PARENTAL EXPERIENCES: THE TRANSITION TO SCHOOL FOR A CHILD WITH CYSTIC FIBROSIS

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ABSTRACT

This research study was designed to explore the ways in which parents of a child with cystic fibrosis experienced their child's transition to school. Previous research has focused on the barriers families have faced, the challenges children with cystic fibrosis place on various systems and the intense medical needs of these children. However, due to changes in the treatment of cystic fibrosis and the improved quality of life of children diagnosed with this disease, a different perspective within the research is now required.

It was discovered during this qualitative study that it is necessary to apply an ecological systems approach to exploring this issue as there are many factors within the family's experience that play a significant role during this time of transition in their lives. The qualitative descriptive analysis of the data revealed eight key themes. These themes included illness narratives, transition to school, strengths, supports accessed, protection, normalization, disclosure and future fears.

The findings of this study allow for a deeper understanding of the families' experiences and document the families' ability to arrange the accommodations their child required, the strengths they relied on, the supports they accessed, and their unique needs and concerns during this time. The discussion highlights the importance for social workers when working with children and their families to work in partnership with families, incorporating strength-based principles into our practice, and applying an empowerment model within a family-centered approach to practice.

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INTRODUCTION

This paper presents the results of a qualitative research study exploring the experiences of parents of children with cystic fibrosis during their child's transition to school. One in every 2500 children born in Canada will be diagnosed with this fatal genetic disease; it is the most common genetic disorder in the Caucasian population (Bush, 2001). Cystic fibrosis affects mainly the lungs and the digestive system yet there is no typical version of the disease.

In the lungs, cystic fibrosis causes severe breathing problems. A build-up of thick mucus makes it difficult to clear bacteria and leads to cycles of infection and inflammation, which damage the delicate lung tissues. In the digestive tract, cystic fibrosis makes it extremely difficult to digest and absorb adequate nutrients from food. Thick mucus also blocks the ducts of the pancreas, preventing enzymes from reaching the intestines to digest food. Therefore, persons with cystic fibrosis must consume a large number of artificial enzymes (on average 20 pills a day) with every meal and snack, to help them absorb adequate nutrition from their food. They must also follow a demanding daily routine of physical therapy to keep the lungs free of congestion and infection (www.cysticfibrosis.ca). It is important to note that this disease affects each individual in different ways, with varying degrees of severity, and a person's health can change considerably from month to month, or even from day to day.

Approximately one in every 25 Canadians carries a version of the gene responsible for cystic fibrosis. It is a recessive gene, therefore, when two people carry the gene there is a 25% chance that the child will be born with the illness (www.cysticfibrosis.ca). When cystic fibrosis was first described in 1938, most infants

died before the end of their first year. In 1960, a child born with cystic fibrosis rarely lived to the age of four. Now, the current median age of survival is 32 years of age. (Bush, 2001). No cure is currently available. Yet, despite their intense medical routines, individuals with cystic fibrosis lead normal lives, for many years, in terms of education, physical activity, and social relationships. Eventually, however, lung disease places increasing limits on daily life.

Previous research has focused on the barriers families have faced, the challenges children with cystic fibrosis place on various systems and the intense medical needs of these children. However, due to changes in the treatment of cystic fibrosis and the improved quality of life of children diagnosed with this disease, a different perspective within the research is now required. The present study shifts the research focus to explore the new challenges families are facing during their child's transition to school. Parents concerns include medical and policy concerns but also focus on the emotional and social concerns experienced during this time in their children's lives.

Reflexivity

I chose to explore the experiences of families who have a child with cystic fibrosis during their child's transition to school for both personal and professional reasons. Personally, I have had a number of friends who have passed away from cystic fibrosis. They all died before they reached 25 years of age. In conducting this study, I recognized that I would need to be aware of my emotions or memories that may have been triggered when I spoke with the families from my own grief for the friends that I have lost. I remained cognizant that the experiences of families who have a child with cystic fibrosis is very different now than it was for the families of my friends. This is due

to changes in the treatment and improved prognosis for children diagnosed with this disease. However, I feel my past experiences allowed me to have compassion and empathy for the families and my interest in this topic has fueled the drive I needed to complete this research project.

Four years ago, I began volunteering with the Canadian Cystic Fibrosis Foundation (CCFF) in memory of my friends. I have worked with the CCFF chapter offices in Ottawa, Halifax and now Vancouver and have been a member of all three boards of directors. Through my volunteer experience with the CCFF, I have met many amazing people who either have a child with cystic fibrosis, who are diagnosed with the disease or who have been affected by this illness through extended family or friends. My interest in the area of a child with cystic fibrosis' transition to school stemmed from the experiences that parents in Nova Scotia have shared with me about the challenges they faced during their child's transition to school. I was interested in learning from parents how social work professionals can better support families during their child's transition to school and to explore what personal strengths they relied on during this time.

Professionally, I value my role as a social worker in the lives of families. I recognized that I needed to allow families to feel comfortable sharing both their positive and negative experiences with all professionals, including social workers, during their child's transition to school. I wanted to discover how social workers could help their clients manage this transition and what changes needed to be made to our current system to allow for a smoother transition. The information shared by parents could inform social work policies and practices to provide improved support to families during this time in their lives.

CHAPTER ONE: CONCEPTUAL CONTEXT

As a foundation for this research study, this chapter will explore the multiple ways of understanding the experiences of parents of children with cystic fibrosis during their child's transition to school. First, an overview of the theoretical foundation of this study will be discussed, namely an ecological approach, which incorporated generally systems theory, family systems theory and stress and coping theory. Second, a review of the academic literature will be provided and gaps in the research will be identified. Finally, the purpose, goals and rationale of this research project will be detailed.

Theoretical Foundation

The theoretical foundation of this study incorporates ecological systems theory as the primary perspective toward a comprehensive understanding of the experiences of parents of children with cystic fibrosis during their child's transition to school. Family systems theory and stress and coping theory were then chosen as the appropriate supporting theories for the purposes of this study.

Ecological Systems Perspective

Ecological systems perspective looks at the fit between person and their environment (Miley, O'Melia & DuBois, 1998). Research conducted using an ecological systems perspective requires knowledge of the diverse systems involved in the interactions between the persons and their environments. Bronfenbrenner (1979) conceptualized an ecological framework comprised of four levels of systems. The microsystem level represents the individual in family and group settings and incorporates their relationships in their day-to-day environment such as home, school, peer group,

classrooms, or work settings; or, group system. The mesosystem level incorporates the interactions of individuals, families and groups within their various microsystems. Exosystem level represents the social structures such as government agencies, religious organizations, education systems, and economic systems; or, organizational system. These systems influence, delimit, or constrain the way the person functions within their environment (Kilpatrick & Holland, 1995). The last level, the macrosystem level, involves societal forces and includes cultural and societal beliefs and values that influence the microsystem and mesosystem levels.

An ecological systems approach to integrating children with chronic health issues into the school system may engage all four levels of these systems during their initial transition to school. At the mircosystem level, both the child with chronic illness and their parents are interacting with their day-to-day environments that include home, employment, school, and community. Linking schools, communities and family then becomes an important part of this transition process and represents change at the mesosystem level. Resources at the exosystem level are needed to meet the child's medical needs during the school day. And finally, creating the institutional structures such as changes in policies within government, health or school systems that reduce discrimination and support access to school for all children in our society requires change at the macrosystem level. But, during a time of transition, changes do not occur only in the systems outside the home, but also take place within the family system itself. This leads us to an examination of family systems theory.

Family Systems Theory

Family systems theory emerged as social scientists took the principles of general systems theory and applied them to the transactions of the family (Zietlin & Williamson, 1994). Family systems theorists consider the family to be a set of interdependent parts that are hierarchical in nature (Cox & Paley, 2003). They are comprised of subsystems, which are systems in and of themselves with distinct relationships and underlying rules. In traditional families, there are usually three subsystems; spousal, parental and sibling (Kilpatrick & Holland, 1995). The spousal subsystem usually has the most power as it provides a key model for the establishment of rules, resolution of conflicts and determination of the kinds of transactions that represent the family's values (Zeitlin & Williamson, 1994). The parental subsystem performs the child-rearing functions and is comprised of the child and the primary caregivers and provides guidance and nurturance to the children. The third subsystem, the sibling subsystem, has the least amount of power in the family. This system is the child's first peer group. For the purposes of this research study, the focus of the exploration will be placed on the interactions that occur within the spousal and parental subsystems during a child's transition to school. A future study may be beneficial to then explore the affects this time of transition has on the sibling sub-system of a family.

Another important concept of family systems theory is that family systems are open, living systems that can adapt to change or challenges (Cox & Paley, 2003). The family system has the ability to reorganize itself in response to outside forces. An ecological systems approach that incorporates family systems theory enables this research study to examine the needs of individual families and their members, rather than applying

the same explanation to every family in similar circumstances. In addition to family systems theory, stress and coping theory must also be explored in order to understand the coping experiences of parents during their interactions with the multiple systems involved during their child's transition to school.

Stress and Coping Theory

When a family is unable to achieve a fit between themselves and their environment, stress can result. Lazarus (1990) argues that stress refers to a particular kind of relationship between person and environment. The stress relationship is one in which demands on a person tax or exceed the person's available personal and external resources to cope. These stressors are then perceived as being potentially harmful or as a challenge. Once a person has appraised a life event or transition as stressful, coping processes are brought into play to manage the inadequate fit between the person and environment relationship. These processes then influence subsequent appraisals and hence the form and intensity of the stress reaction.

Hill (1958) advanced the ABCX family crisis model, which takes into consideration three variables, as a way of explaining why it is that some families, when faced with a single stressor event, vary in their ability to adjust. In this model, A (the stressor event) interacts with B (the family crisis meeting resources), which interacts with C (the definition the family makes of the event) and produces X (the crisis).

Hill's model, however, only focuses on a single stressor event. The notion of pileup of demands was later incorporated into family stress theory. It has been argued that because family crises evolve and are resolved over a period of time, families are seldom dealing with a single stressor in their lives (Lavee, McCubbin & Olson, 1987).

Patterson and McCubbin (1983) have advanced a Double ABCX model to more adequately address family adaptation to a stress or crisis. This model builds on Hill's (1958) ABCX model by redefining pre-crisis variables and adding post-crisis variables in an effort to describe and illustrate the additional life stressors and strains, prior to or following the crisis-producing event. It examines the pileup of demands, the range of outcomes of family processes in response to this pileup of stressors and the intervening factors that shape the course of adaptation (Patterson & McCubbin, 1983). Parents with children with cystic fibrosis are not dealing with a single stressor in their lives. Rather, there are a number of stresses in their lives that have accumulated over time. A child's transition to school then adds another dimension to an already stressful situation.

Each family will then deal with the pile up of demands in their lives in different ways. Stress and coping theory will be used in this study as a tool to explore parents' experiences of stress but it must also draw on family systems theory to gain an understanding of the effect stress has on the family system and the strategies they employed to cope with the strain in their lives.

Summary

For the purposes of this research study, an ecological systems approach that incorporates family systems theory and stress and coping theory allows for a comprehensive understanding of the experiences of parents of children with cystic fibrosis during their child's transition to school. It enables us to obtain an appreciation of the on-going, daily issues that the family must face when coping with external systems, the changes within the family system and to draw on the interwoven theories to explore what helped and what hindered families during this time of change in their lives. The

ecological systems approach directs the researcher to look at the fit between the person and the environment and allows for the exploration of how families are making their environment more responsive to their needs. This approach also provides the conceptual framework to understand how these changes can be put in motion.

Literature Review

In order to gain an understanding of the experiences of parents of children with cystic fibrosis during their child's transition to school, a review of the available academic literature will focus on parents' navigation of the system, the strengths approach, normalization, and access to school for a child with cystic fibrosis.

Navigating the System

Children with cystic fibrosis present a demanding challenge to a number of systems in our society; the medical system, the family system, and the social support system (Stillion & Papadatou, 2002). Each of these environments varies in its ability to facilitate the child's growth and development (Kliebenstein & Broome, 2000). It is the task of parents, then, to establish a support system within their community that can assist them in coping with their child's chronic condition and allow them to maintain meaningful ties with others in the community (Conam, 1993).

Within the medical system, health care professionals greatly influence the illness experiences of families and can help facilitate or inhibit the extent to which they are able to successfully navigate this new and uncharted territory (Steele 2002). Outside of the family, Bywater (1981) found in his study that many mothers received virtually no support from their community. Hospital staff members and the Cystic Fibrosis Research

Trust (CFRT) were cited as their major sources of support and information. The CFRT is a United Kingdom organization that is comparable in mandate and services as the Canadian Cystic Fibrosis Foundation (personal communication, CCFF). Professionals working in the community "need to be aware of the challenges facing families and children with chronic illness and to provide support and understanding of their special needs" (Coyne, 1997, p.126).

A family's successful management of a chronic illness depends on the family's ability to "accommodate the complex treatments into a schedule which permits family activities to continue as before" (Coyne, 1997, p.126). While, the diagnosis of an acute illness may disrupt family functioning for a short period of time, there is an "expectation that life will return to normal once the person has responded to treatment" (Bouma & Schweitzer, 1990, p. 722). However, with a chronic illness such as cystic fibrosis, families must readjust their routines and roles to accommodate the disease and "endure this burden of care for a protracted period of time" (Coyne, 1997). Improved methods of physical therapy and medications, "both of which are predominantly carried out by the parents" (Hidgkinson & Lester, 2002, p. 378) have been essential in improving survivorship among children with cystic fibrosis. Yet, along with these advances in medicine, the care of children with cystic fibrosis has shifted from "the hospital to the home where the family shoulders major responsibility for the routine management of the illness" (Walker, Ford & Donald, 1987, p.239).

Cadman, Rosenbaum, Boyle and Offord (1991) found in their study that the major responsibility of caring for a child with cystic fibrosis still tends to be borne by the mother. Raye (2003) also reported that it was primarily the mothers who left the

workforce or downgraded their participation in paid employment to care for their child with special needs and to organize the supports they required. Fathers then had to bear the greater proportion of the breadwinning. The choice for the women to leave the workforce rather than the men occurred for two reasons: men usually earned higher incomes than women, and women are expected to be the primary caregivers in our society (Armstrong & Armstrong, 1996). Ray (2003) reported that the medical community "depends on the volunteer work of parents, usually mothers, to maintain the child's health and full therapeutic regimen" (p. 296). For most parents, the difficulty then lies in finding a balance between the children's needs, the needs of other family members, employment options, and their own personal health.

Although there is an abundance of literature describing various aspects of caring for a child who has a chronic illness (Anderson, 1986, Conam, 1987), very little is presented from the perspective of the parents' perceived need for support throughout their child's illness. Diehl, Moffitt and Wade's (1991) study was the first to explore the needs of parents from their own perspective through the use of focus groups with parents of children with chronic illnesses. In this study, the researchers found that the needs expressed by parents were not the ones being addressed by most service delivery systems. Knafl and Dietrick (2002) noted that descriptive studies that examine family processes that shape response to chronic illness provide useful data for developing interventions directed to supporting families in their communities and leading to their full integration in community life. However, the small number of intervention studies for families with children with chronic health conditions found in the literature suggests that few researchers are conducting studies in this area.

