Sibling Experiences in Families of an Individual with a Chronic Health Condition: Down Syndrome and Cystic Fibrosis

by

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Abstract

This document is a manuscript-based thesis, exploring the lived experiences of individuals who have a sibling with a chronic health condition, specifically Down syndrome or cystic fibrosis. The first paper focuses on the experiences of having a sibling with Down syndrome, and the second on having a sibling with cystic fibrosis. Both studies used a basic interpretive approach, and were guided by the Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988; Patterson & Garwick, 1994) to explore the difficulties faced by these siblings and the supports and coping behaviours they employed. The data were collected through interviews and analyzed using Interpretative Phenomenological Analysis (IPA; Eatough & Smith, 2017; Smith, Flowers & Larkin, 2009). Results suggested that siblings of those with Down syndrome or cystic fibrosis generally view their experiences positively, though they related various difficulties including taking on various roles, having worries, and the need for more supports for siblings. The results of this study will aid in better understanding the sibling relationship when a brother or sister has a chronic health condition, and will inform appropriate supports for siblings and their families.

Keywords: Siblings, chronic health conditions, Down syndrome, cystic fibrosis, stressors, positive experiences, coping, qualitative, FAAR

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Chapter One: Introduction

Families who have a child with a chronic health condition may have different experiences, including struggles and rewarding situations, than families who have typically developing children. Research often focuses on the impacts of raising a child with a health condition on the parents or family as a whole, and until the 1980s, often overlooked the experiences of siblings (Stoneman, 2005). The child with a health condition affects all individuals within the family as it is a unique shared experience that has positive implications, such as enhancing family cohesion and inner strength, but can have negative effects such as physical and emotional demands as well as substantial financial expenses (Reichman, Corman, & Noonan, 2008). Brothers and sisters emotionally influence each other during childhood (Wennström, Isberg, Wirtberg, & Rydén, 2011), and these influences often continue throughout their lives. Therefore it is crucial to explore the siblings' experiences to further understand the family as a whole.

This study is part of a larger project that examines the experiences of siblings when they have a brother or sister with a chronic health condition or disability. These conditions include Fetal Alcohol Spectrum Disorder, Autism Spectrum Disorder, Down syndrome, and cystic fibrosis, with cystic fibrosis being the newest addition to the research. Similar to the current study, the larger project uses the The Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988) to explore the demands and capabilities employed by the siblings of those with a health condition. The goal of this study was to better understand the experience of having a sibling with a chronic health condition, particularly Down syndrome or cystic fibrosis. A number of factors were explored, such as the stresses, responsibilities, worries, and other

negative features, as well as the coping behaviours, interactions, and various positive experiences. Through this research, the sibling relationship will be better understood, which will provide information on the type of supports and resources that will be beneficial for siblings who have a brother or sister with a chronic health condition.

1.1 Down Syndrome

Down syndrome, or trisomy 21, is a genetic condition most commonly caused when an individual has 3 copies of chromosome 21 rather than 2 (Selikowitz, 2008). Down syndrome is the most common human trisomy seen in live births, occurring in one out of every 700 to 1000 births (Mitchell & Ziegler, 2013; Selikowitz, 2008); however, the incidence at conception is more than twice this rate (Kliegman, Stanton, St. Geme, Schor, & Behrman, 2015). Down syndrome is associated with a number of both mental and physical abnormalities and deficits. It is the most common genetic cause of intellectual disabilities, and all individuals diagnosed with Down syndrome experience developmental delays and may have difficulty with language or verbal communication (Kliegman et al., 2015). As people with Down syndrome age, there is an estimated psychiatric comorbidity of 18-38%, most commonly depression, and they are at much higher risk of developing neurological disorders such as Alzheimer's disease (Kliegman et al., 2015; Mitchell & Ziegler, 2013). However, it is unusual for people with Down syndrome to have behavioural problems, such as defying rules. It is also common that they experience physical disabilities, such as heart defects, thyroid abnormalities, lung defects, and stunted growth, and individuals with Down syndrome are often recognized by their small head, round face, large tongue, and small chin (Mitchell & Ziegler, 2013). The majority of males with Down syndrome are sterile, but some females are able to reproduce and have a 50% chance of having a child with

Down syndrome (Kliegman et al., 2015). Furthermore, the life expectancy for someone with Down syndrome is between 50-55 years (Kliegman et al., 2015), which is nearly 30 years shorter than the typical life expectancy in Canada (Statistics Canada, 2017).

Individuals with Down syndrome may take part in a number of skill-developing programs. For instance, as the individual prepares to enter adulthood, they may be involved in peer groups, recreational activities, gain full employment, and obtain other skills to potentially move out of the family home (McGuire & Chicoine, 2006). When compared to families of typically developing children, families with a child born with Down syndrome can experience more stressors, but families of children with Down syndrome experience less stress when compared to families of children with other disabilities or chornic health conditions, in part due to the lack of maladaptive behaviours and typical positive personalities of individuals with Down syndrome (Fidler, Hodapp, & Dykens, 2000; Hodapp, Ricci, Ly, & Fidler, 2003; Stoneman, 2007). It is important to note that the literature often refers to Down syndrome as a "disability." As such, Down syndrome may be referred to as a "disability" at times throughout this document to mirror the available literature.

1.2 Cystic Fibrosis

Cystic fibrosis is a fatal genetic condition that causes a build-up of mucus in the lungs (Cystic Fibrosis Canada, 2014). Prenatal and genetic testing is possible (Dupuis, Hamilton, Cole, & Corey, 2005) and is usually requested by parents who have another child with cystic fibrosis (Lane et al., 1997). Many individuals are diagnosed after birth, and nearly half of Canadians and Americans diagnosed with cystic fibrosis are under the age of six months (Cystic Fibrosis Canada, 2015; Ratjen & Döring, 2003). Diagnosis can be the result of a genetic or a "sweat test"

to analyze the salt content of one's sweat, as individuals with cystic fibrosis generally secrete more salt (Cystic Fibrosis Canada, 2014). Although cystic fibrosis is often perceived to only affect the lungs, it can affect a number of organs, such as sinuses, pancreas, liver, and reproductive system (Ratjen & Döring, 2003). The excessive mucus, along with the build-up of protein in the digestive tract, makes it extremely difficult to digest and absorb nutrients from food (Cystic Fibrosis Canada, 2014). It is common that individuals with cystic fibrosis experience persistent cough due to thick mucus in the lungs, as well as shortness of breath, frequent chest infections, excessive appetite, weight loss, and bowel abnormalities (Cystic Fibrosis Canada, 2014). Furthermore, 98% of men with cystic fibrosis cannot reproduce, and although the female reproductive system is normal, fertility may be impaired by cervical mucus (Ratjen & Döring, 2003).

Prevalence rates of cystic fibrosis have fluctuated over the years. In the 1970s and 1980s, it was believed that 1 in 2,714 individuals born in Canada had cystic fibrosis (Dupuis et al., 2005). It is currently estimated that 1 in 3,600 people born in Canada have cystic fibrosis (Cystic Fibrosis Canada, 2014). Cystic fibrosis is caused by mutations of the cystic fibrosis transmembrane regulator (CFTR) gene (Dupuis et al., 2005; Ratjen & Döring, 2003). There are more than 1900 variants of the CFTR gene, but between 71% and 87.5% of Canadians with cystic fibrosis have a mutation with the DF508 allele, the most common mutation in people with cystic fibrosis (Cystic Fibrosis Canada, 2014; Dupuis et al., 2005). The condition occurs when a child inherits an abnormal gene from each of their parents, and it is believed that approximately 1 in 25 Canadians carry a cystic fibrosis gene (Cystic Fibrosis Canada, 2014).

There is no cure for cystic fibrosis, but many treatments are available to ease the severity of symptoms and can extend the patient's life expectancy. However, treatment methods are often strenuous and time-consuming. People with cystic fibrosis participate in daily routines of both physical and inhalation therapy in an attempt to clear their lungs of congestion. Additionally, they consume an average of 20 pills a day, many being pancreatic enzymes to help absorb the nutrients from food (Cystic Fibrosis Canada, 2014). If the condition has progressed to end-stage lung disease, a lung transplant is a last-resort treatment option (Ratjen & Döring, 2003). In 2013, half of the patients with cystic fibrosis that died in Canada were under the age of 35 (Cystic Fibrosis Canada, 2015)**,** and survival in women is consistently worse than men (Smyth, 2005).

