having “coped,” “adapted,” or “adjusted.” These were positive ways that the adolescents responded to the challenges of living with a sibling with a chronic illness. The adolescents in this study were able to describe what helped them make sense of chronic illness, how they got away from it when they needed to, how they connected with their ill siblings and family and how this made a difference. Nurses are in a position to make a difference when caring for adolescent siblings by providing educational and emotional support throughout the course of the chronically ill sibling’s illness. Each adolescent should be given an opportunity to meet individually with the family-centered care nurse to express his/her feelings and describe what may be working well and where there are questions, concerns or misunderstandings. Nurses should take into account the developmental level of the adolescent and find ways to relate to them so the adolescent will feel comfortable sharing his/her feelings. Adolescents may express a desire to assist in the chronic illness management and have increased independence and increased responsibility, and may even be empowered through being involved. Participation of the adolescent of a sibling with a chronic illness in the care of the sibling with a chronic illness should be agreed on by all family members so that parental expectations do not exceed what the adolescent is willing and able to do at the time. The adolescent’s willingness to participate in chronic illness management may change over time and nurses can continue to provide education to make this a positive experience.

Nurses can provide anticipatory guidance to adolescents and families over the course of chronic illness. There are specific times in the course of chronic illness that are known to be stressful to other family members: diagnosis, when the ill child transitions from one developmental stage to the next, when parents must keep up with the ongoing

demands of the illness, disease flare-ups and hospital admission (Melynk et al., 2001). Nurses can educate adolescents on this so they are aware of what to expect. In addition, nurses should inform all family members of all possible supports that are available to them, be they web-based or community-based. Examples of possible supports that were identified in this research study included educational programs, group supports, and r family member supports. The adolescents in this study described strategies that they used to normalize chronic illness and stated that normal activities, routines and everyday living were valued. It would be beneficial for the nurse to ask families what their goals are in chronic illness management so they can individualize their plan of care to help them to meet their goals.

Photo-elicitation interviewing may be a potentially beneficial nursing intervention to include when working with children and adolescents to help them express their ideas, feelings, and emotions of what it has been like to be an adolescent living with a sibling with chronic illness. This method provided many benefits that have been found in the literature. The adolescent participants in this research study were given the disposable cameras at the time of consent and they had them for two weeks. This gave the participants time to reflect on their experience of being a sibling to a brother or sister with chronic illness. Clark-Ibanez (2004) noted that photos may bring about a memory and start a discussion based on the photo. The adolescents in this study reflected on past experiences and included photos that reminded them of various times during the course of their brother's or sister's chronic illness, such as diagnosis, which in some cases was many years ago. As noted by Wells et al. (2013), it gave them control as to what they wanted to include in the photos. The adolescents were given an opportunity to remove



any photos that they did not want to talk about during the interview. The photos allowed the participants to discuss issues that may not have been brought up in a spoken conversation (Croghan et al., 2008). When the participants were finished describing how the photo reminded them of their sibling with chronic illness it was helpful to have another photo to refer to for further discussion, as was found by Collier and Collier (1986). All of the adolescents were involved during the interview process and similarly Clark-Ibanez (2004) also noted it was a wonderful way to engage children and adolescents. The photos that the adolescents captured helped them to tell their story of what it was like to be a sibling of a brother or sister with a chronic illness; the photos served to elicit a more in-depth narrative which added more meaning to their everyday experiences in this phenomenological enquiry.

### **Conclusion**

In this interpretive phenomenology study, three themes were identified that were central to the meaning of the lived experiences of the adolescents. The three themes are: *Making Sense over Time*, *Getting Away from It All* and *Creating Common Ground with Siblings and Family*. In *Making Sense over Time*, the adolescent siblings provided examples of how they felt and thought about their siblings' chronic illness and how it affected them and their family. Through the passage of time the adolescents were able to make sense of their siblings' chronic illness. Support from parents, support groups and educational support were identified by the participants as being important in this process. Many of the adolescents incorporated normalization strategies as a way of living with chronic illness so that they focused on "life as normal" and put the chronic illness in the "background." Using an interpretive lens, I found responsibility had different meanings

and meant different things to each of the adolescents who described it; for one it was empowering, for another it meant unfairness and for the other it meant it caused frustration. As nurses who are working with adolescent siblings of children with chronic illness, it is important that we meet with them one-on-one at various points during their siblings' course of illness and listen intently to their voices. As nurses we need to address their concerns and worries and help them to understand what is happening in their siblings' illness and in their families as all members are affected. We need to connect the adolescents with the appropriate educational resources and supports so that they are able to deal with chronic illness.

In *Getting Away from It All* the adolescents described ways that they found a balance to living with chronic illness. Some identified the need to escape, sometimes with urgency; others needed time to relax on their own or with friends. This was an opportunity for a diversion, to provide some balance so chronic illness was not the focus. Being connected with friends and support groups was identified as being helpful. Support groups offered an opportunity to meet others who understood because they were living with siblings with the same chronic illness. Pets provided health benefits; they provided a calming influence in the home and the adolescents recognized their positive contributions in their relationships with the ill siblings.