In addition to services not addressing the perceived needs of parents, fragmentation of care was mentioned several times by parents, along with the difficulty in finding the right services or professionals in their communities (Diehl, Moffitt & Wade, 1991). A more recent study by Gravelle (1997) found similar concerns. Her research found that most families were involved with numerous systems and services. In trying to orchestrate services, parents encountered "fragmentation, duplication of services and gaps in services; all were exceedingly frustrating for parents" (Gravelle, 1997, p. 744).

Gjengetal, Rustown, Wahl, and Hanestad (2003) conducted a study that explored the experiences of growing up and living with cystic fibrosis. They found that in order for families to successfully navigate the various systems in their lives, it was important for families to have continuity and stability in the social service system. Parents in a number of studies expressed a strong need for a competent case manager (Gravelle, 1997; Diehl, Moffitt & Wade, 1991; Steele, 2002). Many studies found that parents felt social workers could do a good job in providing support and information services if they were not so overloaded with heavy caseloads (e.g. Diehl, Wade & Moffitt, 1991, Raye, 2003).

For families with children with cystic fibrosis, the community-based case management model of practice would certainly address the problems imposed on families by fragmentation, duplication and gaps in services (Gravelle, 1997). As the child's eligibility for services increasingly becomes a key condition that affects family care giving, children are going to need to fit certain criteria to be eligible for services such as community care, respite care, social services, and services provided in the school system (Raye, 2003). Currently in Vancouver, there is a community-based case management model in place for families with children with special needs but at this time children with

chronic illnesses are not eligible for early intervention services. Parents of children with cystic fibrosis are left on their own to navigate the various systems required to ensure that their child's needs are met appropriately.

Strengths Approach

In the past, the literature on families with chronically ill children was "overwhelmingly characterized by studies of potential dysfunction, with only a few studies of potential adaptation" (Longo & Bond, 1984) but there is now a growing body of literature that is focusing on the positive coping abilities of families and their successful handling of the stress they experience in their lives (Coyne, 1997; Hymovich & Baker, 1985; Walker, *et* al, 1987). Yet, despite the challenges families faced in navigating the social system and the stress of caring for a chronically ill child, parents of children with cystic fibrosis possess extraordinary strengths.

Early and GlenMaye (2000) identified family strengths, which included survivors' pride, hope for the future, the ability to understand another's needs and perspectives, and the ability to identify and make choices about individual and family goals. Saleebey (2002) more recently highlighted similar aspects that are key to the strengths based approach to research and practice. These include empowerment, membership, and resilience, as well as dialogue and collaboration. .

Empowerment "means believing that people are capable of making their own choices and decisions. It means not only that human beings possess the strengths and potential to resolve their own difficult life situations, but also that they increase their strength" by doing so (Saleebey, 2002, p. 110). Parents need to be empowered to advocate for their children and "should be given positive feedback about their coping

efforts and the importance of their role in contributing to the overall health of their child" (Coyne, 1997, p. 126)

Membership is central to the strengths perspective, for to be without membership is to be alienated and at risk of marginalization. As children with cystic fibrosis are reaching school age and beyond, parents are now demanding equal citizenship for their children and are recognizing their child's right to have the opportunity for participation in play, real friendships, educational opportunities, and movement toward meaningful employment (Raye 2003).

The strength perspective also focuses on resiliency. There is a growing body of literature that makes it clear that resiliency is the rule, not the exception, in the human experience. According to Early and GlenMaye (2000), resilience means that humans often survive and thrive despite risk factors for various types of problems and situations. Parents do indeed overcome adversity, rebound from difficulties and overcome serious and complex situations. Resiliency is not a naïve discounting of life's adversities but rather recognition of the continuing growth, capacities, knowledge, and insight that come about from meeting the demands and challenges of life (Saleebey, 2002). Parents of children with chronic illnesses gain knowledge and skills throughout their ordeals, which help them to move forward with their lives and to encounter new challenges with greater confidence.

Finally, the aspects of dialogue and collaboration are listed as being fundamentally important to the strengths perspective. Saleebey (2002) states, "Human beings can only come into being through a creative and emergent relationship with others" (p. 12). Dialogue and collaboration are key components of working with parents

of children with chronic illnesses. When professionals and families "respect, trust and communicate openly with one another, a partnership is formed" (Turnbull, Turnbull & Rutherford, 1990). Acknowledgement of the strengths both parties bring to this partnership can provide all participants with the opportunity to work together in a relationship that benefits not just the person with special needs, but can benefit all involved.

Normalization

Normalization refers to "a cognitive process used by families to define their own lives and a set of behavioral strategies for management of the child's condition" (Dietrick, Knafl, & Murphy-Moore, 1999). For families with children with chronic illnesses, the child's care and special needs are incorporated into daily routines, and the family "strives to live as normally as possible while caring for and supporting the child with special needs" (Rehm & Franck, 2000, p. 71).

Dietrick, *et al,*(1999) identified the following defining attributes of normalization:

- Acknowledging the condition and its potential to threaten lifestyle;
- Adopting "normalcy lens" for defining child and family;
- Engaging in parenting behaviours and family routines that are consistent with "normalcy lens";
- Developing a treatment regimen that is consistent with normalization; and
- Interacting with others based on a view of child and family as normal.

Within these attributes, a "normalcy lens" refers to the definition's conception of an interpretive lens which was "incorporated to indicate that families may reconstruct their reality to emphasize those aspects of life that remain unchanged in the face of chronic conditions and they use this to manage the tension between their preferred view of their

lives as normal and the problems that they face in their day-to-day lives" (Rehm & Franck, 2000, p. 71).

Morse, Wilson and Penrod (2000) found that the mothers of children with disabilities who participated in their study "were fully aware that the 'normal' they strove to maintain was not the normal in everyday life" (p. 674) yet it was important for them to obtain a sense of equilibrium through maintaining constant routines within their family lives. Knafl and Dietrick (1986) also reported that parents deliberately engaged in routinization of treatments. They deliberately avoided potentially embarrassing situations and also placed an emphasis on children's involvement in typical activities as a way of creating a family life that was experienced as both normal and satisfying. Over time, the outcome of such strategies was the perception of normal living, despite a child's chronic illness (Knafl and Dietrick, 2002).

These attributes of normalization are echoed in a recent study by Gjengedal *et al.* (2003) that explored the experiences of growing up and living with cystic fibrosis. Again, one of the key findings was the families' strong desire to live "a normal life". People living with cystic fibrosis wanted to play down their differences from healthy people and worked hard to participate in normal daily activities and tasks as far as was possible.

For young children, school is the foremost daily task in their lives. But, for children with chronic illnesses, school is not only important for academic and social development, but school also serves as "the primary mechanism for school-aged children to approach normalization after diagnosis and during treatment" (Sullivan, Fulmer, & Zigmond, 2001, p. 11). School plays a significant role in establishing children's routines

and allows children with chronic illnesses such as cystic fibrosis to gain a sense of sameness when compared to their peers (Angst, 2001).

It is important to note that access to school is not just important for the child, but also plays an important role in the normalization process for the parents of children with cystic fibrosis. School attendance allows parents to envision a future for their child (Sullian, Fulmer, & Zigmond, 2003) and to promote a sense of normalcy and hope for the future lives of their children.

Access to Schools for Children with Cystic Fibrosis

The large majority of studies conducted in the area of access to school for children with chronic illnesses focus on the experiences of children who have cancer (Sullivan, Fullmer & Zigmond, 2001, Chekryn, Deegan & Reid, 1987, Peckham, 1993). As more children are surviving childhood cancer, this area of research has continued to grow. Yet, despite an increase in the number of persons with cystic fibrosis reaching adulthood, few studies have focused qualitatively on how people affected by cystic fibrosis experience their lives (Gjengedal *et al.*, 2003) or address the concerns of parents when their children are about to enter school (Kliebenstein & Broome, 2001).

DePaepe, Garrison-Kane & Duelling (2002), outlined key areas in which cystic fibrosis may affect children's performance in school. Medically, children with cystic fibrosis may require the delivery of oral and/or inhaled medications during the school day, the provision of chest physiotherapy routines, and/or invasive medical interventions such as feedings through a gastrointestinal tube (DePaepe, Garrison-Kane & Duelling, 2002). Also, children with cystic fibrosis may have more school absences as a result of

illnesses and hospitalizations related to lung infections and respiratory complications (Coe, 1989).

Raye (2003) discussed ways in which access to the school system was an issue for families with children with chronic illnesses. The first area was the attitudes of school personnel. Due to increasing fear of liability, many teachers are no longer willing to dispense medications, supervise meals, or assist with the use of inhalers and are therefore not able to meet the medical needs of children with cystic fibrosis.

The second area is the categorical aspect of eligibility. As with health care, a variety of categorizations are used in the school system "to ration out available services" (Raye, 2003, p. 292). Children with cystic fibrosis are affected by the categorical allocation of funds in schools if they wish to request a teacher's aid or school nurse to assist with medications, or if they require physiotherapy treatments during school hours. They can also be affected if they wish to access in-school resource services or tutoring to address learning difficulties as a result of their illness or to catch up on work missed during school absences due to illness or hospitalization.

As children with chronic and terminal illnesses are living longer with deteriorating conditions, they begin to present a demanding challenge to professional caregivers, families, the medical system, and, increasingly, to schools (Stillion & Papadatou, 2002). A study by Hodgkinson & Lester (2002) found that the responsibility for providing care for a child with cystic fibrosis was found to be far greater than just the responsibility of keeping up with the child's medical treatments. It also included "ensuring the social and educational welfare of the child" (p.380). Mothers often increased their involvement at the child's school, a "further workload stress in itself" (p.

380). Improved communication between health professionals, parents, and teachers and improved access to community supports could potentially provide a path to better care in the schools for children who have chronic illnesses (Coe, 1989) which would allow parents to step back from having to provide care to their child during the school day.

The child and the family's access to community supports during the school years, their access to supports in their schools, and the beliefs and values experienced during this time all set the stage for healthy patterns of adjustment for the child and the parents, and consequently have an impact on the child's adult years (Angst, 2001). With the proper supports and communication between key persons, children with cystic fibrosis can thrive academically and begin to take the initial steps toward positive adult outcomes related to employment and life satisfaction.

Summary of Literature and Research Question

Assumptions

Based on the theoretical framework and the review of the literature, the research assumptions about a child with cystic fibrosis' transition to school include:

- *Children with cystic fibrosis present a demanding challenge to a number of systems in our society, including the education system.*
- *Families are experiencing in their communities fragmentation of care and are struggling to access the services their child requires.*
- *Parents find it especially difficult to access the support services their child needs to succeed in a school setting.*

All of these assumptions found in the available literature are based on the idea that children with cystic fibrosis are very ill and require constant medical support. It is important to note that the context of cystic fibrosis has changed dramatically over the last

forty years, with changes in the median life expectancy from less than 2 years in 1940 to 32.3 years in 1998 (Cystic Fibrosis Foundation, 1998). There is very little research currently available that reflect these changes in the illness experience. Furthermore, there is little in the way of qualitative research that focuses on the experiences of the parents during their child with cystic fibrosis transition to school.

Purpose of the Study

Today, for many families of children with cystic fibrosis, the school age years are a time when many children evidence only mild disease and is a period free of frequent infections and hospitalizations (Angst, 2001). The illness and its management are often less of a central focus during this time. Other challenges, however, now become more prominent during this time. Issues related to "letting go" as the child enters school, who and what to tell about the disease, the child's increasing autonomy and responsibility for treatments, and peer relationships are just some of the issues that become prominent during a child's transition to school (Angst, 2001). The exploration of these new areas of prominence will guide the focus of this research study. What fears do parents have during their child's transition to school? How do they decide who to tell and how much information to provide? How do parents prepare their child to take on the responsibility of taking their own medications during the school day? What personal strengths did the parents rely on during this time to cope with stress and to ensure their child received the supports they required? Did parents worry about their child fitting in? An understanding of parents' experiences during their child's transition to school in this new era of cystic fibrosis is needed. This leads to my research question: What are the

experiences of parents of children with cystic fibrosis during their child's transition to school?

In this chapter, a review of the theoretical frameworks used in this study, namely an ecological approach, which incorporated generally systems theory, family systems theory and stress and coping theory, was conducted. Next, a review of the available academic literature pertaining to the transition to school of a child with cystic fibrosis was presented with a focus on parents' navigation of the system, the strengths approach, school as a normalization factor and a child with cystic fibrosis' access to school. In conclusion, the research assumptions, which resulted from the theoretical framework and research literature were presented. In the following chapter, research methodology is discussed.

CHAPTER TWO: RESEARCH METHODS

Within this chapter, I will present an overview of the research methods that were used to explore the experiences of parents who have a child diagnosed with cystic fibrosis during their child's transition to school. I will begin by outlining the rationale for choosing the qualitative research methodology. I will then discuss the specific steps taken in my methodological and analytic processes. These include locating participants, research design, data collection, ethical considerations, and data analysis. This chapter will conclude with a brief summary.

Rationale

This research project employed a qualitative research method. I chose this method because this study focuses on the personal experiences of families of children with cystic fibrosis during their child's transition to school. According to Maxwell (1996), the qualitative approach is particularly suited to research studies that attempt to understand "the meaning, for participants, of the events, situations and actions they are involved with and the accounts that they give of their lives and experiences" (Pg. 17). The qualitative approach is then suited to the purpose of this study as this study is attempting to understand the meaning these parents attribute to their child's transition to school. This research also plans to explore the "particular context within which the participants act, and the influence this context has on their actions" (Maxwell, 1996). The illness experience of families with children with cystic fibrosis has changed dramatically in the last decade. New research in the area will provide an enhanced picture of what parents are currently experiencing during this time of transition in the lives of their families.

Research Design

This research study applied a qualitative descriptive approach. I chose this research methodology as it offers "a comprehensive summary of an event in the everyday terms of those events" (Sandelowski, 2000, P. 336). As qualitative descriptive studies are less interpretive and abstract than other approaches, "they do not require researchers to move as far from or into their data" (Sandelowski, 2000, P. 336). "Although no description is free of interpretation, basic or fundamental qualitative description...entails a kind of description that is low-inference, or likely to result in easier consensus among researchers" (Sandelowski, 2000, p.335). Within the qualitative descriptive approach, language is seen as the "vehicle of communication, not itself an interpretive structure that must be read" (Sandelowski, 2000, p. 336). In the context of this study, the qualitative descriptive approach allows for the exploration of the experiences of parents during the child's transition to school through the presentation of the facts of the experiences in everyday language.

Qualitative descriptive studies are less theoretical than other research forms such as grounded theory or ethnographic studies, which are based on specific methodological frameworks that have emerged from specific disciplinary traditions. Qualitative descriptive studies "tend to draw from naturalistic inquiry" (Sandelowski, 2000, p.337). Naturalism involves "observing ordinary events in natural settings, which are not contrived, invented or researcher-created" (Neuman & Kreuger, 2003, p. 361). Data collection for this research study followed naturalistic tenets as there was "no pre-selection of variables to study, no manipulation of variables, and no a priori commitment to any one theoretical view of the target phenomenon" Sandelowski, 2000, p. 337). All

efforts were made to apply data collection techniques that would allow participants to present themselves as they normally would if they were not under study.

Qualitative interviews with participants yield narratives with thick descriptions that provide us with a glimpse into the world in which they are living. According to Cresswell (1998), qualitative research is:

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

The goal then of this qualitative research study is to explore the words and phrases of the participants in order to provide a detailed description of their experience and to explore the themes of meaning participants shared during the interview process.