When a child in one's family is diagnosed with cystic fibrosis, it can result in additional stress and strains on each member of the family, particularly when providing the child with their required treatments (Eiser, Zoritch, Hiller, Havermans, & Billig, 1995). As the mandatory treatment methods and therapies involve daily routines that require a significant amount of time, it often involves all members of the family, including parents, grandparents, and siblings (Foster et al., 2001; William, Mukhopadhyay, Dowell & Coyle, 2007).

1.3 Family Adjustment and Adaptation Response (FAAR) Model

The Family Adjustment and Adaptation Response (FAAR) Model, as shown in Figure 1, was developed by Patterson and is based on the idea that the family attempts to maintain balanced functioning by using resources and coping behaviours to counteract their stressors and strains (Patterson, 1988; Patterson & Garwick, 1994, 1998). In the 1970s, social scientists began to ask questions such as why do some people stay healthy when they face risk or adversity while others do not. This ability to stay healthy during times of adversity is now referred to as

"resilience", which focuses on health and functioning, and the FAAR model is based on a family's ability to be resilient when faced with stress (Patterson, 2002a). The two phases of the model, adjustment and adaptation, are separated by family crisis, which is a period of significant disruptiveness for all members of the family, including parents, siblings, grandparents, and extended members. Crises occur when the number of demands or stressors, such as events of changes, unresolved tensions, or disturbances in daily life, outweighs the capabilities or resources that the family employs (Patterson, 2002b). During the adjustment phase, the family tries to deal with new demands, which may include avoiding the demand and hoping that it will go away, eliminating or taking an active effort in getting rid of the demand, or assimilating and accepting the demand into the family's structure (Patterson, 1988). Then, during the adaptation phase, the family attempts to restore balance by acquiring new coping behaviours, changing the way they view or approach the situation, and by reducing the stressors they deal with (Patterson, 1988). If unable to restore balance, the family becomes vulnerable to repeated crises (Patterson, 2002a). The FAAR model can also be applied to sibling research, as was done in the current study. According to Patterson (1988), the FAAR model focuses on 3 systems, including the individual, the family, and the community. While exploring their experiences, the siblings discussed how their brother or sister's condition affected their meanings and worldview, but also how it their demands and capabilities affected their family, and their ability to connect to others within their community.

Figure 1: The Family Adjustment and Adaptation Response Model (FAAR; Patterson & Garwick, 1994). Reprinted with permission.

There are a number of stressors that are associated with being a sibling to someone with a chronic health condition. Demands in families that have a child with a health issue that may impact the sibling include treatment related stressors, the child's physical impairments, financial limitations, their learning difficulties or troubles in school, challenging behaviour, and hospitalizations, among others. Capabilities may include social support of family and friends, resources from healthcare professionals, support groups, financial assistance, health organizations, and so on. Therefore, the FAAR model is the theoretical framework used for this current study, as it guided the development of interview questions and analysis. As such, the stressors, demands, resources, and coping behaviours will be explored. Literature focusing on the

family as a whole, including parents' experiences, in relation to Down syndrome and cystic fibrosis will be discussed first, followed by studies focused on siblings.

1.4 Family Research

1.4.1 Down Syndrome Family Research. Parenting stress is a common topic of research when raising a person with Down syndrome, and there is often focus on what is referred to as the "Down syndrome advantage" (Fidler, Hodapp & Dykens, 2000; Hodapp et al., 2003; Stoneman, 2007). The Down syndrome advantage suggests that when compared to parents of children with other disabilities, parents of children with Down syndrome generally have less stress, less psychological problems such as depression or anxiety, and are better able to cope (Fidler et al., 2000; Hodapp et al., 2003; Stoneman, 2007), which is attributable to the personality and behavioural patterns typical in individuals with Down syndrome (Esbensen & Seltzer, 2011).

Stoneman (2007) examined the Down syndrome advantage in married couples who had children with Down syndrome compared to parents of children with other intellectual disabilities, such as fragile X, autism, Prader-Willi, and children with intellectual disabilities of unknown etiology. As expected with the Down syndrome advantage, parents of children with Down syndrome reported lower levels of depression, and the observation of parents interacting with the child revealed higher levels of warm parenting compared to the other groups. Additionally, families of children with Down syndrome had higher family incomes, the parents had more education, and they rated their child with easier temperaments than families of children with intellectual disabilities of unknown etiology. However, after the variance attributable to financial income was removed, the Down syndrome advantage disappeared from parent wellness measures (Stoneman, 2007), which counter the findings of Esbensen and Seltzer (2011). The

discrepancy suggests that the causes of the Down syndrome advantage may be more than just the child's behaviour and there may be more contributing factors.

Nevertheless, in many studies, the Down syndrome advantage is observed. For instance, Fidler and colleagues (2000) examined stress in families of young children with Down syndrome, Williams syndrome, and Smith-Magenis syndrome, using families of 20 children from each group. The results supported the Down syndrome advantage, as families of children with Down syndrome showed lower levels of "parents and family problems" and "pessimism" on the Questionnaire on Resources and Stress-Friedrich edition (QRS-F), compared to families of the other two groups. As expected by the authors, when compared to children with Williams syndrome and Smith-Magenis syndrome, children with Down syndrome had significantly lower rates of misbehaviour, and overall had lower scores on the Child Behaviour Checklist (CBCL) with an average score of 30.70 compared to children with Williams syndrome who had an average score of 51.25, and Smith-Magenis syndrome with an average score of 62.20. The results show that overall, stress in families of children with Down syndrome is significantly less when compared to families of children with Williams and Smith-Magenis syndromes (Fidler et al., 2000).

Similarly, in a study that explored the stress experienced by mothers of children with Down syndrome and mothers of children with other learning difficulties such as Prader-Willi syndrome, Williams syndrome, cerebral palsy, and autism, the mothers of children with Down syndrome reported significantly lower levels of parental stress. 29.6% of mothers of children with Down syndrome reported clinically elevated levels on the QRS-F, whereas 73.3% of mothers from the other groups had clinically elevated levels of parental stress (Hodapp et al.,

2003). However, there was no difference in scores concerning child-related stress in the Down syndrome group compared to the other groups. It was also found that the child's maladaptive behaviour strongly related to the overall child-related and overall parental stress; therefore, as the child shows more negative behaviours, the parent experiences more stress (Hodapp et al., 2003).

The Down syndrome advantage is also apparent as the child becomes an adolescent or young adult. Abbeduto and colleagues (2004) examined the psychological well-being and coping of 174 mothers who care for adolescents or young adults with autism, Down syndrome, or fragile X syndrome and found that when compared to the other two groups, mothers of those with Down syndrome were less pessimistic about their child's future. The Down syndrome group also reported more closeness in the relationship and less depressive symptoms when compared with the autism group, but the fragile X syndrome group did not differ from the Down syndrome group in reports of depression and closeness (Abbeduto et al., 2004).

Despite being shown to be less stressful when parenting a child with other disorders, cross-culturally, stress levels of parents to someone with Down syndrome are consistently high. This cross-cultural stress is shown by Norizan and Shamsuddin (2010), who examined parenting stress levels of 147 mothers of children with Down syndrome in Malaysia. They found that the mean score on the Parental Stress Scale was 37.5 and eleven mothers (7.5%) showed levels of very high stress by scoring 52 or above. It was also suggested that negative child behaviour was significantly associated with parenting stress, which was similar to the findings of Hodapp and colleagues (2003). However, the results demonstrated that mothers used a variety of coping behaviours, most frequently using religion, acceptance, and optimism as coping methods, but social support was less frequently used (Norizan & Shamsuddin, 2010).

In an attempt to understand parent senses of competence when raising a child with Down syndrome over time, Gilmore and Cuskelly (2012) examined 25 parents of children with Down syndrome when the child began school, and revisited the same participants 8 years later when the child entered puberty to see if there were any changes. There was a significant increase in parenting satisfaction over the 8 years, and parenting style remained relatively the same over time. However, there was a significant increase in "Respect for Autonomy" as the child reached puberty, meaning that as the child with Down syndrome got older, the parent was more likely to let the child make their own decisions. Overall, findings suggest that the challenges of being a parent to a child with Down syndrome do not significantly impact parenting satisfaction and feelings of self-efficacy during the childhood and adolescent stages of the child's life (Gilmore & Cuskelly, 2012).

Research on families of children with Down syndrome generally supports the "Down syndrome advantage." Parents of children with Down syndrome experience more stress compared to parents of typically developing children; however, the literature suggests that parents of children with Down syndrome show lower levels of stress, lower rates of depressive symptoms, and a stronger parent-child relationship when compared to parents of children with other disabilities, such as William's syndrome, Smith-Magenis syndrome, Prader-Willi syndrome, fragile X syndrome, and autism (Abbeduto et al., 2004; Hodapp et al., 2003).