In *Creating Common Ground with Siblings and Family*, adolescents described routine day-to-day activities that they enjoyed. These activities and routines helped to normalize the chronic illness; it appeared that the adolescents and families were successfully dealing with chronic illness because it was not the focus of their lives. In the adolescents' rich descriptions it was evident that they used normalization strategies to

successfully meet the challenges of living with chronic illness. It appeared family support and the ability to normalize living with chronic illness may lend itself to resiliency.

## References

- Alderfer, M. A., Long, K. A., Lown, E. A., Marsland, A.L., Ostrowski, N. L., Hock, J. M., & Ewing, L. J. (2010). Psychosocial adjustment of siblings of children with cancer: A systematic review. *Psycho-Oncology, 19*(8), 789-805.  
doi:10.1002/pon.1638
- Barlow, J. H., & Ellard, D. R. (2004). Psycho-educational interventions for children with chronic disease, parents and siblings: An overview of the research evidence base. *Child: Care, Health and Development, 30*(6), 637-645. doi:10.1111/j.1365-2214.2004.00474.x
- Barlow, J. H., & Ellard, D. R. (2006). The psychosocial well-being of children with chronic disease, their parents and siblings: An overview of the research evidence base. *Child: Care, Health and Development, 32*(1), 19-31. doi:10.1111/j.1365-2214.2006.00591.x
- Bellin, M. H., & Kovacs, P. J. (2006). Fostering resilience in siblings of youths with a chronic health condition: A review of the literature. *Health & Social Work, 31*(3), 209-216.
- Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing practice* (Commemorative ed., 2001). Upper Saddle River, NJ: Prentice Hall.
- Benner, P. (1994). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness*. (pp. 99-127). Thousand Oaks, CA: Sage.
- Bluebond-Langner, M. (1996). *In the shadow of illness*. New Jersey: Princeton UP.

- Burton, M. (2010). Supporting adolescents who have a sibling with a life-threatening illness: An exploratory study. *Counselling and Psychotherapy Research, 10*(4), 316-321.
- Canadian Paediatric Society Adolescent Health Committee. (2013). Care of adolescents with chronic conditions. *Paediatrics & Child Health, 11*(1), 43-48. Retrieved from <http://www.cps.ca/en/documents/position/care-of-youth-chronic-conditions>
- Clark, C. D. (1999). The autodriven interview: A photographic viewfinder into children's experience. *Visual Sociology, 14*(1), 39-50.  
doi:10.1080/14725869908583801
- Clark-Ibanez, M. (2004). Framing the social world with photo-elicitation interviews. *American Behavioral Scientist, 47*(12), 1507-1527.  
doi:10.1177/00027642042662.36
- Collier, J. Jr., & Collier, M. (1986). Interviewing with photographs. In *Visual anthropology: Photography as a research method* (rev. and expanded ed., pp. 99-116). Albuquerque: University of New Mexico Press.
- Cordaro, G., Veneroni, L., Massimino, M., & Clerici, C. A. (2012). Assessing psychological adjustment in siblings of children with cancer. *Cancer Nursing, 35*(1), E42-E50.
- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches*. Thousand Oaks, CA: Sage.
- Croghan, R., Griffin, C., Hunter, J., & Phoenix, A. (2008). Young people's constructions of self: Notes on the use and analysis of photo-elicitation methods. *International Journal of Social Research Methodology, 11*(4), 345-356.

- Dashiff, C. (2001). Methodological issues in nursing research: Data collection with adolescents. *Journal of Advanced Nursing*, 33(3), 343-349.
- Deatrick, J. A., Knafl, K. A., & Murphy-Moore, C. (1999). Clarifying the concept of normalization. *Journal of Nursing Scholarship*, 31(3), 209-214.
- Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44(1), 131-142. doi:10.1016/j.ijnurstu.2005.11.026
- Drew, S. E., Duncan, R. E., & Sawyer, S. M. (2010). Visual storytelling: A beneficial but challenging method for health research with young people. *Qualitative Health Research*, 20(12), 1677-1688.
- Dreyfus, H. L. (1992, 3rd printing). *Being-in-the-world. A commentary on Heidegger's Being and time, division I*. Cambridge, MA: MIT Press.
- Dunn, J. (1988). Sibling influences on child development. *Journal of Child Psychology and Psychiatry*, 29(2), 119-127.
- Dunn, J. (2000). State of the art: Siblings. *The Psychologist*, 13, 244-248.
- Fochtman, D. (2008). Phenomenology in pediatric cancer nursing research. *Journal of Pediatric Oncology Nursing*, 25, 185-192. doi:10.1177/1043454208319186.
- Friedman, E., & Thomas, S. A. (1985). Health benefits of pets for families. *Marriage & Family Review*, 8(3-4), 191-203. doi:10.1300/J002v08n03\_14
- Friedman, M. M., Bowden, V. R., & Jones, E. G. (2003). *Family nursing: Research, theory, and practice* (5th ed.). Upper Sadle River, NJ: Prentice Hall.