Locating Participants

The research design utilized a purposeful sample or what is sometimes called criterion-based selection. Criterion-based selection is a strategy in which participants were chosen on the basis of whether they could lend insight relevant to the research question (Maxwell, 1996). This is to say that random sampling was not chosen, as I needed to ensure that the participants had a child with cystic fibrosis between the ages of 5 and 10 and were able to lend their view on their experiences.

Unfortunately, in qualitative research there is no concrete formula used to estimate the number of participants in a study required to reach saturation. A number of factors, "including quality of the data, the scope of the study, the nature of the topic, the amount of useful information obtained from each participant and the qualitative method and study

design used" (Morse, p. 3, 2000). The scope of a study can either be broad or focused. The broader the study, the more participants required to reach saturation. The topic of this study was very focused as participants were asked to reflect on their experiences during their child with cystic fibrosis transition to school. The intent was to explore a very specific period of time in their lives. According to Morse, if the nature of the topic is "obvious and clear, and the information is easily obtained in the interviews, fewer participants are needed" (Morse, p. 3, 2000). Closely linked to the clarity and difficulty of study topic is the concept of the quality of the data obtained. Although this research topic did include emotional content, participants were able to reflect on the topic without undue difficulty and were able to articulate their experiences in an understandable fashion. As a result, the data obtained from the interviews with participants during this study were very rich in content. If data is "on target, contain(s) less dross, and are rich and experiential, fewer participants will be required to reach saturation" (Morse, p. 4, 2000). Finally, the research design chosen for this study was a qualitative descriptive approach borrowing from narrative research design. For this study, a statistically representative sample and broadly generalizable data were not the intended outcomes of this sampling approach. Instead, this sampling strategy intended to capture the stories of a small selection of parents reflecting on their experiences during their child's transition to school.

The specific criteria necessary for inclusion in this study were:

- The participant must be a parent of a child diagnosed with cystic fibrosis.
- The child must be between five and ten years of age.
- The child must attend school in the Lower Mainland Area of British Columbia.

- The parent must be English speaking.
- The parent must be able to legally consent to the interview process.

Once permission for the research was received from the University of British Columbia Behavioural Ethics Board (Appendix A), I began to search for participants. I enlisted the help of the Canadian Cystic Fibrosis Foundation (CCFF)– Lower Mainland Chapter. A letter of introduction regarding the research study was published in the winter edition of the Chapter's newsletter. On my behalf, The CCFF Chapter Administrator contacted potential families who fit the eligibility criteria and explained to them the purposes of the study and the time commitment it entailed. The Chapter Administrator then provided me with the names and telephone numbers of those parents who had expressed an interest in participating. All of the families on this list were contacted and further information about the study was provided.

All of the families who chose to participate in this study were located through contacts with the CCFF – Lower Mainland Chapter. All four of the families contacted chose to participate in the research study. An appointed time was arranged to meet with each of the participants. Participants were offered a home interview or an interview in a public place. Three interviews were conducted in meeting rooms at local community centers or schools; the fourth interview was conducted in the participant's home. Of the four families, one father and four mothers participated. This research applied a reflexive approach as all of the parents interviewed were looking back on their past experience regarding their child's transition to school. The children, three boys and one girl, were between the ages of seven and ten years of age. Three of the children attended public elementary school and one child attended an independent elementary school. All of the

children attended school in the communities surrounding the city of Vancouver. Three lived in the city of North Vancouver and the fourth family lived in Coquitlam. All were Caucasian.

Data Collection

Data was collected using semi-structured interviews lasting between one and two hours per participant. The interview questions were based on the literature review, the researcher's previous experience volunteering with families who have a child with cystic fibrosis, and in consultation with members of the Board of Directors of the Canadian Cystic Fibrosis Foundation. Due to the small sample size, the interview guide was not pre-tested. After the initial interview with a participant, the research guide was amended and a number of the questions were modified. According to Rubin and Rubin (1995) adjusting the interview design as you go is a "normal, expected part of the qualitative research process" (pg. 44). Qualitative research often focuses on areas that are relatively unexplored. Qualitative interviewing must be flexible in order to be able to examine new ideas and themes that emerge during the interviews. This flexibility is "better than persisting in a design that is not working or that doesn't allow you to pursue unexpected insights" (Rubin & Rubin, 1995, pg. 44). The initial participant was invited to participate in a second interview that explored the amended questions but the participant declined.

The aim of the interview was to allow participants to share the stories of their experiences during their child's transition to school in a sequence that was comfortable and appropriate for them. The semi-structured format encouraged parents to share their stories but also allowed the researcher to explore areas that were more specific to the

parents' experience during their child's transition to school. Both the initial interview and the revised interview guide can be found in Appendix B.

Ethical Considerations

Permission for this study was obtained from the UBC Behavioural Ethics Board. Participants were recruited through a third party and a letter of introduction outlining the purpose of the study and the nature and extent of their involvement was provided. Participants were asked to sign a consent form outlining their time commitment and their right to withdraw from the study at any time without consequence (Appendix C). Fictitious names were used and all documents were password protected or kept in a locked filing cabinet.

Data Analysis

The intent of the analysis of this study was to focus on the narrative and to extract the meaning and the context of the lived experience of parents with children diagnosed with cystic fibrosis during their child's transition to school. After transcribing the participants' interviews, I applied a content – categorical approach to data analysis to explore the stories of the participants and to develop the study's themes.

Qualitative content analysis "moves farther into the domain of interpretation than quantitative content analysis in that there is an effort to understand not only the manifest (e.g., frequencies and means), but also the latent content of data" (Sandelowski, 2000, p. 338). To begin the analysis, all sections of the text that were relevant to the research question were selected from the verbatim transcript and assembled into a separate document. Sentences and separate utterances of the participants from their interviews

were withdrawn from the total context of the life story and were treated independently (Lieblich, Tuval-Maschiach, & Zilber; 1998). The relevant text was then read "as openly as possible to define the major content categories that emerge from the reading" (Lieblich *et al,* 1998, p. 113). In this study, participants often used the same words or phrases throughout their interviews to express similar ideas.

According to Sandelewoski (2000), qualitative content analysis is "reflexive and interactive as researchers continuously modify their treatment of data to accommodate new data and new insights about those data" (p. 338). This next step of the data analysis was a circular procedure that involved careful reading, then the creation of categories, second readings and then the revision of categories, until each reading brought about the same categories (Lieblich *et al,* 1998). The final step in the analysis process was the development of themes from these categories. For the purposes of this study, a theme is "an implicit topic that organizes a group of repeating ideas" (Auerbach & Silverstein, 1998). Themes will be used descriptively to create a picture of the content experience of parents of children with cystic fibrosis during their child's transition to school.

Reliability, Validity, and Generalizability

Qualitative descriptive studies seek "descriptive validity, or an accurate accounting of events that most people (including researchers and participants) observing the same event would agree is accurate" (Sandelowski, 2000, p.336). To reduce threats to descriptive validity, audiotapes of participant interviews were transcribed within two weeks of their recording. Detailed field notes were kept throughout the research study and both the tapes and the field notes were reviewed at numerous points throughout the length of the project.

Interpretive validity is the accurate accounting of the meanings participants attributed to those events that those participants would agree is accurate (Maxwell, 1996). The main threat to valid interpretation is imposing one's own viewpoint or meaning, instead of listening or reporting the meaning or viewpoint the participants have attached to their experience. To reduce threats to interpretive validity, a number of precautions were taken throughout the research study.

To reduce researcher bias, I have explicitly examined how my personal experiences may influence my beliefs entering into this research process. Specifically, I have outlined my past experience in the reflexivity section of the first chapter, kept a journal throughout the research process to examine my subjective reactions to the participants and their narratives and participated in peer review sessions with my research class. These actions allowed me to examine my own interpretations and to consider alternative explanations of the material at hand.

Another action undertaken was the implementation of member checks. Member checks means "systemically soliciting feedback about one's data and conclusions from the people you are studying" (Maxwell, 1996, p.94). This allowed participants the opportunity to provide feedback on the descriptions that were created and the meanings that were ascribed to their experiences.

Maxwell (1996) discusses two types of generalization in qualitative research. Internal generalizablity "refers to the generalizablility of a conclusion within the setting or group studied, whereas external generalizability refers to its generalizability beyond that setting or group" (p. 97). Internal generalizablility can be threatened by key informant bias (Maxwell, 1996) as a result of a small sample size. Due to the small

number of children diagnosed with cystic fibrosis who are between the ages of five and ten years and are living in the Lower Mainland, a small sample was used when collecting the data. There is no guarantee that the participants' views are typical or representative of the diversity of experiences of parents of children with cystic fibrosis in different regions. Yet, this does not mean that the results are not generalizable beyond this setting. Maxwell (1996) introduces the concept of face generalizability. Face generalizability is when "there is no obvious reason not to believe that the results apply generally" (p.97). Therefore, although this research study focused on developing insight in one area of study, the results could possibly be applied to similar populations in other areas.

Summary

In this chapter, the methods used to describe the experiences of parents who have a child with cystic fibrosis during the child's transition to school were discussed. This study made use of a qualitative descriptive methodology and also applied a narrative approach with its framework. The participants were recruited through the Canadian Cystic Fibrosis Foundation – Lower Mainland Chapter. The sample consisted of four mothers and one father who have children who were diagnosed with cystic fibrosis. The study applied a retrospective approach as the children were between seven and ten years of age. Data was collected through one-hour semi-structured interviews in a private location. Confidentiality has been maintained and participants were offered the opportunity to review the document and to provide feedback regarding possible changes. In the chapter to follow, the findings related to this study are presented and discussed.

CHAPTER THREE: FINDINGS

The study's findings are discussed in this chapter. Once this study began, it quickly became apparent that it was very difficult, if not impossible, to isolate the parent's experience of their child's transition to school from the overall context of their lived experience of their child's illness. In order to understand parents' experiences during their child's transition to school, an ecosystems approach was applied which included exploring not just the element of school accommodations but also an examination of the diverse systems and the various interactions between the parents and their environment. For the parents in this study, their child's transition to school was part of a larger network of systems and many aspects of the family's lives came into play during this time. The transition to school could not be investigated in isolation but rather, had to be explored in the context of how parent's past interactions with health professionals, their support systems, and their family systems influenced this time of transition in their lives.

The findings of this study explore all of these areas in addition to exploring the details of the specific accommodations the children required within the school system and are organized into seven main sections. Section one provides a description of the four families who participated in this study and a brief overview of their family stories. The next eight sections discuss the ten emergent themes that arose from the participant interviews. Section ten will provide a brief summary. Chapter Four will then present the interpretation and discussion of these findings.

Section One: Participant Profiles

Rebecca and Aidan

Rebecca is the mother of Aidan who is eight years old and who was diagnosed with cystic fibrosis when he was an infant. His form of the illness mainly affects his digestive system although he does have some liver involvement, which is controlled with medications. Rebecca and her husband have an older son named Jack who does not have cystic fibrosis. For the most part, Aidan is doing very well but "he has his ups and downs since his initial time" of diagnosis.

Aidan and his older brother both attend an Independent School, which includes students from Kindergarten to Grade 12. The school has a total of about 700 students. It is considered a four-strand school, which includes a focus on Arts, Education, Athletics and Citizenship. Rebecca and her husband chose to enroll their children in an Independent School mainly as a result of concerns they had regarding the education of their older son, Jack. They decided when Jack was entering Grade Three to switch from the public school system to the independent school. Aidan was also starting school that same year so for Rebecca and her husband "it seemed like a good time" to make the transition.

Laura and Daniel and Isaac

Laura and Daniel are the parents of Isaac who is ten and his older brother who is twelve. Their older son does not have CF. Isaac's illness affects his lungs in some ways but his digestive system is "harder hit." He has always struggled with a sore stomach and frequent bowel movements. When he was two and a half years old, Isaac had a

gastronomy tube implant, which is often called a g-tube. A g-tube is an invasive medical intervention that is sometimes used by people with CF to maintain sufficient weight in order to be able to defend against infections. In Isaac's case, his g-tube feedings were conducted in the morning and again in the evening. As Daniel stated, this meant, "when you are looking at school, you've got some careful planning to do." Overall though, Laura describes her son as "our bundle of energy" and says he gets "good physio just running around."

Isaac attends a public elementary school within his community. The school has approximately 400 students who attend grades Kindergarten to Grade 7. It is actually the same school that Daniel attended when he was a child and is within walking distance of their home. As Daniel stated, "It kind of connects you with the community. That we're... we're kind of enjoying."

Maria and Katie

Maria is the mother of Katie, a seven year old daughter with cystic fibrosis. Maria is married and also has a nine-year-old son who has tested negative for cystic fibrosis. Katie's illness mainly affects her lungs. Maria states that Katie has been "very healthy" and has been doing "unbelievably" well.

Both Maria's children attend a public school in their community that includes Kindergarten to Grade Five. The school has approximately 320 students and enrollment has just recently grown as a result of the closure last year of a nearby elementary school.

Beth and Luke

Beth is the mother of a child who is 18 months old, a child who is five years of age and Luke who is eight years old. Luke is the only child diagnosed with cystic fibrosis. When I asked Beth how CF affected Luke's health, she stated that it mostly affects his digestive system. She went on to describe Luke as being "healthy and happy."

Beth, her husband, and their children had been living in London, England and they just moved back to British Columbia in August 2003. Therefore, Luke first made his transition to school while attending a small private school in London. He then made his second transition, into Grade 3, at a local community school in the fall of 2003. This study will focus on his transition to his Canadian school. His current school includes Kindergarten to Grade 7 and has "lots of kids and a large staff". The school receives great support from the community and is proud of its reputation as having "been one of the better schools in the area for awhile" but also "has its faults." Beth feels she and her family are very connected to their community as they are living close to the area where she and her husband both lived as children themselves and both family and friends are nearby.

Section Two: Illness Narratives

This section will explore the theme of illness narratives. Examination of these narratives allows us to explore the initial interaction of the families in this study with their health care team and to discuss how these interactions influence future interactions and dealings of these parents with the various systems in their lives.

Diagnosis

Although the diagnosis of cystic fibrosis occurred many years before the child's transition to school, the parents' memories of their earlier experiences are heightened at this time as parents are required to interact with a new group of professionals and must allow their child to enter into a new and larger social environment. Each interview with a participant began with the parent being asked to tell me a bit about their child. All of the parents in this study immediately began by telling the story of how his or her child was first diagnosed with cystic fibrosis. It was apparent during the interviews that the time of diagnosis had a profound impact on each of the participant's lives. With each of the families, the story was very scripted and well rehearsed. Maria told the story of Katie's diagnosis in great detail while Laura and Daniel's story of Isaac's diagnosis was detailed but mainly highlighted key aspects of their experience. Beth and Rebecca both gave quite short versions of the time during which they were awaiting their child's diagnosis and did not go into extensive detail of this time during their children's lives. Daniel summed up their experiences best when he stated:

> So not knowing a lot about CF and then here you have a child who has it, it's traumatic and there is a tremendous amount of maintenance at the beginning for both of us because of all the procedures, and physio and medicine and the...so on...and not also realizing, much like in schools, you don't realize that it is not, that there can be variations of the disease. There can be severities in different parts of the body and so on so we were figuring a lot of that out as we were going along. And the most difficult I guess would be...ah...trying to come up with a pattern to make the child comfortable. That would be with food and sleep and looking after all the difficulties that he was having...