1.4.2 Cystic Fibrosis Family Research. A number of studies have focused on the stress that the parent experiences when raising a child with cystic fibrosis. Parents, and mothers in particular, will often neglect their own needs when they have a child with cystic fibrosis to care for (Patterson, McCubbin, & Warwick, 1990), and are faced with worries that parents of children

with other conditions (i.e., diabetes or intellectual disabilities) do not have, such as the fatal consequences of the condition (Walker, Van Slyke, & Newbrough, 1992). It was suggested by Patterson and colleagues (1990) that parents need to be encouraged and supported to promote coherence, which will contribute to the health of the child with cystic fibrosis. Cowen and colleagues (1985) found that compared to parents of children without a health condition, parents of a child with cystic fibrosis may feel more pressure to "do the right thing" by taking proper care of their child, have extra demands, and feel as if they constantly need to watch their child. Additionally, compared to parents of typically developing children, it is suggested that parents of children with cystic fibrosis minimize the impact of parenting responsibilities, especially when their child is preschool age, because they face illness-related stressors on a daily basis (Cowen et al., 1985). It is sometimes speculated that mothers neglect their other children because their focus is on the child with cystic fibrosis. However, in a study comparing mothers of a child with cystic fibrosis to mothers of children without chronic health conditions, it was found that they spent less time alone and spent 9% of their time in a medical setting compared to 1% of the control group. Most importantly, it was found that there was no significant difference between the groups in the amount of time spent with their husbands or other children (Quittner, Opipari, Regoli, Jacobson, & Eigen, 1992), which does not support the speculation that mothers neglect their children without cystic fibrosis.

In a study by Janicke, Mitchell, and Stark (2005), they found predominantly negative experiences within families of children with cystic fibrosis, especially during mealtime. It is important to note that mealtime is significant for families when a child has cystic fibrosis, as the child has specific nutritional needs. This observational study explored family functioning in

school-aged children with cystic fibrosis during mealtime compared to families without a child with cystic fibrosis. Families of a child with cystic fibrosis scored lower in many areas, including family functioning, affect management, interpersonal involvement, communication, and behavioural control. However, there were no differences between groups in task accomplishment and role allocation. Problematic interactions occurred through coercive communication, negative affect, inconsistency in behaviour management, limited exchanges about the day's events, and lack of support or affection (Janicke et al., 2005).

Overall, the literature findings show that raising a child with cystic fibrosis requires many demands, such as feeling pressure to take care of their child and having the need to constantly watch them (Cowen et al., 1985). Furthermore, parents are required to invest a large amount of their time into caring for their child with cystic fibrosis, due to time consuming treatments and ensuring that the child is eating high energy and nutritional food. Although it has been shown that mothers often neglect their own needs because of their focus on the child with cystic fibrosis (Patterson et al., 1990), Quittner and colleagues (1992) found no evidence to support the claim that they spend less time with their other children or husband.

1.5 Sibling Research

Siblingship is an important relationship throughout a child's life, providing support, love, intimacy, and friendship throughout all stages of the life cycle (Boer & Dunn, 1992; Goetting, 1986). For most, it is the child's first opportunity to socialize and form friendships, especially because it is someone with whom the child has daily contact and must share common resources (Goetting, 1986). Gass, Jenkins, and Dunn (2007) found that when children experienced highly stressful life events, having a highly affectionate older sibling resulted in less changes in

internalizing behaviours over time compared to children with less affectionate older siblings, suggesting that the sibling's level of affection can moderate the child's adjustment. Sibling affection was shown to be protective regardless of the mother-child relationship or other parental factors, also suggesting that sibling relationships are a significant source of support for children (Gass et al., 2007). Although the sibling relationship is most intense during childhood and adolescence, patterns of emotional support, friendship, and caretaking is evident throughout the siblings' lives (Goetting, 1986). In sibling dyads where one individual has a chronic health condition, the roles of a sibling may be different. Caretaking, for instance, can be very important in sibling relationships when one brother or sister has a health issue, as the typically-developing sibling often takes on a greater supportive role (Heller & Arnold, 2010), and as the siblings get older and the parents are unable to care for their brother or sister, they may be expected to act as a parental substitute (Bigby, 1998).

1.5.1 Down syndrome Sibling Research. Overall, the literature indicates that being a sibling to someone with Down syndrome is a positive experience. In their study, Skotko, Levine, and Goldstein (2011) found that the majority of the sibling participants described their relationship with their brother or sister with Down syndrome as a good relationship and would not trade their brother or sister for someone without Down syndrome. Furthermore, they believe that they are better people because of their sibling (Skotko, Levine, & Goldstein, 2011; Skotko, Levine, Macklin, & Goldstein, 2016).

Hodapp and Urbano (2007) compared siblings of individuals with Down syndrome to siblings of those with Autism Spectrum Disorder. It was found that the Down syndrome sibling group reported more frequent contacts with their brother or sister, and reported closer and more

positive relationships when compared to the Autism Spectrum Disorder sibling group. Hastings (2007) found that siblings of individuals with Down syndrome are reported to have fewer behavioural problems, and in general are typically well-adjusted and show less maladaptive behaviours, when compared to siblings of individuals with Autism Spectrum Disorder (Hastings, 2007). Additionally, Cuskelly and Gunn (2006) found that being a sibling of a child with Down syndrome does not have negative impacts on self-perceptions of competence or problem behaviours, and do not differ in these measures when compared to children who have a sibling without Down syndrome. Stores and colleagues (1998) focused on daytime behaviours in both children with Down syndrome and their siblings. It was found that children with Down syndrome had significantly lower rates of daytime behavioural disturbances compared to children with other intellectual disabilities, and that their siblings showed very similar behaviour scores to children from the general population, suggesting that the behaviour of their brother or sister with a disability does not largely affect the siblings' behaviours. Hastings (2007) and Hodapp and Urbano (2007) found that siblings of children with Down syndrome report low levels of depression and are able to adjust to new situations. Also, the siblings have few behavioural problems when compared to siblings of individuals with other disabilities or health conditions.

However, some siblings sometimes feel anger and guilt if they are unable to meet pressures or obligations (Skotko & Levine, 2006). Furthermore, a study by Cuskelly and Dadds (1992) found that although children with Down syndrome were reported to have more behavioural problems compared to their siblings, their siblings were less approaching, more intense, and were less positive in mood (Cuskelly & Dadds, 1992). However, with the exception

of the study by Cuskelly and Dadds (1992), siblings of individuals with Down syndrome described their experiences as positive and uplifting.

1.5.2 Cystic Fibrosis Sibling Research. Having a sibling with cystic fibrosis can be difficult at times, but in many cases, the sibling does not see their brother or sister with cystic fibrosis any differently than they would a sibling without a health condition. This theme was seen in a number of the studies. Larocque (2006) interviewed 10 adolescent siblings of someone with cystic fibrosis and found that all participants described their family as "normal" and their relationship with their sibling as "typical." Similarly, Wennström and colleagues (2011) found that young adults with cystic fibrosis, as well as their siblings, generally have similar self-concepts of self-esteem, skills, and social relationships as other young adults.

A number of studies have suggested that the treatment process is stressful on the entire family. The child's physiotherapy primarily relies on the mothers, but fathers, grandparents, and sibling are often also involved (William et al., 2007). Foster and colleagues (2001) interviewed 9 parents, 8 individuals with cystic fibrosis, and 8 of their siblings, and found that the demanding treatments required constant parental involvement, which in turn, had a direct impact on the siblings. The siblings believed that they received less parental attention compared to their brother or sister with cystic fibrosis. It was suggested that siblings should be told why certain treatments are necessary and why they require a high level parental involvement (Foster et al., 2001). Larocque (2006) found related results, as some siblings discussed having to stop playing with their sibling so that their brother or sister can do physiotherapy or take medications, and some felt jealous that their sibling received more attention from their parents.

Some studies imply that having a sibling with cystic fibrosis can be a positive experience with few negative aspects. For instance, Havermans and colleagues (2010) found that siblings of children with cystic fibrosis scored higher in quality of life measures compared to siblings of children without health conditions. There were some differences between older siblings and younger siblings. For instance, older siblings scored lower on self-esteem measures, and reported a higher impact than siblings younger than the child with cystic fibrosis, but there were no differences in quality of life between the two groups, nor was there a significant difference between male and female siblings. Compared to their peers, siblings of children with cystic fibrosis reported less restrictions in school or activities with friends because of emotional problems, fewer behavioural problems, less body pain, better physical functioning, and reported being more satisfied and calm, more happy, and pleased with capabilities, appearance, and family and friend relationships. Siblings whose sister or brother was hospitalized were more negatively impacted, particularly because their parents focus on the child in the hospital and there is less time for the siblings (Havermans et al., 2010). Similarly, Boling, Macrina, and Clancy (2003) found that caregiver quality of life correlates with disease severity where quality of life, as measured by the Caregiver Quality of Life Index – Cystic Fibrosis (CQOLCF) scale, decreases with more hospitalizations.