- 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), 23-29.
- Gedaly-Duff, V., Heims, M. L., & Nielson, A. E. (2005). Family health nursing. In S. Harmon-Hanson & V. Gedaly-Duff (Eds.), *Family health care: Theory, practice and research* (3rd ed., pp. 291-321). Philadelphia, PA: F. A. Davis.
- Gibson, C. H. (1986). How parents cope with a child with cystic fibrosis. *Nursing Papers, 18*(3), 31- 45.
- Guite, J., Lobato, D., Kao, B., & Plante, W. (2004). Discordance between sibling and parent reports of the impact of chronic illness and disability on siblings. *Children's Health Care, 33*(1), 77-92.
- Hansen-Ketchum, P., & Myrick, F. (2008). Photo methods for qualitative research in nursing: An ontological and epistemological perspective. *Nursing Philosophy, 9*, 205-213.
- Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies, 17*(1), 13-26. doi:0.1080/14725860220137345
- Havermans, T., Wuytack, L., Deboel, J., Tijtgat, A., Malfroot, A., De Boeck, C., & Proesmans, M. (2010). Siblings of children with cystic fibrosis: Quality of life and the impact of illness. *Child: Care, Health and Development, 37*(2), 252-260. doi: 10.1111/j.1365-2214.2010.01165.x
- Heidegger, M. (1962). *Being and time*. (J. Macquarrie & E. Robinson, Trans.) New York, NY: Harper & Row.

- Hodgkinson, R., & Lester, H. (2002). Stresses and coping strategies of mothers living with a child with cystic fibrosis: Implications for nursing professional. *Journal of Advanced Nursing, 39*(4), 377-383.
- Hollidge, C. (2001). Psychological adjustment of siblings to a child with diabetes. *Health & Social Work, 26*(1), 15-25.
- Houtzager, B. A., Grootenhuis, M. A., Last, B. F. (1999). Adjustment of siblings to childhood cancer: A literature review. *Support Care Cancer, 7*, 302-320.
- Houtzager, B. A., Grootenhuis, M. A., & Last, B. F. (2001). Supportive groups for siblings of pediatric oncology patients: Impact on anxiety. *Psycho-Oncology, 10*(4), 315-324. doi:10.1002/pon.528
- Incedon, E., Williams, L., Hazell, T., Heard, T. R., Flowers, A., & Hiscock, H. (2013). A review of factors associated with mental health in siblings with chronic illness. *Journal of Child Health Care*. Advance online publication. doi:10.1177/1367493513503584
- Kao, B., Plante, W., & Lobato, D. (2009). The use of the impact on sibling scale with families of children with chronic illness and developmental disability. *Child: Care, health and development, 35*(4), 505-509. doi:10.1111/j.1365-2214.2009.00944.x
- Knaf, K. A., Darney, B. G., Gallo, A. M., & Angst, D. B. (2010). Parental perceptions of the outcome and meaning of normalization. *Research in Nursing & Health, 33*(2), 87-98. doi:10.1002/nur.20367
- Knaf, K. A., & Deatrick, J. A. (2002). The challenge of normalization for families of children with chronic conditions. *Pediatric Nursing, 28*(1), 49-56.



- Knafel, K. A., Deatrick, J. A., & Kirby, A. (2001). Normalization promotion. In M. Craft-Rosenberg & J. Denehy (Eds.), *Nursing interventions for infants, children, and families* (pp. 373-388). Thousand Oaks, CA: Sage.
- Knafel, K. A., & Gilliss, C. L. (2002). Families and chronic illness: A synthesis of current research. *Journal of Family Nursing*, 8(3), 178-198.  
doi:10.1177/107484070200800302
- Koch, T. (1996). Implementation of a hermeneutic inquiry in nursing philosophy, rigour and representation. *Journal of Advanced Nursing*, 24, 174-184.
- Lavigne, J. V., & Ryan, M. (1979). Psychologic adjustment of siblings of children with chronic illness. *Pediatrics*, 63(4), 616-627.
- Lee, A., & Rempel, G. R. (2011). Parenting children with hypoplastic left heart syndrome: Finding a balance. *Journal for Specialists in Pediatric Nursing*, 16(3), 179-189. doi:10.1111/j.1744-6155.2011.00289.x
- Lehna, C. (2010). Sibling experiences after a major childhood burn injury. *Pediatric Nursing*, 36(5), 245-251.
- Lewis, M., & Prescott, H. (2006). Impact of life-limiting illness on the family. In A. Goldman, R. Hain, & S. Liben (Eds.), *Oxford textbook of palliative care for children* (pp. 154-178). New York, NY: Oxford University Press.
- Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. In *Naturalistic inquiry* (pp. 289-331). Beverly Hills, CA: Sage.