The interactions with health professionals during the search for their child's diagnosis set the stage for each family's approach to coping with the illness and influenced how each family later interacted with professionals during transitions in their

child's lives. Maria continues to be closely connected with the cystic fibrosis clinic. Laura and Daniel, after their initial experience with the health care team during their son's diagnosis, continue to be strong advocates for their child in both the health system and the school system. Beth and Rebecca both access the clinic to treat the medical aspects of their child's illness but tend to seek social support from within their personal lives more than from within the medical system.

Section Three: Transition to School

This section will explore how the children's medical procedures affected their transition to school. I will begin by exploring the child's medical routines within their homes and how the parents arranged these routines to accommodate school. I will then discuss medication dosages and the changes parents sought to ease the transition to school. This will be followed by a discussion of the paperwork involved in obtaining necessary medical accommodations, location of the medications at school, and the issue of children remembering to take their medications. I will complete this section by discussing the role parents played in educating the educators during their child's transition to school.

Medical Routines

For children with cystic fibrosis, maintaining a daily chest physiotherapy and medication routine at home is key to their survival. All of the children in this study were required to do chest physiotherapy exercises twice a day to keep their lungs clear of mucous and to reduce the risk of infections. Parents had to carefully plan their lives

around meeting their child's daily medical needs. This becomes more of an issue during the transition to school due to increased demands on the family's time.

Of the children in this study, Isaac had the most complex medical needs during his transition to school. Laura and Daniel worked together to ensure that Isaac "got up early enough in the morning to get his tube feeding and to do his physio and then not worry about it until he got home." For Laura and Daniel, it was important to juggle their own schedules to ensure that Isaac did not require treatments during school hours.

Both Maria and Beth also arranged to provide their child's chest physiotherapy in the morning before school and at bedtime. Maria found that when she was working outside the home it was hectic to fit everything into their morning routine. Once she left work, she was able to make it "not my schedule but it became more her (Katie's) schedule." Beth stated that during Luke's first year at his new school, he switched from the traditional percussion and clapping exercises used when he was a child to what is called a PET mask. When asked if this new approach was time consuming, Beth replied:

> We have always allowed for some type of therapy so, just one more kind of thing. It is not the same as when we used to do the clapping so it's not too bad now. He could probably use a bit more sleep in the morning but...

All of the families in this study worked hard to ensure that their children received the majority of their medical treatments at home, before and after school. Children therefore were not required to access support services such as physiotherapy during the school day. The main accommodation that was then required for children while at school was the administration of their medications.

Medication Dosages

Prior to the child's transition to school, two of the parents interviewed spoke about their realization that their children were going to require their medications to be in a dosage and a form that was easy for them to take themselves. Beth and Maria both began exploring ways to ensure that their children were able to swallow pills. At the ages of four and five, they worried that this would not be an easy task. Before starting school, Katie's enzymes needed to be cracked open and put in applesauce in order for her to be able to swallow them. Maria advocated with the medical team for "a dosage that fits that she doesn't have to open them and that she can just take the pills." By working together, they were able to find a dosage that worked for both Katie and her school.

Beth also worried during Luke's transition to school about how they were going to make the necessary arrangements so that Luke could take his medications each day. At that point "he needed to do the applesauce trick, right? Open up the thing and put it into the apple sauce." But Beth felt that the staff would not want to have to do that extra step. So, she asked the medical staff if Luke could start learning how to swallow pills. Everyone was surprised by how quickly Luke was able to acquire this new skill and adapt to a new routine. This made things easier for Beth "because all they had to do, I mean he had it in his snack bag, and they just had to make sure he had the one and watch him swallow it and they were done." This allowed Beth and her husband to have the "feeling that he would be okay. Knowing that he could swallow those pills..."

Both Beth and Maria were able to speak with their child's medical staff and advocate for a medical procedure that fit with their needs and their families' schedules.

In turn, the medical staff listened to the parents' concerns and worked in partnership with them to achieve a solution that worked best for everyone involved.

Paperwork and Policies

The children in this study missed very little time during their first year of school due to fewer hospitalizations. What now became more of a focus for parents was the need for medical accommodations during school hours. Each child was required to take a number of pills at mealtime. Some of these are prescription drugs and others are enzymes which help the child to digest their food and to absorb its nutrients. Each school was different in their policies regarding medications, the amount of advocacy required to obtain accommodations, and the way in which the medication was dispensed to the child.

Three of the four families were required to complete more paperwork than was required for a typical child when they were beginning school, as it was necessary to provide information about the child's health and medical routines during the school day. Maria found that she had to spend a lot of time "trying to explain to them what she's got, what needs to be done" and really felt "it is the first time though that...you go to school... and she is different."

Laura and Daniel filled out the initial registration forms and included the information that Isaac had cystic fibrosis and had a g-tube implant. Within a week, a public health nurse called and came to their home to discuss their child's health care needs with them. The public health nurse was concerned that Isaac could require feedings or physiotherapy while at school but Laura and Daniel explained that these treatments would be completed at home, before and after school hours. At the time,

Laura was "really quite surprised that they were on it right away" and knew "we could have requested certain things if need be."

Beth had a very different experience. Luke's school was not proactive in accommodating Luke's medical needs during school hours. Beth was required to fill out a number of forms but realized during our interview that, although she was supposed to have Luke's doctor sign one of the forms, she does not think she ever did so. She stated:

> This is interesting to me because the school has never come onto me about it. And again, whether it is because the (school) nurse doesn't get as many hours at the school now or whether the secretary is cut back or, I don't know. I don't really know. I am really surprised at that because I am pretty sure I didn't do that.

Rebecca, on the other hand, did not need to complete any paperwork during her child's transition to school. She and her husband had an initial interview with the headmaster of the independent school and "once the initial interview took place and they knew that Aidan had CF, that was where it ended."

Location of Medication

All of the families interviewed in this study needed to arrange a location where the medications were going to be stored during the school day. Each school had a different way of dealing with this issue. Some schools chose to keep the medications in the classroom, others chose the office; sometimes they were kept in the child's lunch bag, and for other schools it was a combination of all three.

Maria has initially worried about Katie's medications once she started school as she had heard from "a few CF parents that I know, some had been to not-so-great schools. 'Oh, they won't give the medications and it really scared me." When Katie started school, she was surprised that the school was very supportive and she was able to

arrange for Katie to have "pills in the office, enzymes, and there are pills in the classroom. The teacher has a locked drawer" and the kindergarten teacher provided them to Katie each day.

Rebecca was not certain if the school Aidan attended actually had a medication policy in place. She felt that because the independent school was quite small, they "handled it on an individual basis." In Aidan's kindergarten classroom, "there was a public nurse, a woman trained as a nurse but she is actually just in the classroom to help the teacher, but she has a medical background and so I was in contact with her before he started." Aidan took his medications to school in his school bag each morning. He "used to take two bags; a snack bag and a medication bag. A snack bag and a medication bag because he couldn't read yet." Also, in case there was a birthday or a special occasion at the school that included treats, Rebecca had arranged for an extra medicine bag with a supply of medications to cover a snack or small lunch to be kept in locked in a room off the Kindergarten classroom. Rebecca felt that "it was mainly his classroom teacher that was not comfortable with the medication. I think it scared her a little bit so it was really the nurse that I communicated with if there was any concern."

Laura and Daniel had a different experience as they worked with their child's school to "establish a rapport there that is a little different with other kids with disabilities." Isaac's medications are kept in two different locations. Due to school policy, Laura cannot pack prescription drugs in his lunch bag so Isaac is required to go to the office to obtain them. This is done as a precaution to ensure that other children do not come across the pills and ingest the medication. But, Laura wanted Isaac to be able to control his own enzymes and to be able to pack them in his lunch bag. She decided to

write a letter to the school. In the letter, she explained that in order for Isaac to digest his meal, he is required to take up to 10 more pills at mealtime and explained that they would not pose a health risk to other children if they swallowed them, aside from mild constipation. The school agreed to allow Isaac to take his enzymes in his lunch bag but chose to continue to dispense the prescription medications from the office. Laura and Daniel then needed to find a way to remind Isaac to go to the office 15 minutes before lunch hour to get his medications. A watch with an alarm was the best solution as it allowed Isaac to remain independent and did not place the responsibility on the teacher to remind Isaac to go take his medication.

Beth's experience at Luke's school has been an attitude of indifference. Luke did not require prescription medications but did require enzymes at each meal. Beth asked Luke's teacher about his medications and "she didn't really want too much to do with it." Beth wanted to arrange to keep a spare dosage at the school but when she asked at the office about leaving some there "they were not too concerned." Beth was a little worried about Luke carrying them in his lunch bag in case another child took them. Her concern was "not that it would harm them" but "then he doesn't have them." Beth was surprised as she thought that the school's staff "would be a little more on top of things here" and would have followed up on his required needs. Beth sighed and stated, "the onus is definitely on him." She wished "that a teacher would have taken that on a bit" and next year would like to arrange to have a few enzymes kept somewhere in the school to ensure that a supply is available in case a situation arises where Luke is in need of them.

Remembering To Take Medication

Prior to their child starting school, parents were worried about their children remembering to take their medications. All of the parents in this study reported that their children sometimes forgot to take their medications during the school day. Three of the families felt it was mainly during hectic times in the classroom when their routines were changed that their children forgot to take their pills, such as birthdays or special occasions.

When Katie was four years old, Maria began teaching her to remember to take her medications before her meals by prompting her with "Are we forgetting something Katie?" at mealtimes. Maria "was training Katie to remember to tell Mrs. March to give her her pills, which worked probably about half and half throughout the year."

When Isaac began school, Laura knew that he forgot to take his pills on occasion. She would remind him of the consequences of forgetting, which included a sore stomach, cramps, gas, frequent bathroom trips, etc. She strongly felt "you just kind of have to let them go and have their accidents and have their mistakes" and "after they do that a few times, they are going to remember that they have to take them."

Educating the Educators

All of the parents in this study made a strong effort to ensure that the staff at their child's school was educated about cystic fibrosis and its symptoms. They each gave to either the school's administers or the classroom teacher a copy of "A Teacher's Guide to Cystic Fibrosis," a pamphlet (Appendix D) published by the Canadian Cystic Fibrosis

Foundation (CCFF). The parents praised the foundation for developing this pamphlet and each of them used it every year as a teaching tool for their child's school staff.

Maria provided the school with a copy of this pamphlet but had decided to only give additional information about cystic fibrosis to the school on an "as needed" basis. Currently Katie's school staff has very little information about Katie's illness. Beth provided Luke's teachers with information about Luke's illness by also using this pamphlet, and strongly stated that as a resource, "they are awesome." Beth customized the information ahead of time by highlighting the information that applied or did not apply to Luke. In the end though, no one on staff at the school "came back with questions or anything, which I kind of thought was surprising."

Laura knew that educating the school's staff was important as the teachers "have this child in their class, they need to know the basics, you know, in case he is coughing a lot or whatever." She provided each of his teachers with the CCFF pamphlet and highlighted the information that was relevant to Isaac. Laura found that all of the teachers responded very positively to the provided information and "would read through it and were like, wow, I never knew."

Rebecca provided the teacher with the pamphlet and also arranged to meet with the teachers at her son's school. At first, Aidan's homeroom teacher "was concerned about the effect his CF would have on him in the classroom." It was not until after the first report card that she "saw that it was probably less a concern than most kids with asthma and that he handles it, that it is no big deal. It is not an issue for him."

Educating the staff at the school was an important component for all of the parents in this study in order to facilitate a successful transition to school for their

children. All of the parents needed to take an active role to ensure that the staff had information about their child's condition. The teachers became more comfortable knowing more about the illness and the families felt reassured knowing the teacher had a general understanding of their child's illness and their unique needs.

Section Four: Strengths

Each of the families in this study brought with them various strengths and values that assisted them throughout their child's illness. These strengths were often drawn on during the child's transition to school. This section will explore the key strengths highlighted by parents during the interview process, which include advocacy and acceptance/a positive attitude.

Advocacy

Advocacy was the key strength mentioned by all of the participants involved in this study. Daniel stated:

> We learned very quickly that whether it be in education, or in the health industry, you really have to pay attention and be an advocate and take on the responsibility to find out about issues. You have to do that.

Laura strongly stated, "Advocacy was definitely one of our things." Together they worked to ensure that their voices were heard and that Isaac's needs were met in an appropriate manner. Laura was proactive during her son's transition to school and took the initiative to write a letter to Isaac's school principal, outlining the areas in which she had concerns for the upcoming year. This allowed the school staff to be prepared for Isaac's unique needs and to make the necessary accommodations to allow a smooth transition to school.

All of the parents in this study stated that they knew they would be willing to speak up in order to get the services their child required. Laura makes sure "the minute I have a question or something, I get it addressed. I don't procrastinate like some families do." Laura used to "be a lot meeker" but now "when Isaac is concerned, I'll definitely speak up." Rebecca stated "I am more willing to put myself out on a limb with my child maybe even more than I am for myself." She recognized the importance of being "able to speak up when I know it is necessary." Beth also felt that one of her strengths was "feeling confident enough to speak up" when the need arose.

Two of the families felt that the staff at the cystic fibrosis clinic, especially the social worker, were instrumental in teaching them that they had to be strong advocates for their children. Daniel believed it was the role of the social worker "to teach the skills to the parent in how to advocate for your child, to get the best for them." Rebecca shared that she remembered the social worker explaining to her that it is the parent that is the best advocate for their child "until the child is able to take over" that role. With this foundation, parents were willing to advocate for their children in order to be able to receive the best possible services and care for them.

Acceptance/Positive Attitude

Maintaining a positive attitude and acceptance of the illness were both strengths that two of the families felt contributed to their ability to cope with their child's illness and the transitions that occurred in their lives. When asked about her personal strengths, Maria stated that a positive attitude was "number one. I think it has to be." In order to cope with her child's illness, Maria has focused on the positive things in her life and "I know that that reflects on Katie and just the way we are."

In addition to a positive attitude, Maria felt that acceptance was important in order for her to deal with Katie's illness on a daily basis. She went on to state she "feel(s) so lucky that Katie has this" not because she wants Katie to be sick but rather, in accepting Katie's illness, Maria has learned to feel fortunate for what she currently has in her own life. She knows that most people "don't get when I say that" but really strongly feels that having Katie for a daughter and accepting her illness has made her a better person. Maria felt that because "you can't change it, you have to accept it."

Daniel and Laura also felt that acceptance was key to moving forward with their lives. They felt that the basis for this acceptance started at the hospital with the cystic fibrosis clinic. The social worker at the clinic emphasized the importance of parents accepting the diagnosis. Daniel stated that by "being very conscientious about that, it has helped him (Isaac) in being able to manage things and to educate others about it."

Section Five: Supports Accessed

In addition to relying on the support of family and friends, parents accessed a number of organized support services during their children's childhood. The various supports accessed have had an influence on how parents were able to cope during their child's transition to school. This section will explore parents' access to social work services at the clinic, access to medical staff, as well as examining the support gained through attending a parent support group for parents of children with cystic fibrosis.

Social Work Services

All of the parents in this study met with a social worker who was part of the cystic fibrosis clinic team at the time of their child's initial diagnosis. The families all felt that

although they did not access social work services on a regular basis, they always knew they could speak with members of the team if they required assistance. Yet, very few of the families interviewed continued to access support from the social work team at the hospital after the time of diagnosis despite their continued involvement with the clinic.