A study published in 1997 by Stawski, Auerbach, Barasch, Lerner, and Zimin examined behavioural problems in chronically ill children and their siblings. The participants included 76 chronically ill children, 13 of whom had cystic fibrosis, their sibling, 76 typically developing children, and 76 psychiatrically referred children. It was found that being a sibling of someone with a chronic illness does not mean an increased risk of behavioural problems, but there is a

significant correlation between the behaviours of the sibling with a health condition and the typically developing sibling (Stawski et al., 1997). Similar to the findings of Havermans and colleagues (2010), older siblings of chronically ill children were at a significantly higher risk for having internalizing problems.

Some studies rely on the report of parents to investigate the sibling experiences, such as a study conducted by O'Haver and colleagues (2010) that examined parental perceptions of their typically developing child's adaptation when their other child has cystic fibrosis. They found that the psychological adaptation of typically developing siblings was affected by certain environmental and psychological factors. Furthermore, parental stress and lack of social support affected the sibling's adaptation. Interestingly, 75% of the siblings without a health condition had never spoken to anyone on their sibling's medical team about the illness; however, it was suggested that children who spoke with their sibling's healthcare providers showed less externalizing behaviours and they benefited from the discussion. Parental reports also revealed that mothers and fathers are often unaware of their well child's perception of the situation with their sibling (O'Haver et al., 2010).

Compared to other health conditions, siblings of individuals with cystic fibrosis do not see caregiving as a major factor in the sibling relationship. Despite Larocque's (2006) finding that the majority of their participants sometimes or always worry about their sibling, their worries about the future are not caregiving related. For instance, one participant worried that their sibling would not be able to get married or have children, and another had concerns about his own children having cystic fibrosis because he carries the gene. Finally, it is evident that these siblings are resilient and are able to cope with their negative emotions associated with their

brother or sister's condition in many ways. Siblings reported various coping methods, including spending time with their brother or sister with cystic fibrosis, talking about the condition but also not always thinking about it, and feeling hopeful that there will one day be a cure for cystic fibrosis (Larocque, 2006).

Although being a sibling to someone with cystic fibrosis can be stressful or provoke negative emotions, a common theme in the literature is that siblings would not see their brother or sister any differently if they did not have cystic fibrosis (Larocque, 2006). The required treatments can be stressful on the entire family (William et al., 2007), which may cause the child to become jealous or feel neglected by their parents (Foster et al., 2001). However, siblings show less problem behaviours and score higher on quality of life measures as individuals who have siblings without cystic fibrosis (Havermans et al., 2010; Wennström et al., 2011). Sibling also reported using many coping methods, such as spending time with their brother or sister, talking about the condition, or speaking to the sibling's healthcare providers to learn about the condition (Larocque, 2006; O'Haver et al., 2010). Overall, research indicates that being a brother or sister to someone with cystic fibrosis is generally a positive experience.

1.6 Purpose

The purpose of this study is to explore the experience of being a sibling to someone with a chronic health condition, specifically Down syndrome and cystic fibrosis. Through this study, the struggles, the rewards, and the overall experiences one has when being a sibling to someone with a chronic health condition will be better understood. By using the siblings' personal accounts, the sibling relationship will be better understood, and supports and programs can be designed specifically to address the needs discussed by the siblings.

1.6.1 Research Questions. The goal of the current study was to answer the following questions: What are the experiences, including demands and capabilities, when being a sibling to someone with a chronic health condition? How are the experiences different and similar between siblings of individuals with Down syndrome and cystic fibrosis?

1.6.2 Rationale. Family research often focuses on the caregivers of individuals with health conditions, and previously overlooked the experiences and feelings of their siblings. However, studies are now emerging that include the sibling's experiences to better understand the entire family. By researching sibling experiences, it adds to the current literature and explores both the positive and negative aspects of having a sibling with a chronic health condition. To the author's knowledge, there has been no study exploring and comparing the sibling experiences of the two groups included in this study. Down syndrome and cystic fibrosis are very different health conditions, and Down syndrome is often referred to as a "disability" as opposed to a health condition. However, they are similar in the sense that siblings of individuals with these ailments may experience additional stressors and caregiving responsibilities, hospital visits, and other negative features. Both Down syndrome and cystic fibrosis are present at birth, and although there may be supports or treatments available, they are both life-long conditions that can affect the individual and their families. By exploring the overall experiences, this study investigates the meanings, including both negative and positive, of growing up with a brother or sister that has a chronic health condition.

The literature surrounding siblings of those with a chronic health condition presents some limitations. Firstly, most sibling research was conducted or published in the 1990s or early 2000s, with only a few studies being published in the last ten years (e.g., Havermans et al., 2010;

O'Haver et al. 2010; Skotko et al., 2011; Skotko et al., 2016; Wennström et al., 2011). Past studies focus primarily on the stresses and negative consequences of having a family member with a health condition, rather than exploring their experiences as a whole. Additionally, few studies use a qualitative approach. For instance, the results of a quantitative study may report that the sibling experiences more stress than an individual that does not have a brother or sister with a health condition. However, the participant is unable to provide further explanation as to what stress means to them, why they may experience the stress, and if they are able to overcome these negative feelings with suitable coping behaviours.

An important aspect of this study is that the researcher spoke directly to siblings. The interview gave the sibling an opportunity to speak openly about their experiences, and provides personal and direct information that offers a better understanding of the sibling experience. It also provided the siblings the chance to express their thoughts and feelings about being a brother or sister to someone with a health condition without being judged, which may be a support within itself for the sibling. Finally, many siblings take on the role as future caregiver, rather than admitting their brother or sister with a disability or health condition to a hospital or institution. This study provided the sibling with the opportunity to speak openly about this responsibility.

1.7 Reflexivity

In qualitative research, a fundamental concept is the "human as instrument" (Guba & Lincoln, 1981; Denzin & Lincoln, 2017). Reflexivity involves being aware of and reflecting on how one's beliefs and personal experiences influence the qualitative research process, and how this may affect the outcomes or results (Denzin & Lincoln, 2005). Toma (2006) explains that the researcher must self-reflect and articulate their biases. Reflexivity also includes methods of

confronting the biases when completing research and understanding how it may affect the process.

My interest in family research began while completing my undergraduate degree. I recall learning about the supports for the individual with health conditions (including mental health), but rarely about the help available for their family. As a result, I conducted my undergraduate thesis on parents' perceived social support and coping behaviours when they have a child with a mental health issue. Upon realizing that their children's conditions affected the entire family as a whole, I chose to apply to the Masters in Applied Psychology program at Laurentian University, under the supervision of Dr. Shelley Watson.

I felt that while growing up, I was not always exposed to individuals with different family backgrounds, abilities or disabilities, or various health conditions. I recall going to elementary and secondary school with very few individuals with Down syndrome, and knowing very little about the condition, other than that it is caused by a chromosome deficit and that these individuals required more support in school and daily living. I was familiar with the term "cystic fibrosis," but I knew very little about the ailment other than it being a breathing or lung condition. When I entered the program at Laurentian University, some of my fellow lab-mates were completing research in the field of siblings' experiences and I immediately became interested. When I was presented with the opportunity to learn more about people with Down syndrome and cystic fibrosis, and how it affects their siblings, I felt that this was my chance to learn more about conditions affecting the families of thousands of Canadians.

During the interviews with participants, I was often reminded of my own relationship with my younger brother and I recognized that I would inadvertently compare my own

experiences to that of the sibling being interviewed and kept note of that throughout the process. At times, I felt inadequate or unskilled in interviewing and feared that it could interfere with the data I was collecting and how I was interpreting it. I often made notes about my thoughts and feelings during the interviews, but upon transcription and re-reading the transcripts, I realized that my original notes might be biased. Furthermore, I reflected on the theoretical orientation used in this thesis, the FAAR model, when interpreting the data. Over the course of the study, I felt that I became more confident in my skills and by keeping an audit trail of my notes, I was able to identify where I have grown and where I needed to develop more skills in qualitative research.