- Looman, W. S., O'Conner-Von, S., & Lindeke, L. L. (2008). Caring for children with special health care needs and their families: What advanced practice nurses need to know. *The Journal for Nurse Practitioners*, 4(7), 512-517.  
doi:10.1016/j.nurpra.2008.04.021
- Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research*, 14(5), 726-735. doi:10.1177/1049732304263638
- MacDonald, H. L., & Gibson, C. H. (2010). Parenting children requiring complex care at home: Re-visiting normalisation and stigma. *Journal of Nursing and Healthcare of Chronic Illness*, 2(3), 241-250. doi:10.1111/j.1752-9824.2010.01065.x
- Mackey, S. (2005). Phenomenological nursing research: Methodological insights derived from Heidegger's interpretive phenomenology. *International Journal of Nursing Studies*, 42(2), 179-186. doi:10.1016/j.ijnurstu.2004.06.011
- Melnyk, B. M., Feinstein, N. F., Moldenhouer, Z., & Small, L. (2001). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing*, 27(6), 548-558.
- Menke, E. M. (1987). The impact of a child's chronic illness on school-aged siblings. *Children's Health Care*, 15(3), 132-140.
- Nabors, L. A., Kichler, J. C., Brassell, A., & Thakkar, S. (2013). Factors related to caregiver state anxiety and coping with a child's chronic illness. *Families, Systems, & Health*, 31(2), 171-180. doi: 10.1037/a0031240

- Newton, K., & Lamarche, K. (2012). Take the challenge: Strategies to improve support for parents of chronically ill children. *Home Healthcare Nurse, 30*(5): E1-E8.  
doi:1097/NHH.0b013e318252c3d5
- O'Brien, I., Duffy, A., & Nicholl, H. (2009). Impact of childhood chronic illnesses on siblings: A review of the literature. *British Journal of Nursing, 18*(22), 1358-1365.
- O'Haver, J., Moore, I. M., Insel, K. C., Reed, P. G., Melynk, B. M., & Lavoie, M. (2010). Parental perceptions of risk and protective factors associated with the adaptation of siblings of children with cystic fibrosis. *Pediatric Nursing, 36*(6), 284-291.
- Patton, M. Q. (2002). Purposeful sampling. In *Qualitative research & evaluation methods* (3rd ed., pp. 230-248). Thousand Oaks, CA: Sage.
- Petty, N. J., Thomson, O. P., & Stew, G. (2012). Ready for a paradigm shift? Part 2: Introducing qualitative research methodologies and methods. *Manual Therapy, 17*, 378-384.
- Plager, K. A. (1994). Hermeneutic phenomenology: A methodology for family health and health promotion study in nursing. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness*. (pp. 65-83). Thousand Oaks, CA: Sage.
- Plunkett, R., Leipert, B. D., & Ray, S. L. (2012). Unspoken phenomena: Using the photovoice method to enrich phenomenological inquiry. *Nursing Inquiry*.  
doi:10.1111/j.1440-1800.2012.00594.x

- Ray, M.A. (1994). The richness of phenomenology: Philosophic, theoretic, and methodologic concerns. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 117-133). Thousand Oaks, CA: Sage.
- Robinson, C. A. (1993). Managing life with a chronic condition: The story of normalization. *Qualitative Health Research*, 3(6), 6-28.  
doi:10.1177/104973239300300102
- Saewyc, E. M. (2007). Health promotion of the adolescent and family. In M. Hockenberry & D. Wilson (Eds.), *Wong's nursing care of infants and children* (8<sup>th</sup> ed., pp. 811-848). St. Louis, Missouri: Mosby
- Santelli, J. S., Smith Rogers, A., Rosenfeld, W. D., DuRant, R. H., Dubler, N., Morreale, M., English, A., . . . Schissel, A. (2003). Guidelines for adolescent health research: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 33(5), 396-409.
- Schneider, M., Steele, R., Cadell, S., & Hemsworth, D. (2011). Differences on psychosocial outcomes between male and female caregivers of children with life-limiting illnesses. *Journal of Pediatric Nursing*, 26, 186-199.  
doi:10.1016/j.pedn.2010.01.007
- Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology*, 27(8), 699-710.  
doi:10.1093/jpepsy/27.8.699