Rebecca was the only parent who mentioned a specific time where she had called the social work staff with an issue. Rebecca liked knowing that if she needed to call, she could but "it was not there in our face." Beth and her family, however, did not access social work services aside from the initial meetings after Luke's diagnosis. She stated,

> We are really lucky and I am glad that the social workers are part of the CF team at the Children's Hospital setting and I don't, they're great but even from day one it just, it just wasn't us.

Beth and her husband have a large social support network in their community as both their families and friends live in their area. Also, the social worker at the clinic had initially turned them off social work services with "the whole empathy thing and hearing what I am saying and repeating back and all that stuff." Years later, they again experienced a similar interaction with a social worker at the clinic. Looking back, Beth felt that the social worker had not offered her family any concrete services or information. Beth was not against social work services but strongly felt that the way the services were being offered was not a fit for her and her husband.

Cystic Fibrosis Clinic

All of the families interviewed attended the cystic fibrosis clinic on a regular basis and received support and guidance from the medical team at the Children's Hospital. Laura and Daniel spoke of how supportive the clinic staff has been throughout Isaac's illness. They found that even when they were out in the community, the clinic staff was

"there all the time" to answer questions both by phone and by email. Laura, when speaking about Isaac's future transition to adult care, stated, "I'm going to miss them at Children's as they have been really, really supportive of Isaac and of us as a family."

Maria spoke extensively about the clinic and how supportive they have been to her and her family. When talking about the cystic fibrosis clinic she stated, "I love them. Unbelievable! I love them with all my heart." During Katie's transition to school, Maria went to the clinic with a number of questions but had already been involved with the school for two years with her son, so was already familiar with the school staff. She felt she would have required more support had Katie been her first child attending school with cystic fibrosis, as "when my son went to school, you know, I didn't know one person in the school." By the time her daughter was making this transition, Maria knew more people within the school system and with the assistance of the information provided by the clinic she stated, "I really just helped myself and prepared myself."

All of the parents in this study lived quite close to the location of the cystic fibrosis clinic at the Children's Hospital. They felt fortunate that this was the case as the children visited the clinic a number of times per year. Children in this study were required to miss only a couple of hours of school to attend medical appointments. Children from rural areas would have to miss at least a day of school each time in order to accommodate the additional travel time. Daniel stated, "Something that we have heard is that people outside of the lower mainland...I think they may find it a little more difficult than us just because the resources aren't there."

Parent Support Group

All of the families in this study attended a parent support group for parents of children with cystic fibrosis when their children were between the ages of infancy to age five. For all of the families, this group was a great form of support and information concerning their child's illness. The group provided an opportunity for parents to share their experiences, to hear different guest speakers and to attend education sessions concerning topics related to cystic fibrosis. Although the group was no longer meeting when these children were about to enter school, many of the parents in this study recalled information they had gained during their involvement with the group and this later influenced their adjustment to their child's school transition.

Laura and Daniel found the group to be a great source of support:

> ...because I felt I needed it then, at the early first two or three years. It was, you just had some moments where you thought 'Oh God, this is just like horrible' but for the first year or so those meetings were kind of helpful.

Daniel especially found the workshops and medical presentations offered by the support group very helpful in assisting him in coping with Isaac's illness. The group provided Laura and him with the facts and information about the research being done and it "gives you, in the background, not a feeling of comfort, but of acknowledging that some efforts are being made."

Beth, Rebecca, and Maria also felt the group was beneficial and especially found the guest speakers to be very helpful and informative. Beth and Maria found it interesting to "hear a sibling talk" about their experience growing up with a brother or sister with cystic fibrosis. Maria found it really affected her to hear from an adult with cystic fibrosis and remembers that she "would just stare at them" as until that time she

had never met an adult with the illness. It reinforced for her the possibility that her child would live to be an adult and would not die in childhood.

Unfortunately, after a number of years, the group began to dissolve. Eventually, Laura and Daniel got "accustomed to the whole living with the child with an illness, you just sort of fall into a pattern where you get comfortable with it." They found there came a point where they no longer felt they needed to be involved. But, three of the families have since had occasions when they wished that the group was still meeting so as to be able to talk with other parents about what they are experiencing.

Maria felt that had the group been meeting during Katie's transition to school, she "would have had a lot more questions" to ask the other parents. Beth mentioned that she liked attending the group and felt that "it would be nice to have something" again where parents could get together and talk about "what was maybe going to come our way." Beth missed having the group when she was debating whether or not to send her son Luke to an overnight class activity. She felt it would have been helpful to have been able to talk to another parent whose child "with CF, a little bit older than him, who probably did it a few years ago" and to hear about their experience. Beth thought "you just kind of need to hear some of those stories" to be more confident allowing your child to try new things. Laura also felt it would be interesting to meet with other parents, as "it's been a while since we actually sat down with some of the families and discussed anything."

The parent support group discussed in this study provided families with opportunities to share their personal stories and to obtain information about their child's illness. Parents found support and encouragement through meeting together and

discussing their shared experiences of having a child with cystic fibrosis. Also, the group enabled parents to gain a sense of understanding of their circumstances and to begin to hope for their children's future.

Section Six: Protection

Although children with cystic fibrosis are much healthier during their elementary school years than they have been in the past, these children are still at much greater risk of becoming ill than their peers. Parents must walk a tight balance between monitoring their children, protecting their children from germs, and allowing their children to have the independence they need to live as normal a life as possible. These concerns were intensified during a child's transition to school as the child was being introduced to a new environment where parents had little control.

Monitoring

Of the parents interviewed, Maria struggled the most with wanting to protect her child and keep her safe from harm. In particular, Maria found the transition to school very emotional and found "it was more stressful on me because I wasn't there. I found it very stressful." For the first two weeks of school, Maria "was that parent that showed up every lunch hour." Although she had everything in place so that the school could dispense Katie's medications, she "just went to watch." After the first two weeks, Maria felt a lot better as she was able to see that both the teacher and Katie were organized and she saw that Katie remembered to take her pills each day. Maria stated, "My monitoring, it was just my, just making sure the teachers were aware." Now, rather than going to the

school each day, Maria currently monitors Katie's medication intake by checking her lunch bag at the end of each day to ensure that the medications are no longer there.

Laura and Daniel felt it was important for one of them be home to take care of their children at all time as they had decided "way back if we were going to have kids, one of us would be staying home because daycare just wasn't an option for us." Daniel felt that it was important for someone to stay at home with the children "to make sure they are getting the proper guidance." Laura chose to stay at home and "only worked, Daniel being a teacher, so when he was on holidays I would go back to my old job and do relief work." Laura was therefore always available to watch over Isaac (and his brother) and to be available at all times should the school require her assistance.

It is interesting to note that when the child with cystic fibrosis entered school, all four of the mothers interviewed in this study chose to be at home full time. This allowed them to be available to the school should a problem arise. Yet, after their children had been in school for a year or two, three of the mothers interviewed chose to return to work or school on a part time basis.

Germs

Parents' concerns about their children catching colds, about the importance of their children washing their hands, as well as concerns about the physical environment at the schools were intensified during this child's transition to school. Three of the four families were very worried about their child's contact with germs during this time of change.

Rebecca, when asked about her concerns about germs during the transition to school, felt the word "paranoid would be a good way to describe it." She found this

aspect of her child's transition to school to be very stressful. Rebecca found it hard to "see a kid with green mucous running out of their nostrils...it does sometimes make me think 'Why are you here?'" But, she eventually came to realize that "half the time they are exposed to things before someone even comes down with symptoms" and has worked to improve her "ability to let it go."

In order to remind Aidan to wash his hands before mealtimes, Rebecca included a little picture of a tap on his medication bag. Also, in Aidan's school each classroom has its own washroom with a sink at the back of the class which Rebecca hoped allowed the teacher to better monitor the kids getting cleaned up before lunch. Rebecca is "not sure that he washes his hands before he eats. I hope he does but I've had to let go a little bit there." Laura also used to be much more concerned about Isaac's exposure to colds but had come to the conclusion that her child was "going to be exposed to all kinds of viruses and whatever, so now I think, I'll just deal with it when it happens."

Maria also expressed concern about the importance of Katie washing her hands and worried about her catching colds from her peers. Maria knew that the teachers at Katie's school were very good about getting the students "to wash their hands before meals" so she tried not to worry about it too much but stated "you know, you're not there for all those things now."

Beth was the only parent interviewed who was not very concerned about her son being exposed to germs or about the importance of washing hands. She stated, "I probably should be a little more concerned but that never really bothered me." She felt that "because he is SO healthy," it has given them "a lot of confidence. We really didn't worry because we knew he would be okay."

Physical Environment at School

Three of the parents interviewed also expressed concern about the physical environment of the school. Rebecca was concerned that if Aidan were to attend public school there would be "a lot of mold and stuff growing." One of the benefits of her child attending an independent school was knowing that "they have the money to clean the carpets or to take them out, if things start to grow in them." Also, the fact "they have soap in the washrooms which I like and I find very important."

Maria also struggled with worrying about the physical environment at her daughter's school. Maria was "not big on anything public" such as the washrooms or the water fountains but stated that she tried not to worry too much about things she could not control and because "I am not about to go in and clean all the school washrooms and fountains" she made an effort to "let it go."

Laura and Daniel also felt that in the public school where Isaac attends, the "standard of health in schools is not something that they uphold." They complained that there was no soap in the soap dispensers and the "bathrooms are deplorable." Laura and Daniel's concern "was kids that were getting sick, being in contact with him and I remember conversations we had about that, because we didn't want him to get unnecessarily ill." But, Laura felt for Isaac "there is only so much you can do to protect your child. I mean, you can't put them in a bubble." Daniel added to this by saying, "It's really easy to be overly protective of them, but that can create problems too. So we don't want to be overly protective but to try and find some middle ground."

Section Seven: Normalization

Despite the desire to protect their children, all of the parents in this study reported that it was extremely important to them for their children to lead "a normal a life" despite their illness and for them to fit in with their peers. This desire for a sense of normalcy was heightened during their child's transition to school.

Both Laura and Maria mentioned that since their children had been diagnosed with cystic fibrosis since infancy, the children don't really "know anything different." Maria stated that Katie feels "her life is....as she feels, is as normal as it's always been." Maria worked hard to ensure that they were able to "live a very normal life" despite Katie's illness.

Rebecca found that during her child's transition to school "there were a couple of things that surprised me I guess about my child." For the first week of school, Aidan was taking two separate lunch bags, one for his medications and one for his food. After the first week, "he came home from school one day and said, 'I can't take two because no one else does.'" Somebody at school had teased him about his having two lunch bags and so Rebecca was able to work out a solution by finding a lunch bag that had two separate sections. Aidan "is very concerned about being the same as everybody else" and "doesn't really like other people to know."

Laura and Daniel wanted to make sure that Isaac wouldn't be different from his peers during the day and juggled their own schedules to make sure that Isaac was able to get his g-tube feeds in before he went to school. They did this as they knew "it was much easier for him at school, so he wouldn't have to feel like he stood out as far as, you know, being different than everybody else." Laura didn't think that Isaac worried all that much

about being different from his peers and wasn't sure if "it was really for his sake. I think, maybe it was more for mine." She was worried that he would be teased and wanted to minimize the chances of this happening as much as possible.

Maria stated that the thing she worried about most "is other kids making fun of your kid." She worried that something "as simple as taking a pill, they can just turn on you, at very young ages is what I find." Beth also mentioned that she did not "want Luke ever to feel that, you know, that he is missing out." She doesn't want him to have to stay in longer at lunchtime and miss out or have to leave places early in order to receive his therapies. Beth doesn't want any of his medical care "to get in the way of being sort of a normal functioning kid in the class or wherever." Beth feels they have been very lucky as so far Luke has not complained of experiencing any teasing and has gotten along well with the children in his classes. One occasion that made Beth realize how accepting kids can be occurred when she was helping out with one of Luke's field trips. Beth was talking with one of the other mothers and mentioned her son's name. The woman's son, who was standing nearby, piped up saying, "Oh yeah, Luke. Nice boy. Takes pills." Beth realized that the child didn't care that Luke took pills, it was just a fact that made him Luke.

Feeling Fortunate

Families in this study attempted to normalize the experience of their child's illness by comparing their experiences to those less fortunate. These feelings of good fortune became a theme that arose repeatedly throughout this research study. For the parents who participated in this study, this approach to normalization became a coping strategy throughout their child's illness and during times of transition in their lives.

Of the families interviewed, Maria was the parent to most emphasize her feelings of good fortune. She was especially moved by one occasion at a local swimming pool that occurred a number of years ago. It was during a "scare" when she was waiting to receive from the clinic the second test results that would eventually show that Katie did not have the bacteria they feared. Maria and her sister had had taken Katie to a local swimming pool. While they were watching the children swim, four people came into the pool area who were quite challenged physically and mentally. Maria felt that there was "not a lot of quality of life" for these individuals. Immediately, Maria was overwhelmed with a sense of being extremely fortunate. Maria strongly believes that it could not be just coincidence, but rather that it had been a positive sign as "that week, I don't think I was feeling so positive or so lucky." Even still, she will often look at Katie and remember that day and think, "We can do this. It will be hard but we can do this."

Beth and Maria both spoke about how lucky they were in comparison to other families they saw at the Children's Hospital. Maria "tells a lot of people that don't have anything wrong with their kids, that they just have to spend a day at Children's Hospital and you will be thankful every day." Sometimes, when Luke questions why he has to do his treatments or gets frustrated with taking his medications, Beth will remind him of some of the other children they have met and seen at the hospital. Beth hates "to play that card, but you need to make him realize that gee whiz, swallowing three or four pills with each meal and doing a bit of therapy, which you get to do in front of the television that you are going to watch anyways...you are pretty lucky. You are pretty lucky."

The parents in this study all worked very hard to achieve a sense of normalcy in their lives despite the daily, lived experience of their child's illness. Through

implementing consistent routines, minimizing the amount of medical care conducted outside the home and comparing their experiences to those less fortunate, parents of children with cystic fibrosis were able to move forward with their lives as a family despite their child's illness.

Section Eight: Disclosure

Now that children with cystic fibrosis are living longer and are quite healthy during their childhood years, the illness in many cases has become invisible, yet the disease remains fatal and without a cure. On the outside, children show few, if any, symptoms of the illness that is hidden inside their bodies. Parents must now choose to whom outside the family they wish to disclose information, how much information to disclose and finally, how much information they wish to disclose to their child. Although this is a dilemma throughout the child's lifetime, awareness of this issue becomes heightened during the child's transition to school. This occurs as a result of the families having to interact with groups of people outside their close personal networks such as the school staff or the parents of their children's classmates.

Invisible Illness

Three of the families interviewed for this study talked about the invisible aspect of their child's illness. Maria quickly learned that cystic fibrosis is "the silent disease." Katie does not look sick but for Maria, "that first cough when you hear it, you kind of, my heart skips a beat. And then, okay, go into different mode." The shadow of the illness is always with her.

Beth realized that with Luke "nobody would ever predict that anything is wrong, right? Which is great in a way. Because he is so normal so to speak." Beth found "lots of times you do forget that it is because he has CF...because he is sick on the inside" that he requires the therapies and his medications. Recently though, Beth was struck by the weight that cystic fibrosis places on their lives while attending a funeral. The funeral was to honor the life of a woman who passed away in her early fifties and the service included a reading of the 23rd Psalm. In this reading, the scripture talked "about living in the valley of the shadow of death." Beth "kind of thought, well you know, that is kind of like things for us." Even though nobody talks about it and her family rarely mentions Luke's illness, "it is still there, the concern and the worry" and "when he does get a cold, and starts really coughing, I think, 'this is it, this is it, this is our big hospitalization.'" Beth talked about how she sometimes "gets this sinking feeling and so that is, that is always sort of hovering there. Not a lot. And not often in the front of your consciousness but it is, its there. Its absolutely there."