While completing this study, I was often reminded of my desire to continue in the field of family psychology and working with parents, siblings, and the entire family unit when faced with challenges and uplifting experiences. During my Master's degree, I have been exposed to people of many different family backgrounds. Additionally, towards the end of my graduate degree journey, I became pregnant with my first child, giving me a new insight into family relationships, particularly from a parental standpoint. I was constantly reminded of the stories told by these siblings throughout my pregnancy, particularly when doctors, nurses, and ultrasound technicians approached the topics of genetic health issues and pre-natal screening, as I witnessed the stigma and misunderstanding surrounding disabilities and chronic health conditions. This study also made me consider how my life may be affected if my child was born with a disability or chronic health condition, and I often wondered how I would be able to juggle being a parent to a child with a health condition, while still caring for and meeting the needs of my other children. Through my research, my coursework, and my personal experiences and motherhood, my

passion for family relationships has grown. I hope to continue in this field, especially working with children who have various disabilities or health conditions and their families, after graduation.

1.8 Methodology

This thesis is part of a larger study that explores sibling experiences. This qualitative study uses a basic interpretive approach, where the researcher aims to understand the participants' meanings of experiences and phenomena. Qualitative research focuses on exploration, induction, and hypothesis generating, where the interviewer is the principal instrument (Johnson & Onwuegbuzie, 2004). Interviews were used to collect data, which provide the researcher with an in-depth look into the experienced meanings of siblings, which offers more insight into the sibling's personal experiences, but also the meanings of the entire family of a child that has a chronic health condition.

1.8.1 Participants. Seven individuals who have a sibling with Down syndrome and eight individuals who have a sibling with cystic fibrosis participated in this study. These participants are typically developing and did not identify as having a chronic health condition. After obtaining ethical approval from Laurentian University's Research Ethics Board (see Appendix A), participants were recruited through flyers and emails (see Appendix B) to disability support and health organizations, postings on social media, as well as word of mouth and response-driven sampling. Participants included primarily biological siblings and one adoptive sibling. Very few interviews were conducted with siblings under the age of 16, and although they provided their experiences of having a sibling with a chronic health condition, the older siblings were better able to articulate their experiences and provide more in-depth responses. While

examining the interview transcripts, it was clear that siblings ages 16 and older had a better understanding of their sibling's condition; therefore, participants were excluded if they were younger than 16. Furthermore, many studies, particularly on cystic fibrosis, focus on childhood sibling dyads. As those with Down syndrome and cystic fibrosis are living longer, it is crucial to explore the adult sibling relationship, as was done in this study. Siblings' names were replaced with pseudonyms to protect their identity and privacy. Demographic details of the participants in this study are shown in Table 1.

Table 1: Participant Demographics

Demographic Characteristics	
Siblings of individuals with Down syndrome (*n*)	7
Average age (*SD*)	26.9 (*8.5*)
Age range	16-39
Relationship to sibling with Down syndrome	
Biological sister (*n*)	7
Biological brother (*n*)	0
Sibling with Down syndrome (*n*)	6
Gender (% female)	16.67
Average age (*SD*)	25.2 (*11.5*)
Living at time of interview (%)	100
Siblings of individuals with Cystic fibrosis (*n*)	8
Average age (*SD*)	21.8 (*4.7*)
Age range	16-28
Relationship to sibling with Cystic fibrosis	
Biological sister (*n*)	4
Biological brother (*n*)	3
Adoptive sister (*n*)	1
Adoptive brother (*n*)	0
Sibling with Cystic fibrosis (*n*)	5
Gender (% female)	60
Average age of living siblings (*SD*)	19.4 (*2.4*)
Living at time of interview (%)	75

1.8.2 Qualitative Interviews. Participants were interviewed with a series of semi-structured questions. These questions were informed by a basic interpretive approach (Merriam,

2002), as the goal of this approach is to understand a participant's experiences (demands and capabilities), based on what makes sense to them.

A semi-structured interview guide consisting of 20 questions, with prompting questions as needed (see Appendix C), was developed for a previous study, and was used in this current study. Interview questions were open-ended, with the exception of demographic questions such as "how old are you?" The questions were developed as a means to explore the participants' experiences, such as "how would you describe your sibling?" or "tell me about a typical day in your household." Interviews lasted at least 20 minutes in length, and were conducted over the phone, video messaging, or in-person. Due to the expanding nature of the larger project, other researchers conducted some interviews.

1.8.3 Analysis of Interviews. Interviews were audio recorded and transcribed verbatim, and analyzed using Interpretative Phenomenological Analysis (IPA). IPA is an exploration of the participant's personal world by recognizing important or interesting statements the participant says, followed by distinguishing themes in their responses (Smith & Osborn, 2008). Examples of statements include what the participant may deem as significant to them, or a concept that is either unique or seen throughout a number of participant interviews. It is suggested that IPA is an effective method when there are approximately 10-15 participants, and focuses on the individual and their personal experiences (Larkin, Watts, & Clifton, 2006; Reid, Flowers, & Larkin, 2005).

Qualitative research involves the interviewer as the primary instrument (Johnson & Onwuegbuzie, 2004). Therefore it is crucial to remember the aims of IPA, such as trying to understand the participant's world and relating their descriptions to a wider social and theoretical context (Larkin et al., 2006), which in this study is the FAAR model. The transcription was read

a number of times and notes were made in the left-hand margin of the page, logging noteworthy, unique, or significant statements that the participant made. Then the transcript was read again and the other margin was used to note emerging themes, then connections were made between themes and within the transcription (Smith & Osborn, 2008).

1.9 Overview of Subsequent Chapters

This manuscript-based thesis explores the lived experiences of having a brother or sister with a chronic health condition, particularly Down syndrome and cystic fibrosis. Both papers used a basic interpretive approach (Merriam, 2002) and were informed by the FAAR model (Patterson & Garwick, 1994). Data was collected using semi-structured interviews, and these interviews were analyzed using Interpretative Phenomenological Analysis (Smith & Osborn, 2008).

The first paper focuses on the experiences of siblings of individuals with Down syndrome. The results suggest that having a sibling with Down syndrome is a generally positive experience, but siblings reported uplifting situations as well as stressors. Participants saw their sibling as "normal" and discussed how their siblings have enriched their lives, but recognized that they are faced with situations that can be difficult. They discussed a lack of understanding about Down syndrome from others and the need to make adjustments in the family to better care for their brother or sister. Further research may be warranted to better understand the sibling experience, especially a brother's experience, as all participants were female.

The second paper explores the lived experiences of having a brother or sister with cystic fibrosis. Siblings reported taking on additional responsibilities within the family, including acting as caregiver, which some took on with pride but others were annoyed by it. They have many

worries about their sibling's health, due to the fatal consequences of cystic fibrosis. Also, siblings discussed how their brother or sister's genetic health condition might affect their own children or their own personal decisions, such as career choices or the possibility of donating a lung to their sibling. Implications and suggestions for further research are also explored.

The final chapter provides a summary of the findings in both papers, a comparison of the experiences of siblings of individuals with Down syndrome and cystic fibrosis, and concluding remarks. Ensuring the quality of qualitative research and the studies' relation to the FAAR model is also discussed. Lastly, limitations, recommendations, implications, and knowledge translation considerations are provided.

“He’s kind of shaped me into who I am today”:

Experiences of Being a Sibling to an Individual with Down syndrome

Kristina Trandovski

Laurentian University

"He's kind of shaped me into who I am today":

Experiences of Being a Sibling to an Individual with Down syndrome

Families who have a member with a chronic health condition or disability, such as Down syndrome, have different experiences, including struggles and rewards, than families who have typically developing children. Research often focuses on the impact on the parents or family as a whole, and until the 1980s, often overlooked the experiences of siblings (Stoneman, 2005). The person with a chronic health condition or disability affects all individuals within the family as it is a unique shared experience that has positive implications, such as enhancing family cohesion and inner strength, but has negative effects such as physical and emotional demands as well as substantial financial expenses (Reichman, Corman, & Noonan, 2008). The Family Adjustment and Adaptation Response (FAAR) Model guided this study. The FAAR Model discusses how the family uses capabilities, such as coping behaviours and various resources, to meet the demands (i.e., stressors) that are faced (Patterson, 1988), in this case, when having a family member with a disability or health condition. Brothers and sisters emotionally influence each other throughout the lifespan (Wennström, Isberg, Wirtberg, & Rydén, 2011); therefore, it is crucial to explore the siblings' experiences including demands and capabilities to further understand the family as a whole.