- Smith, E. F., Gidlow, B., & Steel, G. (2012). Engaging adolescent participants in academic research: The use of photo-elicitation interviews to evaluate school-based outdoor education programmes. *Qualitative Research, 12*(4), 367-387. doi:10.1177/1468794112443473
- Smythe, E. A., Ironside, P. M., Sims, S. L., Swenson, M. M., & Spence, D. G. (2008). Doing Heideggerian hermeneutic research: A discussion paper. *International Journal of Nursing Studies, 45*, 1389-1397.
- Steele, R., & Davies, B. (2006). Impact on parents when a child has a progressive, life-threatening illness. *International Journal of Palliative Nursing, 12*, 576-585.
- Streubert Speziale, H. J., & Carpenter, D. R. (2003). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia: Lippincott Williams & Wilkins.
- Swallow, V., Macfadyen, A., Santacroce, S. J., & Lambert, H. (2011). Fathers' contributions to the management of their child's long-term medical condition: A narrative review of the literature. *Health Expectations, 15*, 157-175. doi:10.1111/j.1369-7625.2011.00674.x
- Tak, Y. R., & McCubbin, M. (2002). Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease. *Journal of Advanced Nursing, 39*(2), 190-198.
- Thibodeau, S. M. (1988). Sibling response to chronic illness: The role of the clinic nurse specialist. *Issues in Comprehensive Pediatric Nursing, 11*, 17-28.

- van Manen, M. (2007). *Researching lived experience: Human science for an action sensitive pedagogy*. London, ON: The Althouse Press. (Original work published 1997)
- Vermaes, I. P. R., van Susante, A. M. J., & van Bakel, H. J. A. (2012). Psychological functioning of siblings in families of children with chronic illness: A meta-analysis. *Journal of Pediatric Psychology, 37*(2), 166-184.  
doi:10.1093/jpepsy/jsr081
- Waite-Jones, J. M., & Madill, A. (2008). Amplified ambivalence: Having a sibling with juvenile idiopathic arthritis. *Psychology and Health, 23*(4), 477-492.  
doi:10.1080/14768320701299906
- Wells, F., Ritchie, D., & McPherson, A. C. (2013). 'It is life threatening but I don't mind': A qualitative study using photo elicitation interviews to explore adolescents' experiences of renal replacement therapies. *Child: Care, Health, and Development, 39*(4), 602-612. doi:10.1111/j.1365-2214.2012.01399.x
- Wennick, A., & Hallstrom, I. (2006). Swedish families lived experience when a child is first diagnosed as having insulin-dependent diabetes mellitus. *Journal of Family Nursing, 12*, 368-389.
- Wennick, A., & Huus, K. (2012). What it is like being a sibling of a child newly diagnosed with type 1 diabetes: An interview study. *European Diabetes Nursing, 9*(3), 88-92.
- Williams, P. D. (1997). Siblings and pediatric chronic illness: A review of the literature. *International Journal of Nursing Studies, 34*(4), 312-323.

Williams, P. D., Ridder, E. L., Setter, R. K., Liebergen, A., Curry, H., Piamjariyakul, U.,  
& Williams, A. R. (2009). Pediatric chronic illness (cancer, cystic fibrosis) effects  
on well siblings: Parents' voices. *Issues in Comprehensive Pediatric Nursing*,  
32(2), 94-113. doi:10.1080/01460860902740990

## APPENDIX A

### LETTER OF INTRODUCTION TO HEALTH CARE PROFESSIONALS

Giving a Voice to Adolescents Living with a Sibling with Chronic Illness

**Principal Investigator:** Jill MacMullen BScN RN  
Master of Nursing Student, Dalhousie University  
Nurse Educator, Cape Breton University  
Department of Nursing  
CBU Tele: (902) 563-1919  
Email: jill\_macmullen@cbu.ca

**Supervisor:** Megan Aston PhD RN  
Associate Professor  
Dalhousie University School of Nursing  
Megan.aston@dal.ca  
Dalhousie Tele: (902) 494-6376



## Letter of Introduction

Dear \_\_\_\_\_,

I am conducting a research project with adolescents who are living with siblings who have a chronic illness. I want to hear more about their experiences. This is an important topic today; it has garnered much attention due to the vast numbers of children who are living with chronic illness and the impact that it has on all family members, including siblings. I will be giving the adolescents disposable cameras and asking them to take pictures of things that they like to do or may not like to do, places that they may like to go to either alone or with their brother or sister. I want to find out what it is like for them, living with a brother or a sister who has a chronic illness. After they have taken 8-10 pictures, I will meet with them and conduct a photo-elicitation interview so they may tell their story.

This research study is being conducted as part of the requirements for the Master in nursing thesis stream program at Dalhousie University. The purpose of my study is to learn more about the experiences of the adolescent siblings living in Cape Breton Regional Municipality (CBRM). In this study, adolescent siblings will be invited to discuss their experiences and take pictures of things or places that represent their life since their brother or sister has been diagnosed with a chronic illness.

The sample proposed for this study will include approximately 8-12 adolescents between the ages of 11-17 years residing within the CBRM and who have a sibling living with a chronic illness. Chronic illnesses, for the nature of the study, will be listed primarily as being diabetes mellitus, cancer, asthma, rheumatoid arthritis, cystic fibrosis, and chronic genetic disorders as they all share attributes of the diseases that include the need for daily treatment regimens and periods of stability mixed with periods of exacerbations. The study will involve giving adolescents a disposable camera at the time of consent and then interviewing each adolescent on one occasion and asking them to describe their experiences of living with a child who has a chronic illness.