For Daniel and Laura, they are very accepting of the illness but they too felt the weight of the illness. Daniel stated they

> knew from day one the child was sick and I thought, you know, I just want to get this sorted out and get on with it. And as devastating as the prognosis of the whole thing is, I mean it is fatal, but you just, you kind of put that to the back of your mind to just get on with it, because...I mean, what choice do you have, right?

Each of these families has needed to find a way to go on with their lives while knowing that their child has an incurable life-limiting illness. The parents in this study reported that although it is not something they think about often, it is still always there, lingering in the back of their minds.

Disclosure to Others

All of the parents in this study made choices about whom to tell about their child's illness and how much information to share. Maria tried to be "very open and up front about it" but was still quite selective in whom she told about Katie's illness. Once Katie started school, Maria found it was "friends ...sleepovers...birthday parties....all of that becomes a big issue." Although Maria is "not embarrassed to tell anyone," she found it was difficult when Katie "gets invited to these parties of people I don't know, who I might never be close to, and you have to inform them." Beth also found that Luke's diagnosis was not something she shared with everyone. It was "not until there is a time when somebody is having a birthday party and I'm going to leave him" that she then was required to share information about Luke's illness with the child's parents.

Laura stated that there were some times when, as a parent of a child with a chronic illness, you "just don't want to get into it." In casual social situations, many people think that children with cystic fibrosis have asthma or maybe just a really bad cold. Sometimes Laura would "get up the discussion, you know, about it but otherwise I just...sometimes I've even said, 'Yes, he does.'" She did not do this often but every now and then with strangers there were times when it was easier just to agree.

Disclosure To The Child

All of the families interviewed struggled with how much and at what age to tell their child about their illness. All of the children in the study knew that they had cystic fibrosis. What that term meant to each child likely varied.

Maria tells Katie "very little." She knows she has cystic fibrosis but "she doesn't really know what that is." Maria felt Katie was still too young to hear about her illness. She knows she has cystic fibrosis and knows she has to take medications and do physiotherapy but only knows why "in a child's terms." She does not necessarily know how the illness and the treatment are linked.

Laura and Daniel have "always explained to Isaac along the way, but in terms he could understand." When he had questions, they never tried to hide anything from him but "made the answers age-appropriate." They have always encouraged Isaac to explain to others about his medications and he was able to answer very simplistically based on his age and reply, "'Well, I just need those to digest my food.' Rebecca and her husband also have always "talked openly about what the drugs are" that Aidan takes and he has an understanding of why he must take each of them.

Three of the families in this study mentioned experiencing difficulty knowing how to deal with the issue of the progression of the illness and how to deal with questions about death once they came about from their children. Laura knew that Isaac's

> questions will get a little more involved as he gets older. Like the death issue will come into it. But, it hasn't so far so we haven't brought it up because I don't see the purpose that would serve, you know, and it is certainly something we will have to deal with eventually.

Beth's son Luke "knows that there is no cure and he knows that there are researchers trying to get new medicines" but she had not told him about the life limiting nature of the illness. Beth vividly remembered hearing about a child with cystic fibrosis who was at school when another child "came up to him and said 'Oh, you have CF, you're going to die'" and the child came home very distraught, asking his mother to explain why the child would say that. Since hearing of this incident, Beth is more

guarded when telling other people about Luke's illness and keeps it "at a minimal need-to-know kind of level, because I am, I am concerned about stuff getting back to Luke." Beth's fear "is that, you know, it will come out of the blue. Someone will do a research project for science or something and they'll suddenly discover this." Also, two of the parents interviewed expressed concerns that their child would look up cystic fibrosis on the internet and discover the disease trajectory. Beth wanted to find out from a social worker or a psychologist or from other parents how best to bring up the topic with her child and when is the appropriate time to tell them that" it is a bit more serious than we've been leading you (the child) to know" but has not yet taken the step to request their assistance. Unfortunately, of all of the families interviewed, no one felt that social workers or other health care professionals had provided them with the resources they needed to be able to discuss this topic with their child.

Despite the relative invisibility of the illness, parents in this study constantly have to make choices about whom to tell about their child's illness and how much information to share. This becomes even more apparent during the transition to school, as the child has entered into a much wider network of social interactions that is outside of the family's circle of influence. Parents must also deal with the progressive nature of the illness and must choose when and how to tell their child about the seriousness of their illness. As a child enters school, parents fear what classmates, their parents, or their teachers might share with their child about their illness. As a result, the choices about how much information to provide to the child about their illness and when to do this becomes even more pressing and is a choice that is quite difficult for parents to make.

Section Nine: Future Fears

Now that the transition to school had been successfully navigated, many of the parents were already looking ahead with apprehension toward their child's future life transitions. Even though Isaac's transition to high school is years away, Laura is already thinking ahead to the advocacy work that will need to be done at that time. She is aware that she will have to start over, educating the staff about his illness, but

> again, it's a matter of advocacy. I'll have to go and make appointments with the principal and say this is the way it is, and just really be a strong, in-their-face kind of, for a little while until they get to know me and my child.

Laura was also beginning to worry about Isaac's transition to high school and then after that, his transition from pediatric health care to the adult care facilities. Maria was also worried about when Katie entered the adolescent years. Beth on the other hand felt that "certainly by the time Luke gets there they are going to have that all figured out." Beth had some parental insight into other parents' fears about the transition to adult care. She felt that some of the parents' concern is related to their fear of losing control over their child's care. Not only are the children "going to do the normal teenage things and wanting to have more responsibility and have mom and dad back off more" but now "mom and dad are even going to have to back off the medical side" allowing their child to attend appointments on their own. Beth felt that during this time of change, it would be the parents as well as the young adults who would need support in order to ensure a smooth transition.

Section Ten: Summary

All of the families in this study were required to advocate for some accommodations during their child's transition to school but, overall, they felt that things

had gone quite smoothly. Accommodations were made to meet the children's medical needs during the school day, required paperwork was completed, and arrangements were made concerning the child's medications. Maria stated that the school was very supportive and there was "nothing negative. Nothing. 'What more can we do for you? Are you sure we are doing enough?'" Laura felt "the door was always open" and "it was actually quite smooth, because I was worried" about how it would all work out. Laura and Daniel were surprised by the positive response they have received "with the school and any group he has been involved with. There has never been a problem." Beth also did not experience any major barriers to accommodations and "there wasn't a problem. I think that was the nice thing in a way, was that the teachers didn't say 'Oh, I couldn't possibly, we don't do that, it is not in my job description, I will not handle any medications."

Now that the parents had fewer concerns about the medical implications of the illness on their child's transition to school, they then turned their concerns to issues of protection, normalization and disclosure concerning their child's illness. Chapter Four will provide an interpretation and discussion concerning these findings and will discuss this study's limitations and future implications.

CHAPTER FOUR: DISCUSSION, SUMMARY, LIMITATIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

Introduction

This chapter will provide a discussion and interpretation of the study's findings and the implications for social work practice. A summary of the research and its limitations will then be discussed. This chapter will conclude by providing recommendations for future areas of research in this area.

Discussion

This section provides a discussion and interpretation of the findings discussed in Chapter Three and places a particular focus on the implications to social work practice. The areas discussed include: the impact of diagnosis, facilitating a successful transition, sources of support, protection and normalization, disclosure, future fears, and suggested approaches to practice.

Impact of Diagnosis

The findings of this study strongly indicate that the diagnosis narrative remains an important element of these families' identity throughout the child's lifetime. A study by Stein & Wooley (1990) supports this finding for when they studied 42 families who had children with chronic illnesses, they discovered that parents were "preoccupied with memories of the initial diagnosis and the way it was conveyed even though the diagnosis had been made several years previously" (p. 123). This study reinforces the findings of Steele (2003) and Sloper and Turner (1993) whose studies have found that the early experiences of the family with professional supports during the time of diagnosis can influence family adaptation and experiences in the years that follow. All of these studies

support the fact that although the diagnosis of cystic fibrosis occurred many years before the child's transition to school, it continued to have a significant influence on the family's coping styles and future interactions with the various systems in their lives, including the school and medical systems.

Social workers need to respect the lasting effect of the time of diagnosis and the profound need for parents to tell their stories (Andersen, 2001). Work by Davis (1993) in this field highlights the importance of listening to parent's stories about their child's illness as it "allows for, indeed expects, great variation in parent's personal constructs about disability and difference in their child" (Anderson, 2001, pg. 5-12). By actively listening to parents' stories of their child's illness experience, health professionals, including social workers, can begin to acknowledge that the family's story gives shape and creates meaning in their lives. We can then work in partnership with families to assist them accepting this reality into their daily functioning.

Facilitating a Successful Transition

A study by Coe (1989) reported that children with cystic fibrosis face a number of barriers due to increased school absences due to illnesses and hospitalizations. Yet, this study found that due to the changes that have occurred in the context of this illness as a result of better treatment regimens, children with cystic fibrosis are spending less time in clinical settings and more time in their communities. Starting school then signifies "a certain therapeutic independence and an opportunity for health professionals to increase their direct involvement with the child and their family" (Slatter, Francis, Smith & Bush, 2004, pg. 1139).

This study reinforced the earlier findings of Walker, Ford and Donald (1987) who found in their study that the care for children with cystic fibrosis has shifted from the hospital setting onto the shoulders of the child's family. Due to the on-going medical concerns of children with cystic fibrosis, adherence to prescribed regimes is viewed as essential to daily well being and longer term prognosis of cystic fibrosis patients (Abbot, Dodd, Bilton, & Webb, 1994). As a result, the use of medication at school was frequently raised as a concern and included anxiety about "how it would be organized, educating the teachers, ensuring adherence to therapy and supporting the child who may be stigmatized" (Slatter, Francis, Smith & Bush, 2004, pg 1138). This study highlights the need for parents and professionals to work in partnership to address these areas of concern to ensure a successful transition to school.

It is interesting to note that all of the mothers in this study left work or stayed at home during their child's transition to school. This allowed them to be available to respond should an issue arise. All of the mothers have since returned to part-time work or education now that their child has successfully navigated the transition to school. This finding reinforces a study by Raye (2003) who also reported that it was primarily mothers who left the workforce or downgraded their participation in paid employment to care for their child with special needs and to organize the supports they required.

In addition, Hodgekinson and Lester (2002) highlighted particular problems for mothers of children with cystic fibrosis in the management of medication, decision-making and liaising with health professionals. The "constraints and burdens of the medication regimen were referred to many times, in particular, the impact of the time consuming administration on the life of the child and the parent" (Slatter, Francis, Smith

& Bush, 2004, pg. 1139). Therefore, medication must be periodically reviewed in light of the demands on the parent so that issues such as four times a day administration regimens or starting a new school can be taken into account and an appropriate dosage arranged.

The administration of medications during the school day is complicated by the fact that in the province of British Columbia, there is no standard policy regarding medications. Even within the Lower Mainland area, there is no consistent approach or policy that is implemented in elementary schools. Each school board varies in its approach to dealing with the issue of medication distribution. North Vancouver, for example, has no specific policy on record. Yet, the Coquitlam School Board has a very detailed policy (Appendix F) in place that clearly outlines who is responsible for the organization, administration and training of staff regarding the administration of medications to students. This policy states that "medication will only be administered by school personnel to a student upon completion and receipt of a 'Request for Administration of Medication' form signed by the parent or legal guardian" (http://docushare.sd43.bc.ca/dsweb/Get/Document-270/medical+treatment+of+students.pdf).

The Vancouver School Board (VSB)/Vancouver Teachers' Federation (VTF) Collective Agreement (1999) also has a policy regarding the distribution of medications to students but it is much more vague in assigning responsibility. It states, in Article 7M:

> ...teachers will not be required to administer medication or supervise the self-administration of medication, except in emergency situations. If medication is required while the student is attending school, the special education assistant, an administrative officer, or any person designated by him/her shall administer or supervise the self-administration of medication (http://www.vsb.bc.ca/districtinfo/policies/j/jhcdadminmedstudents.htm).

Parents are then left with the responsibility to seek out for themselves a person within their school who will be willing to administer or supervise the administration of their child's medications. Overall, policy and support from school administration therefore appears idiosyncratic, according to the ethos of individual schools, the personal interest of individual teachers, medical consultants, and the level of knowledge of individual school health staff (Lightfoot, Mukherjee, & Sloper, 2001).

Parents must then take an active role in coordinating the distribution of their child's medications. As parents may not always be available to supervise medication use themselves, they often had to 'educate' others regarding the need for and the appropriate administration of the child's medications (Slatter, Francis, Smith & Bush, 2004). This finding is reinforced in a study by Raye (2003) who found that the attitudes of school personnel about the child's illness has a profound impact on the child's ability to achieve a smooth transition to school. To educate the staff, all of the parents in this study chose to provide the teachers and the school's administrative staff with the Canadian Cystic Fibrosis Foundation's pamphlet "A Teacher's Guide to Cystic Fibrosis." Parents felt it was important for their child's teachers to have an understanding of their child's illness and the implications it may have on the classroom environment as:

> ...a teacher who understands is crucial for appropriate support: that is, teachers who knew about their health condition, understand its impact on school life, can then make any special arrangements needed in the school (Lightfoot, Mukherjee, & Sloper, 2001, pg. 61).

Pupils with a chronic illness or physical disability currently straddle the policy boundary between education and health. In particular, cystic fibrosis is an illness that includes such a broad range of severity that the accommodations made for one child may not work for another. Individualized service plans are essential when working with these

families. Social workers must work with families to empower them to take an active role in fighting for their rights and access to services for themselves and their children (Anderson, 2001). By advocating for change, school boards could be persuaded to strengthen their policy guidelines in respect to students with chronic health conditions in two key ways. First, by making more explicit the accommodations required to respect the individual health-related support needs of pupils and their teachers. Secondly, administration could encourage and promote better communication between education and health care staff (Lightfoot, Mukherjee, & Sloper, 2001).

Sources of Support

In order to cope with the impact of cystic fibrosis on the child and the family's life, many families sought support in a variety of places, both formal and informal. This study supports the findings of Coyne (1997) who reported in her study that parents found the services offered by cystic fibrosis clinics and organizations such as the Canadian Cystic Fibrosis Foundation were helpful in assisting them in coping with their child's illness. All of the parents in this study felt that both the clinic and the foundation were strong sources of support and information. Social work services, although not often accessed, were also cited as being helpful. Parents found counseling services to "be of benefit to them for reasons such as helping them 'come to terms' with their problems, easing future uncertainty, and offering explanations, information, and practical advice and emotional support" (Case, 2000, pg, 280).

It is important for social workers to remain a part of the cystic fibrosis clinic team at the pediatric hospital. But, in addition to demonstrating empathy and providing emotional support, this study highlights the need for social workers to also provide

families with children with chronic heath conditions with concrete information and referrals to local community services. Social workers need to work in partnership with parents to develop interventions that keep in mind the specific goals required to meet each family's unique needs.