Down Syndrome

Down syndrome, or trisomy 21, is a genetic condition most commonly caused when an individual has 3 copies of chromosome 21 rather than 2 (Selikowitz, 2008). Down syndrome is the most common human trisomy seen in live births, occurring in one out of every 700 to 1000

births (Mitchell & Ziegler, 2013; Selikowitz, 2008). Down syndrome is associated with a number of both mental and physical abnormalities and deficits, and it is the most common genetic cause of intellectual disabilities (Kliegman et al., 2015). People with Down syndrome often have difficulty expressing language (Kliegman et al., 2015) and can have physical disabilities, such as heart defects, thyroid abnormalities, lung defects, and stunted growth (Mitchell & Ziegler, 2013).

Families of individuals with Down syndrome. Parenting stress is common when raising a person with Down syndrome, particularly when compared to parents of those who are typically developing. However, it is often shown in research that when compared to parents of children with other disabilities or chronic health conditions, parents of people with Down syndrome generally have less stress, less psychological problems such as depression or anxiety, and are better able to cope. These positive outcomes are referred to as the "Down syndrome advantage" (Fidler et al., 2000; Hodapp et al., 2003; Stoneman, 2007). According to Esbensen and Seltzer (2011), the Down syndrome advantage is attributable to the Down syndrome behavioural phenotype, meaning the personality and behavioural patterns typical in individuals with Down syndrome result in less parental stress, rather than other factors such as maternal age or social supports.

Siblings of individuals with Down syndrome. Siblingship is an important, and potentially the longest, relationship during a person's life. Siblings provide support, love, intimacy, and friendship throughout all stages of the life cycle, and can influence one's learning and behaviours (Cicirelli, 1995; Dunn, 2015; Goetting, 1986). The sibling relationship changes as the siblings grow older, especially as they become more autonomous (Dunn, 2015). In typically-developing sibling dyads, these changes may include a decrease in warmth towards

their sibling and less caregiving responsibilities for their sibling (Dunn, 2015). Although many factors contribute to sibling relationships, including socialization, adjustment patterns, personality traits, and family structure (Dunn, 2015; Scharf & Shulman, 2016), Goetting (1986) suggests that patterns of emotional support, friendship, and caretaking are evident throughout the siblings' lives. In sibling dyads where one individual has a health condition such as Down syndrome, the roles of a sibling may be different or more intense than the roles of a sibling in a typically-developing dyad.

In general, the literature suggests that being a sibling to someone with Down syndrome is a positive experience. One study in particular by Skotko, Levine, and Goldstein (2011) used questionnaires and found that the majority of the 822 sibling participants described their relationship with their brother or sister with Down syndrome as a good relationship. Additionally, a small number of siblings across all age groups stated that they felt sad or sorry for their brother or sister, or that their parents pay too much attention to their sibling with a disability or health condition (Skotko et al., 2011). However, the majority of siblings overall would not trade their brother or sister for someone without Down syndrome, and they believe that they are better people because of their sibling (Skotko et al., 2011; Skotko, Levine, Macklin, & Goldstein, 2016). In fact, Heller and Arnold (2010) found that siblings of individuals with a disability often take on a greater supportive role than in sibling relationships without a disability.

Many studies compare siblings of those with Down syndrome to other developmental disabilities, such as Autism Spectrum Disorder. Hodapp and Urbano (2007) compared siblings of individuals with Down syndrome to siblings of those with Autism Spectrum Disorder and found that the Down syndrome sibling group reported more frequent contacts with their brother or

sister, and reported closer and more positive relationships. Similarly, Hastings (2007) found that compared to data from a United Kingdom normative sample, siblings of children with Down syndrome are generally better able to adjust to new situations. Siblings of individuals with Down syndrome are reported to have fewer behavioural problems, and in general are typically well-adjusted and show less maladaptive behaviours when compared to siblings of individuals with Autism Spectrum Disorder (Hastings, 2007).

Skotko and Levine (2006) reported that siblings of individuals with Down syndrome feel capable and helpful when helping their sibling with tasks. However, the siblings sometimes feel anger and guilt if they are unable to meet pressures or obligations (Skotko & Levine, 2006). Another study reported that siblings of people with Down syndrome have lower levels of distress and better ability to adjust to new situations when compared to siblings of those with a pervasive developmental disability (Fisman, Wolf, Ellison, & Freeman, 2000). It was also found that although sibling relationships change over time, their levels of distress and adjustment remain static.

Not all studies suggest that having a sibling with Down syndrome is a positive experience. A study by Cuskelly and Dadds (1992) found that although children with Down syndrome were reported to have more behavioural problems compared to their siblings, their siblings were less approaching, more intense, and were less positive in mood (Cuskelly & Dadds, 1992). With the exception of this study by Cuskelly and Dadds (1992), siblings of individuals with Down syndrome described their experiences as positive and uplifting. In fact, Hastings (2007) and Hodapp and Urbano (2007) found that siblings of children with Down syndrome

report low levels of depression, are able to adjust to new situations, and have few behavioural problems when compared to siblings of individuals with other disabilities or health conditions.

The current literature provides insight into the sibling relationship; however, many of the studies compared siblings of people with Down syndrome to siblings of those with other disabilities or health conditions and used quantitative measures to collect data. This study provides a more in-depth exploration of the sibling relationship as the researchers spoke directly to siblings, using open-ended questions. This approach gave the siblings an opportunity to discuss their experiences and provide explanations when needed, which may not have been available to participants that participated in questionnaire studies. Therefore, the goal of the current study is to explore the overall experiences of siblings who have a brother or sister with Down syndrome, including demands and capabilities.

Methodology

This study is part of a larger project, looking at the experiences of growing up with a sibling who has a chronic health condition. Biological and adoptive siblings were recruited through social media advertisements, respondent driven sampling, and with the assistance of Down syndrome organizations throughout Canada. This study used a basic interpretive approach (Merriam, 2002), which focuses on exploration and induction. The goal is to understand a participant's experiences, based on their construction of their world and what makes sense to them. The researcher gathers information based on the interviews to develop theories and concepts (Merriam, 2002).

The Family Adjustment and Adaptation Response (FAAR) model guided this study. The FAAR model focuses on the activities that families perform that balance family demands with

family capabilities. When faced with a crisis, a family may have more demands (i.e., stressors) than capabilities (i.e., coping behaviours), which affects the family's balance. During this adjustment phase, the family must develop and employ various coping behaviours and resources until they have the appropriate resources to face their stressors. At this point, the family is in an adaptation phase (Patterson, 2002). Using this model, the interview questions were developed with the understanding that families experience many hardships and daily hassles, but also use various resources to help cope in those situations.

Twenty questions were developed, and with the exception of demographic questions, such as "was your sibling adopted?," the questions were open-ended and were meant to explore the participants' experiences of growing up with a sibling with Down syndrome. The goal of this study was to explore the positive and negative experiences of these siblings, including the hardships, coping behaviours employed, and to provide a better understanding of how having a brother or sister with Down syndrome affected the sibling's daily life. Sample questions include "how would you describe your sibling?" and "tell me about a typical day in your household." Participants were asked to participate in semi-structured interviews that lasted between 20 and 60 minutes. Siblings were interviewed over the phone, via video messaging, or in-person at a place in which they felt comfortable. These interviews provided an in-depth look into the experiences of siblings, including the uplifts and hardships of having a brother or sister with Down syndrome. Prior to collecting data, this study was reviewed and approved by the Laurentian University Research Ethics Board and the participants provided informed consent. They were also given phone numbers and information on community mental health agencies, if desired, at the commencement of their participation.

Participants

Seven siblings of individuals with Down syndrome participated in this study. All participants were biological siblings, were female, and lived in Canada, with the majority (6 siblings) residing in the province of Ontario. Siblings ranged in age from 16 to 39, with a mean age of 26.9 (*SD*=8.5). Four participants had an older sibling with Down syndrome, where the remaining three had a younger brother or sister with Down syndrome. Most siblings had a brother with Down syndrome, with the exception of one. Participants' names have been changed to pseudonyms to protect their identity and privacy. Two participants, Brooke and Sabrina, are sisters; therefore, although there were seven participants, there were only six siblings with Down syndrome that were discussed in the interviews. Information pertaining to the participants' demographic information can be found in Table 2.

Table 2: Down syndrome Participant Demographics

Pseudonym	Age	Gender of Sibling with Down syndrome	Age of Sibling with Down syndrome
Anna	39	Male	36
Brooke	31	Male*	34*
Emily	34	Male	38
Jillian	21	Male	7
Leeann	16	Female	19
Sabrina	28	Male*	34*
Stephanie	19	Male	17

*Denotes the same sibling, as Brooke and Sabrina are sisters with one brother with Down syndrome.