As a health care professional that provides care to children and families living with chronic illness, I am contacting you to explore the possibility of meeting with you and providing you with more information. I will also provide you with pamphlets that you may give to families living with chronic illness who have an adolescent sibling between the ages of 11-17 years. **Your role would be to provide pamphlets to families who meet these criteria.** Potential participants will be encouraged to contact me if they have questions or if they are interested in participating in the study.

Participating in this study in this capacity will contribute to research that has the potential to provide valuable information for families, children, and health care professionals involved with children and families living with chronic illness.


I would like to meet with you in person or by phone to discuss your interest in participating in this study in the above noted capacity. I will be happy to answer any questions or to provide additional information regarding the study. Please contact me at (902) 563-1919 or email [jill\\_macmullen@cbu.ca](mailto:jill_macmullen@cbu.ca)

Sincerely,

Jill E. MacMullen

## APPENDIX B

### PAMPHLET



We would like to find out more about being a brother or a sister to someone who has an ongoing health issue.


**Interested?**

If you are between the ages of 11-17 years old and you are interested in being part of a research study or would like more information please call or contact the investigator:

**Who:** Jill MacMullen  
*A Dalhousie Master of nursing student*

**Phone:** (902) 563-1919

**E-mail:** [jill\\_macmullen@cbu.ca](mailto:jill_macmullen@cbu.ca)



Do you have a brother or sister who has?

- ❖ Asthma
- ❖ Diabetes
- ❖ Cystic Fibrosis
- ❖ Some other ongoing health issue

### Purpose of the Study

The purpose of the study is to find out more about what it is like living with a brother or sister that has a chronic illness.



### Who can be in this Study?

- Teens between the ages of 11-17 years old who are living with a brother or sister who has an ongoing health issue that may include:
  - Asthma
  - Diabetes
  - Cancer
  - Cystic Fibrosis
  - Rheumatoid Arthritis
  - Chronic Genetic Disorders
- Living in the Cape Breton Regional Municipality

### The Camera

You will be given a disposable camera to take 8-10 pictures of things or places that help to tell your story.



### The Interview

- One interview will be set up after you take the photographs.
- You will describe the photographs that you have taken and describe how the pictures make you feel about living with a brother or sister who has a health issue.
- You will be given a \$20 movie gift certificate to thank you for your time.

## APPENDIX C

### POSTER

#### DO YOU HAVE A BROTHER OR SISTER WHO HAS?

- ❖ ASTHMA
- ❖ DIABETES
- ❖ CYSTIC FIBROSIS
- ❖ SOME OTHER ONGOING HEALTH ISSUE

#### Purpose of the study

The purpose of the study is to find out what it is like living with a brother or sister that has a chronic illness.

#### Who can be in the study?

- Teens between the ages of 11-17 years old who are living with a brother or sister who has an ongoing health issue that may include:
  - ❖ Asthma
  - ❖ Diabetes
  - ❖ Cancer
  - ❖ Cystic Fibrosis
  - ❖ Rheumatoid Arthritis
  - ❖ Mental Health- such as Autism
  - ❖ Chronic Genetic Conditions-such as Crohn's Disease, Sickle Cell Disease
- Living in the Cape Breton Regional Municipality

**The Camera** You will be given a disposable camera to take 8-10 pictures of things or places to help you tell your story.

**The Interview** One interview will be set up after you take the pictures. You will describe the photographs that you have taken and describe how the pictures make you feel about living with a brother or sister who has a health issue.



You will be given a \$20 movie gift certificate to thank you for your time.

#### INTERESTED?

If you are between the ages of 11-17 years old and you are interested in being part of a research study or would like more information please call or contact the investigator:

**Jill MacMullen**  
*A Dalhousie Master of nursing student*

**Phone:** (902) 563-1919

**E-mail:** [jill\\_macmullen@cbru.ca](mailto:jill_macmullen@cbru.ca)

## **APPENDIX D**

### **LETTER OF INTRODUCTION AND CONSENT FORM TO PARTICIPANTS**

Giving a Voice to Adolescents Living with a Sibling with Chronic Illness

**Principal Investigator:** Jill MacMullen BScN RN  
Master of Nursing Student, Dalhousie University  
Nurse Educator, Cape Breton University  
Department of Nursing  
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**Supervisor:** Megan Aston PhD RN  
Associate Professor  
Dalhousie University School of Nursing  
Megan.aston@dal.ca  
Dalhousie Tele: (902) 494-6376

## **Introduction**

Hello, my name is Jill MacMullen. I am a Masters in nursing student at Dalhousie University. I am doing a research project to find out about the experience of being a brother or sister to someone who is living with an ongoing health issue such as asthma, cancer, diabetes, or cystic fibrosis. We want to find out more about the experience and we think this research will help us.