Along with support from professionals and family members, many families reported peer support, whether it be in the form of parent support groups, parent advocacy organizations, or 1:1 parent mentoring programs, as being one of the most important sources of social support and information they have (Sloper & Turner, 1993). Studies by both Diehl, Moffitt & Wade (1991) and Holaday (1984) reinforce this finding as they reported that families found support groups to be extremely helpful as they allowed parents to increase their understanding of their child's illness and provided families with opportunities to share information with others who have experienced similar life circumstances.

Social workers must recognize the value of parent support groups in the lives of parents of children with chronic illnesses and be supportive of their development. By being aware of the support groups that are currently available in their communities and referring families, social workers are able to provide families with an opportunity to interact with one another, provide support, and to share information which can assist families in coping with the changes they are experiencing in their lives.

Protection and Normalization

Parents of children who have chronic health conditions, especially those that are progressive in nature, have a tendency to want to protect their child. Yet at the same time, families recognize the importance of allowing their child to have a sense of

independence and to have the freedom to explore and discover the world around them. For children with cystic fibrosis, this is an especially difficult balance. Their children can be both healthy and vulnerable at the same time. The transition to school is a time of additional stress as the child is entering a larger environment that is beyond the parent's control. A study by Eiser, Zoritch, Hiller, Havermans, & Billing (1995) found that families experience more "difficulties when their children are well, but sick, at one and the same time" (p.646). It was determined that families whose children straddled the worlds of illness and wellness appear to have a more difficult time adjusting to new environments.

Studies by Dietrick, Knafl, and Murphy-Moore (1999) and Rehm and Franck (2000) highlight the importance of normalization as a coping technique for parents of children with chronic illnesses. This study reinforces the above findings as parents of children with chronic illnesses expressed a strong desire for their children to have a sense of normalcy in their lives despite their desire to protect them. This study also supports the findings of Knafl and Dietrick (1986) as parents in both studies deliberately engaged in the routinization of treatments and purposefully avoided embarrassing situations. Parents in both studies emphasized the child's involvement in typical activities as a way of creating a family life that was felt to be normal and satisfying.

It is important for professionals to respect families' needs to have the ability to create patterns and conditions in their lives that are as close to possible as the norms of mainstream families in our society (Brynelson, 1990). Parents work hard to ensure that the daily routines and treatments required to treat cystic fibrosis not be allowed to intrude too much on other aspects of daily life (Slatter, Francis, Smith & Bush, 2004). They

want their child to live a "normal life" but families living with the consequences of children's chronic illnesses must modify and individualize the meaning and role of normal activities and behaviours to fit the particular circumstances and ongoing uncertainties of their own lives (Rehm & Franck, 2000; Dietrick, Knafl, & Walsh, 1988; Robinson, 1993). Social workers must work with families to find a balance between protecting their child and allowing them to have the independence they require to live as normal a life as is possible with a chronic illness.

Disclosure

The most unexpected finding of this study was the trepidation parents expressed regarding disclosing aspects of their child's illness both to people outside the family and to the child themselves. This theme was unexpected in that it arose spontaneously through the data. This topic was not explored in the original literature review nor was there a research questions specifically designed to create discussion concerning this topic area.

The theme of disclosure was especially highlighted during the transition to school, as many parents were fearful that once the child entered school, someone would disclose to the child the progressive nature of their illness. Many parents reported that they did not know when or how to tell their child that cystic fibrosis was a life-limiting illness. Parents recognized that:

> disclosure to their child is the beginning of the end of normalcy. Their child will never be the same again, both to themselves and to the rest of the family and community. The child will never achieve what every other child is able to accomplish in adulthood (Buckingham & Meister, 2001).

A study by Goldman & Christie (1993) revealed that, in spite of staff advocating for open communication with children regarding their illness, a very small percentage of families actually had open discussions. Furthermore, these were families with already existing good communication styles. Much work continues to need to be done. We live in a society that is fearful of death. Social workers need to be encouraged to develop a level of comfort in discussing these issues with their clients as it is clear that open communication "between a counselor and a child about their disease and its diagnosis may serve as a context in which a child can discuss his or her fears about death" (Slavin, O'Malley, Koocher, & Foster, 1982, pg. 180).

Many studies have highlighted the importance of open communication between parents and their child regarding the illness trajectory. Dongen-Melman and Sanders-Woudstra (1986) discovered that, regardless of age, children who discussed their disease openly demonstrated better overall adjustment than children who did not have such open discussion. Slavin, O'Malley, Koocher, and Foster (1982) found, even for children under age 6, that the earlier they were told of their diagnosis, the better their treatment adjustment. Furthermore, Katz and Jay (1984) demonstrated that children who were protected from the true nature of their condition showed increased confusion, isolation, and mistrust of others. There is therefore a clear need for social workers to continue to counsel parents regarding the importance of open communication with their child about the progressive nature of their illness and to work with parents on both the content and the process of this communication.

Future Fears

Now that the families had successfully navigated their child's transition to school, families were already beginning to worry about future transitions in their children's lives. A study by Hymovich and Baker (1985) found that 64% of parents of children with cystic fibrosis experienced a moderate amount or great deal of concern about their child's future. Social workers need to offer parents "alternative strategies and therapies with which to accommodate a realistic future outcome for themselves and their children" (Case, 2000, pg. 284) and to provide support and information not just at the immediate time of transition but also in the years prior in order to assist them in preparing for these times of change in their lives.

Suggested Approaches to Practice

One of the key aspects of support services for parents centers on interpersonal aspects of the relationship between the families and the service providers. It matters "as much *how* professionals assist families in mobilizing resources as it does *which* supports are mobilized" (Dunst, Trivette, Deal, 1994, pg ii). It is important for social workers to enter into a relationship with the client rather than providing services from an expert model. Parents and staff suggested a number of benefits derived from these close relationships. Parents primarily emphasized the emotional support received while staff noted that as relationships were established, they found signs of easier joint problem solving, greater acceptance of program limitations, and parents' increased willingness to try new behaviours (Dunst, Trivette, Deal, 1994).

The above findings highlight the importance of providing services to families from a family-centred approach to practice and applying an empowerment framework.

Brynelson (1995) has outlined four key principles underlying family-centered care. Within this framework, it is recognized that children are dependent on their families and their environment to meet their developmental needs. Secondly, it is important to create interventions that respect the diversity of families and their needs and families should determine the level at which they wish to be involved in services. Also, families and professionals must collaborate to provide the best possible services to their children. And finally, it must be recognized that the principles of normalization must guide our practice (Brynelson, 1995).

Partnership is recognized as a key component of family-centered care. Social workers must recognize that families are not only to be involved in the decisions regarding the services in which their children participate but more importantly that parents should be "put at the heart or centre of services" (Brynelson, 1995, pg. 25). Davis (1993) states that the "partnership model implies that the professional is not assumed to be superior to the parents merely because of his or her professional knowledge" (Anderson, 2001, pg. 5-13). Another cornerstone of family-centered practice is the belief that "all families have strengths and that they are capable of acquiring more coping skills, given adequate support" (Anderson, 2001, pg. 1-23). Social workers applying this approach to their practice should not see themselves as the experts and take over control. Instead, the social worker should talk with the family to identify their strengths and to decide which actions are appropriate to meet their family's needs and desires.

In addition, this study indicates that services offered to families should apply an empowerment framework to their practice. The empowerment model complements the

strength-based approach to care, for it emphasizes a focus on client's strengths and abilities to obtain the skills they require to support their child's needs in their family. Families need to be given opportunities to become empowered in order to have influence over resources that are affecting them (Berns, 1997). All four families in this study attributed the success of their child's transition to school to their advocacy work in the schools, education of the staff, and on-going communication between the parents and the teachers. This is consistent with the second principle of the empowerment model, which emphasizes that all people have strengths and the ability to become more competent (Dunst & Trivette, 1994).

The final assumption within the empowerment model is that people need support not because they have deficiencies but because of "the failure of social systems to create opportunities for competences to be acquired or displaced" (Dunst and Trivette, 1994, pg. 162). This assumption is in keeping with the family-centered care's foundation in ecological systems theory. Ecological systems theory acknowledges that "neither a child's biological make-up nor their environment influences development independently, but that both occur jointly and actively" (Anderson, 2001, pg. 2-5). Professionals must work in partnership with families to assist them in finding the best fit between themselves and their environment. This may be achieved through advocating changes in the various systems in which the family is involved, creating change within the family unit itself, or more likely, a combination of the two. We must work with families to assist them in seeing themselves as 'agents' of change in their children and their environment (Anderson, 2001) and to help them work toward achieving the goals they set for their child and their family.

In conclusion, this discussion has highlighted the importance for social workers when working with children and their families:

- To recognize the profound lasting affect of receiving the diagnosis
- To assist with both the logistical and emotional aspects of the transition to school
- To continue to provide support through the cystic fibrosis clinic
- To support the creation of parent support groups
- To assist parents in achieving a balance between protection and independence
- To respect families use of normalization in their lives to cope with their child's illness
- To assist parents in finding ways to disclose to their child the progressive nature of their illness
- To discuss future fears with families throughout their involvement in social work services
- To apply a strength-based perspective and a family-centered approach to practice

Social workers must work in partnership with families and apply an empowerment model within a family-centered approach to practice. We must trust that clients have the strengths they need to sustain them through times of transition in their children's lives and must work with parents to identify and build on these inner strengths to assist them in achieving the best possible outcome for their child.

Summary

This study was designed to explore the ways in which parents of children with cystic fibrosis experienced their child's transition to school. In addition to gaining information about the child's transition to school, it was discovered during this study that it is necessary to apply an ecological systems approach to exploring this issue as there are

many factors within the family's experience that play a significant role during this time of transition in their lives. This study enabled the researcher to gain a deeper understanding of the families' experiences and to document their ability to arrange the accommodations their child required, the strengths they relied on, the supports they accessed, and their unique needs and concerns during this time.

Limitations

It is recognized that the small sample size does not allow for generalizations to be made about experiences. Also, it is noted that there are no guarantees that the views of the participants who chose to participate in this study are typical or representative of the diversity of experiences among families who are caring for children with cystic fibrosis. For this reason, rather than trying to generalize to the larger population, this study instead focuses on capturing the stories of a small selection of parents to provide insight and understanding into their experience with their child's transition to school.

Recommendations for Future Research

The findings and implications revealed of this study point to the areas where future research is required. This study provides insight into the changing needs of families with children with cystic fibrosis and assists professionals to better understand their current experiences.

This study relied on the information obtained from a small sample size and all interviews were conduced with families living in the Lower Mainland area of Vancouver, BC. It would therefore be interesting to replicate this study with a larger sample size with participants from areas within and outside the Lower Mainland of Vancouver, BC or

other parts of Canada. The experiences of those families living in rural areas vs. those living in urban areas would be of particular interest to explore.

Three mothers and one father participated in this research study. Therefore, the experiences of mothers were more heavily represented in this sample. A future study that explored the differences in parental experiences of their child's transition to school based on the parent's gender would be of benefit and would add to the current research available concerning families' experiences of their child's transition to school.

Many of the parents in this study expressed their fear and discomfort with informing their child of the progressive nature of their illness. A study that explored the ways in which parents of children with progressive illnesses dealt with this issue would be beneficial to health care teams working with families to assess the amount of support and information parents require when disclosing this information to their child, the parents' experience of providing this information, and ways in which the health care team could assist in easing the difficulty of this task.

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APPENDIX A – ETHICS APPROVAL CERTIFICATE

APPENDIX B – INTERVIEW GUIDES

Original Interview Questions

Interview questions will include:

- Tell me about your child..../their school...../ your community.....
- Tell me about your experience of being a parent of a child with cystic fibrosis during your child's transition to school....
- What did you feel your role was during this time (mother, advocate, etc)?
- Why was it important for you to ensure your child attended school in the community?
- What personal strengths did you rely on to help your child make the transition to school?
- What supports were you able to access in your community?
- What did you feel was missing in your community during this time?
- Did you feel you or your child fit the eligibility criteria for services you required?
- Who helped you the most?
- What or who created barriers?
- What would you like to see changed to allow assist future families in a similar situation?

Revised Interview Questions

Introduction:

- Tell me a bit about your child, their school, your community....
- How does CF affect your child's transition to school?
- How does it affect your daily lives?
- How does it affect your family?

Community Support:

- Did you feel you had adequate support and information during your child's transition to school?
- What social supports did you access at this time? Friends, Support Groups, Counselling, Guidance Counsellor, Social Worker, CF Foundation etc....
- How did you find out about them?
- What supports do you wish had of been available?
- What or Who helped? What or who hindered?
- Was it difficult to navigate the various systems you had to work with?
- What role did you feel you played during this transition? Mother, advocate, etc??
- What personal strengths did you rely on during this time?
- Did you attend or wish you could have attended a support group for parents of children with CF?

Transition to School:

- Thinking back to before your child started school, what were some of your concerns?
- What did you do to alleviate or cope with these concerns?
- Was your child's transition to school an easy transition? A difficult one?

- Was this a calm or stressful time in your life? If stressful, how did you deal with the stress?
- Was it important for your child to attend school in the community? If your child does not attend school in their community, what have you done to ensure their inclusion in their school community? Their community at home?
- What things did you feel needed to be in place to ensure your child's needs were met in the school?
- Who did you meet with to ensure those needs were met?
- Did any school policies affect your child's transition? I.e. distribution of medication, sending work home to children who are off sick, etc
- Were you satisfied with the health conditions within your child's school?
- Was the school supportive and understanding?
- What are your concerns now for your child in school?
- What if anything would you like to see changed for future families?

APPENDIX C – PARTICIPANT CONSENT FORM

Contact for concerns about the rights of research subjects:
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

Consent:
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

_____

Participant Signature Date

_____

Printed Name of the Participant signing above.

APPENDIX D – "A Teacher's Guide to Cystic Fibrosis" Pamphlet

A Teacher's Guide to Cystic Fibrosis

When reading this brochure, please bear in mind that cystic fibrosis (CF) affects each individual in different ways with varying degrees of severity, and a person's health can change considerably from month to month - or even day to day. There is no typical individual with CF.

Students with cystic fibrosis

As a teacher, having a child with CF in your class means that you are teaching a child who has a chronic disorder. Though it can cause severe respiratory and digestive problems, CF has no effect on intelligence and is not contagious. Because CF affects each person differently, the physical health and emotional attitude of a student with CF must be assessed on an individual basis. Your student with CF may be a kindergarten pupil or a high school senior. Whatever the age or condition, he or she is an individual, not a disease.

What is cystic fibrosis?

Cystic fibrosis is an inherited disorder, affecting mainly the lungs and digestive system.

In the lungs, where the effects of the disease are most devastating, CF causes increasingly severe respiratory problems. In the digestive tract, CF often results in extreme difficulty in digesting and absorbing adequate nutrients from food.

Most persons with CF eventually die of lung disease.

It is estimated that one in every 2,500 children born in Canada has CF. At present, approximately 3,300 Canadian children, adolescents, and adults with cystic fibrosis attend specialized CF clinics.

What causes cystic fibrosis?

Cystic fibrosis is a genetic disease. About one in 25 Canadians carries a defective version of the gene responsible for CF. Carriers do not have cystic fibrosis nor do they exhibit any of the symptoms of the disease. Cystic fibrosis occurs when a child inherits two defective versions of the gene responsible for CF, one from each parent.

Each time two parents who are carriers have a child, there is a 25% chance that the child will be born with cystic fibrosis; a 50% chance the child will be a carrier; and a 25% chance that the child will neither be a carrier nor have CF.