Analysis

Interviews were audio recorded and transcribed verbatim. The transcripts were then analyzed using Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2008; Smith, Flowers, & Larkin, 2009). IPA is an exploration of the participant's personal world by recognizing important or interesting statements the participant says, followed by distinguishing themes in their responses (Smith & Osborn, 2008). Important or interesting statements may include what the participant may deem as significant to them, or a concept that is either unique or seen throughout a number of participant interviews. IPA is meant for a small number of participants, as it focuses on the individual and their personal experiences (Larkin, Watts, & Clifton, 2006; Reid, Flowers, & Larkin, 2005).

The transcriptions were read a number of times and notes were made in the left-hand margin of the page, logging noteworthy, unique, or significant statements that the participant made. Then the transcripts were read again. The other margin was used to note emerging themes, and then connections were made between themes and within the transcription (Smith & Osborn, 2008). From these connections, themes and subthemes were developed and are explored below.

Results

Throughout the interviews, siblings described their overall experiences of having a brother or sister with Down syndrome. The stories they shared included many uplifting experiences, but also some hardships. Using the data analysis method of IPA, four main themes were uncovered within the interviews, including the idea of normalcy, lack of understanding from others, personal growth, and shifting of roles within the family.

Normalcy

Siblings described their families using words such as "normal" or "typical" in their descriptions. The FAAR model suggests three levels of family meaning. The levels include situational meanings, such as a family's understanding of their demands and their coping behaviours, their identity as family and how they see themselves, and their worldview, including how they see their family in regards to society (Patterson & Garwick, 1994). Although siblings recognized that they face different situations that a family of a child without Down syndrome, they used the words "normal" and "typical" in their descriptions. To these participants, having a sibling with Down syndrome is all they have ever known. Therefore, their idea of normalcy may differ from those in families with typically developing members. Although adjustments are often made within a family, including changing of roles or the need to be their sibling's voice, they see their sibling and family as having many of the same uplifting experiences and stressors as their friends' families and siblings. However, the differences are in the types of positive and stressful experiences that those in typically developing families may not have. Two subthemes, including "Not seeing their sibling as 'different'" and "Like any other family," provide a detailed understanding of this theme.

Not seeing their sibling as "different." Siblings explained how they believe that having a brother or sister with Down syndrome was not any different than having a "typically-developing" sibling. In fact, Jillian explained how she did not know her younger brother had Down syndrome for many years, saying,

> I used to see him as a normal…. A normal child that doesn't have anything… I would say the other kids developed quickly right and he didn't, so I started asking myself questions, and then my parents told me he had Down syndrome.

Jillian viewed her brother as "typical" for years, and only began noticing the differences between her family and her friends' families when she saw that he was not developing as quickly as his peers. Four of the participants were younger than their sibling with Down syndrome, and therefore could not recall how they found out their sibling has Down syndrome. For these siblings, having an older brother or sister with Down syndrome was all that they have ever known and for them, it is "normal."

Siblings also talked with pride as they explained how open the communication within their family has been about their brother or sister's condition. Similar to Jillian, Leeann discussed how her parents never had to explain that her older sister had Down syndrome, stating, "my parents are always like very open, so they told me how, when I was growing up that… they said that I knew something was different, and when I was like old enough to actually understand, like, [my parents] had told me"

Overall, siblings saw their sibling as any other person. Most siblings were younger than their brother or sister with Down syndrome, so they could not recall how they found out about their sibling's condition, and Jillian discussed how she did not know her brother had Down syndrome for years. Most siblings also talked about how their family spoke openly about Down syndrome. Despite their brother or sister's health condition, they often saw their family as "typical."

Like any other family. Some siblings also talked about how their family dynamics were not affected by their sibling with Down syndrome. They described their families as any other family without a health condition, and Emily said, "It was a pretty normal childhood like we have you know family dynamic issues… but it wasn't, uh, it was not a result to having [my brother with Down syndrome] in our family." When asked what activities participants liked to do with their siblings growing up, most explained that it was the same as if they their sibling did not have Down syndrome. Some siblings discussed playing games with their brother or sister, going on family vacations, and sometimes disagreeing with their sibling. Anne explained, "[my friends and I] weren't necessarily including [my brother] like in the same way as if you had a much younger sibling you wouldn't include them … if you were, you know, 12 or whatever, like if you had a 3 year old sibling, you wouldn't be including them if you had another friend over if they were 12."

For most, having a sibling with Down syndrome was not a negative experience because they believed that their difficult experiences were comparable to those in families of children without a disability. When a child with Down syndrome is in one's family, the entire family changes and grows around that individual until they see their family as "typical." Relating back to the FAAR model, the families have changed their family identity and worldview to adjust to having a member with Down syndrome. Therefore, from a young age, these siblings were able to handle situations of crisis and develop appropriate coping behaviours to maintain balance. As the siblings learn to adapt to having a brother or sister with Down syndrome, they described leading happier lives than they would have without their sibling. As a result, all participants talked about how their sibling has made their family, as well as themselves, better people.

Lack Of Understanding From Society And Healthcare Or Teaching Professionals

Although participants viewed their family and relationship with the siblings as "normal" or "typical", they recognized that there is still a lack of understanding from others. They may have been able to adjust their family identity and worldview when approaching situations, but explain how individuals that do not have a family member with a disability are not as accepting. Some siblings have witnessed their brother or sister with Down syndrome treated poorly and inhumanely. This ultimately became a demand for the siblings, as many faced this obstacle while in public with their brother or sister. As a result, some siblings were able to employ coping behaviours (i.e., capabilities) and took it as an opportunity to educate others. Although Down syndrome is one of the most well-known developmental disabilities, there is still lingering stigma and ignorance. This theme is separated into two subthemes, "Ignorance within society" and "Lack of understanding from trusted healthcare and teaching professionals."

Ignorance within society. Stephanie, who is 19 years old and has a younger brother with Down syndrome, would agree that those in the general population require more education on disabilities. She began by describing her experiences of growing up in a small town with a brother with Down syndrome. She said,

> [The people in our town] were all pretty educated but like if there was new kids or something they would be like 'I don't want to be in the class with like a diseased kid' and stuff like that. Like a lot of kids who didn't know him were like… they wanted to stay away from him.

When Stephanie moved to a new town, she expected the attitudes to differ; however, she felt that discrimination and lack of knowledge in her new environment as well. She shared stories of

outings in which he had been called names and treated unfairly, saying, "I hate seeing people like stare and like a lot of the times we'll go to [restaurants] and people refuse to serve him."

Other siblings, including Brooke, discussed their frustration with others' ignorance. Brooke talked about how she sometimes needs to be abrupt and encourage her brother's autonomy,

> My biggest thing is that I'm always on the lookout that everybody is treating him well, you know, because there are so many people out there in the general public that I find aren't educated about Down syndrome and other disabilities… if someone's staring or anything like that I'll give them the opportunity to come say hi and all of that, because we'll go into a restaurant sometimes and I find that sometimes the waitresses, we've been to a few of them where they would just talk to me, and I'm like 'well he's right there, why don't you ask him'

Although some may argue that the awareness surrounding disabilities such as Down syndrome has improved greatly in the last thirty years, siblings in this study explained that there is still a ways to go. For Leeann, she wants others to learn more about disabilities and recalls many of her peers asking questions about her older sister. She said, "I do remember getting a lot of questions and kind of explaining to people how my sister has a disability that's why she has a support worker with her." However, as shown through the siblings' stories, many individuals do not seek more information and make assumptions about their sibling's abilities, or lack thereof.

Lack of understanding from trusted healthcare and teaching professionals. Families often put their trust in health and teaching professionals, including doctors, nurses, disability support staff, and teachers. Parents may put some of the responsibility of their child's health and

academic growth in the hands of these individuals. However, siblings explained that not all health and teaching professionals are educated or competent in working with those with Down syndrome.

Anna explained how the medical staff approached the situation when her brother was born over 30 years ago. She stated,

> He was born and the nurses and whoever was around in the room kind of looked at him and said 'oh okay we need to do some tests' and they basically took him away from my mother and they had him… for a long time and she doesn't know what's going on. All she knows is that they were kind of looking horrified [when] he was born right so she was wondering what the heck is wrong with my child, right? And so they finally bring him back and then somebody kind of told her um that he had Down syndrome, and um anyway, it wasn't handled very well, ha, but uh, again this was sort of you know back in the day. Hopefully things are a lot better these days

However, some siblings disagreed and said that although there is more awareness and education available on Down syndrome, there is still misunderstanding amongst healthcare professionals and teaching staff. Throughout the interviews, it was clear that the stigma and belief that having a family member with Down syndrome is a burden is still apparent.