I would like to invite you to be part of the research study. I will give you some information so you can decide if you want to be involved. I am discussing this research with you and your parent(s)/guardian so you both know that we are asking you for your agreement. If you are going to participate in this research, your parent(s)/guardian also has to agree. If you do not wish to take part in the research, you do not have to, even if your parents have agreed.

If you have any questions when I am reviewing this form, with you please ask me to stop at any time and I will take the time to explain.

## **Purpose: Why are we doing this research?**

The purpose of this research is to learn more about the experiences of adolescents living with brothers or sisters who have an ongoing health issue.

## **Who can participate in the Study: Why are you asking me?**

You may participate in the study if you are between the ages of 11-17 years and living with a sibling that has an ongoing health issue within the Cape Breton Regional Municipality.

## **Participation is voluntary: Do I have to do this?**

You do not have to do this research if you do not want to. It is up to you. If you say “yes” now and change your mind later and that is okay.

## **Study Design: What I will be asked to do**

If you decide that you want to do this, two things will happen:

- 1) I will give you a disposable camera with an instruction sheet. You will be asked to take 8-10 photographs. The photos that you take will help to show what it is like for you, knowing that your brother/sister has an ongoing health issue. You may take pictures of places you like to go or things that you like to do, or do not like to

do. You will be asked to give each photo a title. **Please do not take pictures of people for privacy reasons.**

- 2) After you have taken the photographs, I will pick up the camera and we will schedule an interview that may last up to 60 minutes. The photos will be developed at Wal-Mart and I will not look at the pictures. You will be the first to see them. During the interview, I will show you the photographs and ask you to tell me about them.

**Who will be doing the Research?**

I will be doing the research. My supervisor is Dr. Megan Aston and my other team members are Dr. Marilyn MacDonald and Dr. Beth Bruce.

**Possible Risks: Is this bad or dangerous?**

There is very little risk. Sometimes talking about your experiences may bring up uneasy feelings. These types of feelings may come from thinking and talking about any experiences that have made you mad, sad, or upset. Remember, you do not have to answer any questions that you do not want to answer and you can end the interview at any time. I can turn off the tape recorder and you may take a break if needed. You may speak with me during the interview or following the interview.

If there is, a need to discuss uneasy feelings in more detail you can follow up with the pediatrician, the family doctor, or a health care professional in the Emergency Department.

**Possible Benefits: Is there anything good that happens to me?**

You may feel good telling someone your story. You may also add to research that can help others.

**Reimbursement: Do I get anything for being in the research?**

I will attempt to make this as easy as possible for you or your parent(s)/guardian by scheduling the interview at a convenient time and place, your home or the hospital.

I am giving you a \$20.00 movie card as a token appreciation for taking part in the study.

**Confidentiality: Is everyone going to know about this?**

We will not tell other people that you are in this research and we will not share information about you to anyone. Your name or any personal information you provide during the study will not be shared with anyone else. Your name or anything about you that could identify you will not appear in any report or publication of the research. Information about your brother or sister, which could identify the family, will not be given out.



Information about you that is collected for the research will be put away and no one but the researchers will be able to see it. The information about you will have the name on it that you have picked (not your real name). All information that relates to this study will be put away in a locked filing cabinet for 5 years after the study is completed. After this time, all the information will be destroyed.

If you tell me about ways you are being harmed by anyone (abuse or neglect) I have to report that to the Children's Aid Society for your protection.

### **Further Information about the Study**

You will be given a copy of your signed consent form for your own records at the beginning of the study. When we are finished the research I will mail you a letter to share what we have learned. Afterwards we will share the research results with other nurses and doctors. We will be writing papers and going to meetings to share the information that we have found out.

### **Questions**

If you have any questions related to this study, please contact me, Jill MacMullen at (902) 563-1919 or my supervisor, Megan Aston at Dalhousie University School of Nursing at (902) 494-6376.

### **Problems or Concerns**

If you have any difficulties with, or wish to voice concern about, any part of your participation in this study, you may contact Catherine Connors, Director, Research Ethics, Dalhousie University at (902) 494- 1462, [ethics@dal.ca](mailto:ethics@dal.ca) Please feel free to call collect.