Children with CF are often physically active and interested in many sports and various other activities. Most have excellent school attendance records. Outwardly, they may not appear to be sick or to be different, and may look very healthy; however, children with CF have a condition in which many of their glands do not function normally, which in turn affects breathing, digestion, and sweat production.

Breathing

The mucus produced in the lungs of people who don't have CF is normally thin, slippery and clear. In individuals with cystic fibrosis, this mucus is thick and sticky. It clogs the airways and, if not cleared away, can lead to recurrent lung infections and lung damage.

Each day individuals with CF follow a treatment routine to control the accumulation of this thick and sticky mucus. Because CF affects each individual differently, the therapy prescribed for one child by a physician may not be appropriate for another child with CF.

The treatments that help to clear abnormal mucus include inhalation of medications followed by chest physiotherapy. Chest physiotherapy is usually done by the parent or caregiver and it involves clapping and vibrating the child's chest wall to dislodge small mucous plugs in the airways. As the child gets older alternate airway clearance techniques may be prescribed to increase and promote independence.

Chest therapy is usually performed two or three times a day - typically once before school, once upon arriving home, and once before bedtime. Some children with CF may benefit from having chest therapy done during the school day. This can be arranged through the local CF clinic, home care, and the school. Receiving this treatment at school may help the child breathe more easily.

To defend the lungs against the harmful mucus accumulation, or when they have a cold, a student with CF may cough frequently - and should not be discouraged from doing so. Cystic fibrosis is not contagious. Classmates cannot develop this condition from being with a child who has CF.

Children with CF may grow accustomed to coughing, and may not even be aware of it. It is important to remember that any attempt to suppress the coughing could be a health risk. Paying undue attention to an affected student can be very embarrassing. By accepting the coughing, the members of the class will likely follow your example.

Help students with CF feel more comfortable by making it easy for them to slip out of the classroom for a 'drink of water'. It may also be helpful to let the child have a water bottle at his/her desk. Many children have been taught to clear their mucus into a tissue after they cough. Therefore, encourage your student with CF to keep a box of tissues and a means of disposal nearby.

Physical activity also helps your student to clear mucus from the lungs. Include the child with CF in all games and activities in which he/she is able to participate. Exercise is not only healthy but it also gives children the psychological boost needed to make them feel like part of the group. It is, however, important to remember that CF may limit the extent to which your student can participate, and a child's tolerance level can vary from time to time, even from one day to the next.

Digestion

The gastrointestinal problems associated with cystic fibrosis result in malabsorption of fats, proteins, and carbohydrates. Individuals with CF usually require special pancreatic enzyme supplements to aid digestion, a special diet with increased calories and protein, and vitamin supplements. When teaching your class about proper nutrition, be sensitive to the child with CF who has a diet that may appear unhealthy by most nutritional standards.

Your student with CF may need to take capsules containing pancreatic enzymes with meals and snacks. These enzymes help the body absorb nutrients from food, and reduce both the number and bulk of stools, the amount of flatulence, abdominal pain, and distension. These medications are not habit-forming nor will they alter a student's attitude or emotional behaviour. Students may still need to make a quick exit to the washroom, as flatulence can be odorous and embarrassing. It is important to allow them to feel comfortable about leaving the classroom whenever the need arises.

It is very important not to treat children with CF differently. Most of these children have been taking enzymes since infancy, and can take them on their own. These enzymes are naturally produced by our body, and would not cause any harm if accidentally ingested by another child.

Children with CF should be allowed to be responsible for keeping enzymes with them to avoid having them leave the classroom when it is time to eat. There is no need to lock these medications in a desk or store them in an office. The enzymes must be taken immediately before they eat, as their action is time limited. In most cases, a student can carry a day's supply of enzymes in a lunch box, and take them with lunch and snacks. Parents are responsible for the number of pills and for a proper storage container. The CF clinic can provide a letter for the school if necessary.

Occasionally, in trying to avoid taking pills in front of their classmates, some children with CF may 'forget', hide, or throw away their enzymes. A student with CF who neglects to take enzymes will experience abdominal pain, and need to go to the bathroom more often than usual. If this scenario becomes a problem the teacher and the parents may need to meet and arrange supervision for the child at lunchtime.

As with coughing, the less attention paid to the child's diet and pill-taking, the more comfortable the child will feel. The enzymes that children with CF take are a naturally occurring product derived from an animal source. They are not a prescription product.

Finally, as it is often recommended that a child with CF take in more calories, it may be necessary to allow a child with CF some extra time to eat.

Sweat

The sweat glands are also affected, and individuals with CF may sweat more and will have very salty sweat. Consequently, children who are affected can lose a great deal of body salt through perspiration, and salt crystals may actually form on their skin. In very warm weather and with prolonged exertion, this can be

a problem. Drinking plenty of fluids is important, and it is often recommended that they drink sports drinks or have a salty snack handy.

Individuals with CF also need to add salt to their diet to replace the excessive amounts they lose through sweat.

Psychological Health

A student with CF has the same emotional needs as others in your class. Cystic fibrosis tends to make a child feel different, even though the disorder can be categorized as 'invisible' for the most part; sometimes, a student with CF may be somewhat smaller than his/her classmates. Group acceptance is paramount.

It may be helpful to have a classroom discussion about CF (if the student agrees). Peer teaching has been shown to be particularly successful. Thus involving the parents and the affected child may be beneficial. It may also be possible for a member of the medical team to give a talk with the help of the parents and child.

A child with CF may find it hard to participate in group situations. For example, shortness of breath may limit physical activity in the playground or schoolyard. A teacher can help strengthen a child's self-image by encouraging the student to excel at what he/she can do best, and by stimulating valuable relationships with other children by helping him/her gain acceptance in the classroom.

Finally, regular CF clinic visits, and possible periods of hospitalization, are facts of life for individuals with CF. During hospitalization, it is important that a child with CF keep pace with regular schoolwork. You may be asked to provide lesson plans and materials by the hospital schoolteacher. For the most part, hospital visits are pre-planned, giving you time to pull materials together.

Encouraging notes and messages from classmates can often lift the student's spirits.

Summary

- Cystic fibrosis does not affect mental ability.
- CF is inherited, and is therefore not contagious.
- CF is a disorder of the lungs and the digestive system.
- A student with CF may need special medications. These are not habit forming and do not alter attitude or behaviour.
- Individuals with CF may cough frequently. It can be harmful to try to restrain this cough either physically or through the use of cough suppressants.
- Students with CF may need to slip in and out of the classroom, to attend to their health needs. It is important for a teacher to recognize and support this need.
- Individuals with CF may have special psychological needs. Help your student and classmates adjust to the situation.
- There are striking variations in the severity of CF and each person should be treated as an individual. Discuss your student's medical condition with parents /caregivers.
- CF is a great masquerader and often is misdiagnosed as pneumonia, chronic bronchitis, asthma, celiac disease or malnutrition. If you are concerned about a student's health, you may inform the parents/ caregivers of the symptoms you have observed (such as constant cough, unusual appetite, frequent bowel movements), and suggest that they seek medical advice.
- Not too many years ago, many children with CF did not live long enough to reach school age. Today, children with cystic fibrosis are growing into adults, and planning for post secondary education, careers and families. By making the most of their school years, teachers can help them achieve these long-term goals.

What is the Canadian Cystic Fibrosis Foundation?

The Canadian Cystic Fibrosis Foundation (CCFF) is a national, voluntary health charity incorporated in 1960. Its mandate is to help those with cystic fibrosis by funding research into improved care and treatment with the goal of finding a cure or effective control for CF, promoting public awareness of the disease and raising and allocating funds for these purposes.

For further information on cystic fibrosis, contact a local CCFF chapter, or the Canadian Cystic Fibrosis Foundation at

Canadian Cystic Fibrosis Foundation

2221 Yonge Street, Suite 601
Toronto, Ontario M4S 2B4

Telephone: (416) 485-9149
1 800 378-2233
Fax: (416) 485-0960
E-mail: info@cysticfibrosis.ca
Web site: www.cysticfibrosis.ca

In Quebec, you may also contact:

Quebec Cystic Fibrosis Association*

425 Viger Street West, Suite 510
Montreal, Quebec H2Z 1X2

Telephone: (514) 877-6161
1 800 363-7711
Fax: (514) 877-6110
E-mail: info@aqfk.qc.ca
Web site: www.aqfk.qc.ca

* an association of the Canadian Cystic Fibrosis Foundation

Cette publication est aussi disponible en français.

APPENDIX E – COQUITLAM SCHOOL BOARD MEDICATION POLICY

MEDICAL TREATMENT OF STUDENTS

Procedures

Supervision and care shall be provided for students who have a medical problem that requires, or might require, regular or emergency treatment. When such a student is enrolled within a school in the district, the level of supervision and appropriate treatment is to be specified on the child's Medical Alert Forms.

A member or members of the school staff (secretary, teacher, teaching assistant, administrative officer), when necessary, will undertake such training as will ensure adequate supervision and treatment.

Medical Alert Forms – Instructions

The test of the following should be communicated to parents or legal guardians prior to or at the beginning of each school year in a special memorandum, or in the first regular newsletter.

RE: COMPLETION OF MEDICAL ALERT FORMS

We are required to maintain a safe and efficient procedure for all students who attend school. If your child has a medical condition that requires precautionary treatment or medication at school, and you have not filled out the required "Medical Alert Form" and/or the "Request For Administration of Medication at School Form", please contact your school and complete the required forms. Please have the form completed, sign it yourself, and return it to the school as soon as possible. This procedure complies with School Board Procedures. If there are any questions, please contact the principal.

When a student moves from elementary to middle/secondary school, the elementary school should send a list of the students who have Medical Alert Forms to the middle/secondary school.

Procedures for Medical Alert Forms

The principal should make certain that procedures are in place to ensure that:

a. The parent/guardian is informed of his/her responsibility to complete, sign and/or update Medical Alert Form each September and as the need arises.

b. All forms returned by parents or legal guardians are kept in an easily accessible location.

c. Teacher-on-Call and substitute support staff are informed of the medical problems of students in their classes.

d. The transportation company or any personnel transporting students should be provided with a copy of the Medical Alert Form.

Procedures for Administration of Medication

Administration of Medication

a. Medication will be administered by school personnel to a student in regular attendance at school only upon completion and receipt of a "Request for Administration of Medication" form signed by the parent or legal guardian.

The principal should make certain that procedures are in place to ensure that:

i) The completed form is received by the school prior to administration of medication.

ii) The parent/guardian is informed of his/her responsibility to update medical information each September and as the need arises.

iii) All forms returned by parents or legal guardians are kept in the student's file and a copy with the medication.

iv) Teachers-on-Call and substitute support staff are informed of the medical problems of students in their classes.

b. If the principal learns from information provided on the standard Student Registration Form, Medical Alert Card, or from any other source, that a student is, or may be, required to have medication administered while attending school, the principal should immediately contact the student's parents or legal guardians and request that they complete a "Request for Administration of Medication at School" form.

c. If the school is required to store medication, then the parent or legal guardian shall be informed that it is the parent's responsibility to have the medication delivered to the school in a properly labeled prescription container.

d. If required, it is the responsibility of the District to arrange for appropriate training of the school personnel. In all such cases, more than one staff member shall be trained in the administration of the medication in order to provide an alternative person in cases of absence or unavailability.

e. A record sheet for the administration of medication for each student shall be maintained in the location where medication is stored, such sheet to show date, time and dose of each medication administration, any other pertinent information, and the initials of the administering person.

f. Where a student may require medication in an emergency situation, for example, an injection of adrenalin for an allergic reaction, the principal shall make all teachers who normally supervise the student aware of this fact and the steps to be taken should such an emergency occur.

g. Role of Public Health Nurse

The Public Health Nurse will assist in the establishment of routines for the implementation of the Medical Alert Forms and Administration of Medication Forms. When requested, the Public Health Nurse will review the information contained on the forms. The administration of medication and medical alert procedures are not conditional upon this review.

If there are any concerns regarding the information obtained, please consult the Public Health Nurse.

SCHOOL DISTRICT #43 (COQUITLAM)

MEDICAL ALERT FORM

*** Parents must complete Section I and II and sign on reverse.
If necessary the school will complete Section III. ***

I. Student Name: _____ Date of Birth: _____

Parent/Legal Guardian: _____

Contact Telephone #'s: (Home): _____

(Mother's or Guardian's Work): _____

(Father's or Guardian's Work): _____

Other: (Name and Phone Number): _____

Name of Physician: _____ Telephone Number: _____

Indicate what medical condition this student has that may require emergency care at school:

_____

_____

_____

_____

_____

Describe the potential problem (include symptoms that might be observed):

_____

_____

_____

_____

_____

THIS FORM MUST BE REVIEWED AT THE START OF EACH SCHOOL YEAR

..Continued on reverse side

II. Describe the necessary action or intervention to appropriately treat this medical condition:

Step 1: _____

_____

Step 2: _____

_____

Step 3: _____

_____

Step 4: _____

_____

Step 5: _____

_____

Is medication needed? (Circle One) YES NO

If yes, what medication?: _____

Parents or legal guardian must complete a REQUEST FOR ADMINISTRATION OF MEDICATION FORM which is also available from your school principal. Parents/Guardians need to assure that this medication does not go past its expiry date. It is the obligation of the parents/guardians to keep a current supply of any required medication at the school.

_____ _____

Signature of Parent/Legal Guardian Date

III. If training is required to administer the medication, please identify who has given the training and when it was completed. Please be aware that parents/guardians are most often the trainer. However, if assistance from the Public Health Nurse is required, please contact your school nurse:

* Training on: _____

* Name of Trainer: _____ Date of Training: _____

* People Trained:

Print Name	Signature	Date

THIS FORM MUST BE REVIEWED AT THE START OF EACH SCHOOL YEAR

SCHOOL DISTRICT #43 (COQUITLAM)

REQUEST FOR ADMINISTRATION OF MEDICATION

NOTE: No medication will be given until this form is completed and returned to the school. It is to be completed by the parent or legal guardian.

Student's Name: _____ School: _____

Birthdate: _____ Address: _____

_____

Parent/Legal Guardian: _____

Phone (Home): _____ (Work:): _____

Other people to contact in emergency:

1) _____ Phone: _____

2) _____ Phone: _____

Family Physician: _____ Phone: _____

Prescribing Physician: _____ Phone: _____

Medical Condition: _____

Medication Required: _____

Please complete information on next page

I request that staff give medication as prescribed on this form to my child:

- If non-prescription medications are to be given, a note from the doctor will be provided.
- I agree to supply the medication to the school in the original container with the child's name, prescribing physician's and pharmacist's direction for use including dosage.
- Consequences of missing medication dose or increased dosage given (as identified by prescribing physician), side effects (as identified by parent/guardian and student) is included.
- If changes occur I will contact the school and provide revised instructions. I am aware I am required to update this information each September.
- I am aware that the Public Health Nurse for the school will be informed of my child's condition and medication and that the nurse may contact me as necessary.
- I am aware that staff and other personnel working with my child will need to know of my child's condition and of the medication required.

_____ _____

Signature of Parent/Legal Guardian Date

Name of Medication:

1. _____

2. _____

3. _____

Dosage:

1. _____

2. _____

3. _____

Directions For Use and Storage:

1. _____

2. _____

3. _____

Side Effects:

1. _____

2. _____

3. _____

Result if Missed or Wrong Dose:

1. _____

2. _____

3. _____