**GIVING A VOICE TO ADOLESCENTS LIVING WITH A SIBLING WHO HAS  
CHRONIC ILLNESS  
VOLUNTARY CONSENT FORM FOR PARTICIPANTS**

**I, \_\_\_\_\_, have read, or have been read the information about this research study. I have had my questions answered and know that I can ask questions later if I have them. I agree to take part in the study. I know that I can stop being part of the study at any time and that is okay. I agree to have my interview audio recorded.**

**I agree for words that I say during the interviews to be quoted in the researcher's thesis and other research publications and presentations with other nurses or health care people. I know that my name and other information that could identify my family will not be connected to my words.**

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Investigator's Signature

\_\_\_\_\_  
Date

**Copy provided to the participant \_\_\_\_\_ (initialed by researcher)**

**Parent/Guardian has signed consent \_\_\_\_ Yes \_\_\_\_ No (initialed by researcher)**

**I would like to receive a summary of the findings of the study:    yes ( )  
no ( )**

**Mailing Address :** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**APPENDIX E**

**GIVING A VOICE TO ADOLESCENT SIBLINGS OF CHILDREN LIVING  
WITH CHRONIC ILLNESS  
PARENT/GUARDIAN CONSENT FORM**

**I, \_\_\_\_\_, have read, or have been read the explanation about this study. I know that my child is taking part in this research study and I support their involvement. The interview may take place in a private room in the hospital or in our family home. I am aware my child will need privacy for the interview.**

**I understand that the researcher, Jill MacMullen, has recently passed a criminal record check.**

**I agree for my child to take part in the study. I understand that their participation in this study is voluntary and that he/she may withdraw from the study at any time without penalty.**

\_\_\_\_\_  
Parent/Guardian's Signature

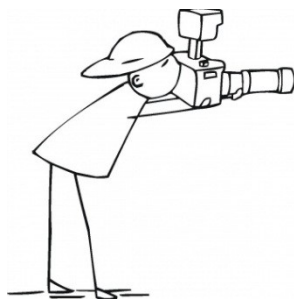
\_\_\_\_\_  
Date

\_\_\_\_\_  
Investigator's Signature

\_\_\_\_\_  
Date

## APPENDIX F

### INSTRUCTIONS FOR CAMERA USE



We would like to find out more about being a brother or a sister to someone who has an ongoing health issue. Examples of ongoing health issues are asthma, diabetes and cystic fibrosis. We want you to tell your story through the pictures you take.

We are giving you a disposable camera. Please take **8-10 pictures** of things or places that help to show what it is like for you, knowing that your brother or sister has an ongoing health issue. Some examples may include pictures of things you like to do with your brother/sister, or maybe things you like to do alone. It could include places you like to go or maybe do not like to go. You are the expert!

**Please do not take pictures of people for privacy reasons.**

**Follow these steps:**

1. To get use to the camera, practice with it first. Write a name on a piece of paper. This should not be your real name but a name you can pick to keep private. Take a picture of the name written on paper. This is the first picture.
2. Now you can start taking pictures of things or places that you want to. I will ask you to give every picture that you take a title. I will ask you what title you have given it in the interview when we meet. Remember you are the expert!
3. I will give you a call to see if you have any questions after week one with the camera.
4. I will give another call after week two with the camera. We will pick a day; time and place that I can pick up the camera after you have taken 8-10 pictures.
5. I will have the pictures developed. You will be the first to see the pictures when we meet for the interview. At the interview, you will tell me more about the pictures that you have taken.

## APPENDIX G

### INTERVIEW PROTOCOL

**Date of Interview:**

**Time:**

**Place:**

**Interviewee Pseudonym:**

**Researcher:** Thank-you for agreeing to be part of the study. We want to find out more about what it is like to be a teen living with a brother or a sister that has an ongoing health issue. Today I just want to have a conversation with you to hear your story. I have an interest in learning about what is good and what is hard about being a brother or sister to someone with ongoing health issues. If you want to ask me any questions, you can do that too. There is no right or wrong answer.

You have a brother/sister that has *fill in chronic illness.*

Here are the pictures. I have not seen them yet. You look at them first and you can pick the order that you want to talk about them. You can put them on the table to put them in the order that you want. If there are any pictures that you would like to remove, you can take them out. When you are done, you can pick a picture you want to start with.

**Prompts:**

1. Tell me about this photograph.
  - Why did you pick this picture?
  - Tell me what title you have given it.
  - Why did you give it that title?
  - How does it make you feel?

2. How does this photograph connect to your brother or sister with an ongoing health issue?

- Tell me about it.
- What makes it easy?
- What makes it difficult?
- Has it gotten easier or harder? Tell me about this.
- What helps? Family relationships? Has chronic illness affected this?
- Do friends and extended family help? Tell me more.
- Do others from the outside affect you and the experience of the ongoing health concern with your sibling?

3. Which is your favorite picture and why?

Thank-you for your time and thank-you for sharing your story with me. All of this information will be kept private.

**APPENDIX H**

**GIVING A VOICE TO ADOLESCENT SIBLINGS OF CHILDREN LIVING  
WITH CHRONIC ILLNESS  
PARTICIPANT/PARENT PHOTOGRAPH CONSENT**

**We have seen all of the photographs taken for the research study. We have taken out any photographs that we do not want to be used or may identify us in any way. We agree that the pictures can be used in the researcher's thesis and other research publications and presentations with other nurses and health care professionals.**

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Parent/Guardian Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Investigator's Signature

\_\_\_\_\_  
Date