Stephanie, who grew up in a small town, indicated that many of the other children in her town were accepting of her brother with Down syndrome. However, she explained with sadness and anger in her voice how her brother was treated unfairly in school. She explained,

> One of his [educational assistants] like pushed him against a wall in the gym and then…I went down stairs to go check on him in one of his life skills classes, and they didn't have

> like a Snoezelen room, so what they did was they would put him in the janitors closet. Since it didn't lock, they would like hold the door from the outside until he calmed down and they would just kind of stick him in there. And like, no one knew what, that this was happening. And then like I went down and I checked and then he wasn't in his classroom, and they're like 'she's taking him for a walk they've been gone for like 2 hours', and then I turn the corner and [the educational assistant] was like holding the door shut.

Siblings shared a number of stories about times they witnessed their brother or sister being degraded and treated as less than those without Down syndrome. The interview transcripts suggested that siblings want others to learn more about Down syndrome, and understand that each individual, just as those without Down syndrome, have different abilities and personalities.

Personal Growth

Despite the lack of understanding from health professionals and society in general, siblings discussed how their brother or sister with Down syndrome has enriched their lives. They explained how they are better people because of their brother or sister, and that it has influenced their view of the world and their view on family relationships. Many participants have learned lessons from their siblings and cannot imagine their life without their brother or sister, which has improved the relationships within their family. These siblings were able to change their worldview by modifying their goals and sense of purpose to help manage the demands of having a sibling with Down syndrome. Personal growth is further explored within the following two subthemes, "Learning from their sibling" and "Improving family relationships."

Learning from their sibling. All siblings explained how they have learned lessons from their sibling. These lessons included appreciating the "little things" in life, as well as being more

accepting and loving individuals. Sabrina spoke highly of the lessons she learned from her brother, saying "I think he's kind of shaped me into who I am today, made me like a very empathetic person naturally, and made me see the world a bit differently." Having a brother or sister with Down syndrome provided these siblings with an opportunity to learn more about disabilities, as well as individual differences. Emily said, "there's a very unique but very social joy in being [my brother]'s sister and watching him grow and reminding me of what I want to become and where I'm going…he's a very a beautiful gift that was given to me." Overall, siblings spoke about their brother or sister with pride, and were appreciative of the lessons that they have learned from being a sibling to someone with Down syndrome.

Improving family relationships. Jillian discussed some stressors within her family, including her mother's need to resign from her employment due to her brother's condition, and how this affected her and her family. However, she explained how she learned to cope in these situations, and these changes brought her family closer together and improved her relationship with her sibling. She said, "I think he made the family even more closer than it was [because of my brother with Down syndrome]." Similarly, most siblings felt that they could not imagine their life without their sibling. Brooke said,

> If we had a sibling that didn't have Down syndrome – I don't know, it's hard to explain really, I just can't imagine it being any other way than our family is right now, but I think that we grow up, um, well I don't want to say closer than other families, but in a way, closer because we had so many different situations.

As Emily described previously, she sees her brother as a gift. Although siblings explained that their family is "normal" or like any other family, adjustments often have to be made when a

child with Down syndrome is born into the family. For most siblings, this is a welcoming change that brings growth, acceptance, and new roles to the family.

Shift in Roles

Lastly, all siblings discussed how having a brother or sister with Down syndrome has affected their family members' roles. In many families, adjustments need to be made when a child is born. For families of children with Down syndrome, these adjustments may include the changing of roles and being an advocate for their sibling, being involved in organizations, and changing their view when approached with difficult situations. According to the FAAR model, a family member will often make changes in their life to adapt to the needs of the family. Siblings of individuals with Down syndrome re-evaluate their goals and take on roles within the family that someone without a sibling with Down syndrome may not. In "typically-developing" sibling relationships, a brother or sister rarely has to take on the role of being an advocate for their sibling or being very involved in their sibling's life as they reach adulthood. Therefore, for families of individuals with Down syndrome, these changes may differ or be more drastic to ensure that he or she is receiving the best care. Subthemes, including "Being the voice of their sibling" and "Involved in disability organizations or their sibling's care," provide a further understanding of the shift in roles.

Being the voice of their sibling. In some situations, individuals with Down syndrome may not be able to express their wants or needs. Many individuals with Down syndrome have difficulties with communication or speech, or the intellectual deficits associated with Down syndrome may affect their ability to understand or convey their needs. For many siblings, they see this as an opportunity to be the voice of their brother or sister and to be their advocate.

Brooke, who described herself as the "bulldog" of her family and very protective of her older brother with Down syndrome, said, "I just want to make sure that everyone treats him the way that he deserves to be treated." Without the involvement of the family, the individual with Down syndrome may not get the quality care that they deserve. Brooke continued by explaining,

> At the hospital, I make sure things get done… I don't think [the medical staff have] done their jobs for supporting him in the hospital, so we were very much advocates. I think they hate when I go there (laughs) because I make sure he gets the treatment he deserves and the services, and if he doesn't, we go elsewhere, you know.

Emily, like many of the siblings, wants to ensure that her brother is autonomous and capable. Many people with Down syndrome are able to live independently or within a group home setting. Although Emily's brother is living within a group home with other individuals with disabilities, she still wants to protect her brother's rights as a human being. She stated,

> [My brother] has a right to make choices whenever he is capable to do so and it makes it easier for me knowing that I'm doing what [he] wants … so that that's already validating and helps me stay strong and convicted with what I'm doing.

The interview transcripts revealed that siblings were concerned about their brother or sister's wellbeing and happiness. Although some have not taken on the advocacy role as strongly as Brooke and Emily, all siblings in this study wanted to ensure that their brother or sister with Down syndrome is treated fairly and that their needs and wants have been met.

Involved in disability organizations or their sibling's care. In addition to speaking up for their brother or sister when others are not accepting or being ignorant towards their siblings' condition, they also see the need for individuals to educate themselves on Down syndrome. As a

result, they may become involved in disability organizations or their sibling's care. Stephanie feels that it is sometimes necessary to be involved in the planning and maintenance for her brother's care, attending meetings with his support worker and potential group homes. She said, "now I'm older and I have training in [disabilities and mental health] too, I like to go and like kind of see how their look on it is."

Sabrina talked about being involved in various Down syndrome organizations as a child, saying, "there's a lots of programs and stuff that [my brother has] been in growing up. Like, my family is part of the Down Syndrome Association of [our town] so we'd always go to the Christmas parties and everything." At these parties, Sabrina and her family had the opportunity to interact with other families of children with Down syndrome and become more knowledgeable about the condition. In a family where a sibling does not have a brother or sister with Down syndrome, it may be unusual to be this involved in their sibling's life. Taking on these roles to support their brother or sister is a way to maintain balance within the family, and improve family adaptation, as shown in the FAAR model (Patterson, 2002). With these shifts in roles, the family is able to employ healthy coping behaviours and improve relationships between family members, especially siblings.

Discussion

A review of the literature suggested that research often focuses on the parents of individuals with Down syndrome, rather than the sibling relationship. The available studies describe the sibling relationship as a positive one, noting that those who have a brother or sister with Down syndrome have lower levels of distress, are better able to adapt to new situations, and

have a close relationship with their sibling, especially when compared to those who have a sibling with a different disability, such as Autism (Hastings, 2007; Hodapp & Urbano, 2007).

This study aimed to explore the experiences of those who have a brother or sister with Down syndrome through qualitative interviews. Similar to the findings of Skotko and colleagues (2011), most siblings stated that they could not imagine their life without their brother or sister with Down syndrome.

The siblings who participated in the current study see their sibling and family as "normal;" however, they recognize the lack of understanding from society, including formal caregivers, direct support workers, and the general public, about Down syndrome and how this impacted their sibling and their family. Siblings also reported stories of others acting inappropriately or discriminatory towards their brother or sister, but they took this as an opportunity to discuss the positives associated with Down syndrome, rather than believing it to be an embarrassment or burden. Again, these results are similar to the findings of studies that suggest that having a sibling with Down syndrome gives them an opportunity to develop empathy and compassion, and a chance to adapt to new situations (Skotko et al., 2011; Skotko et al., 2016). However, other studies have not discussed the negative views of others in much depth. This study provides examples of how society views people with health conditions and disabilities, and further research may be warranted to uncover ways to approach these situations, both for the families and to provide more education to the general public.

Siblings also discussed their shift of roles within their family or their sibling's life. Many take on an advocacy or caregiving role for their sibling, which was also reported in a 2006 study by Skotko and Levine. Skotko and Levine (2006) suggested that siblings of individuals with

Down syndrome felt that they were capable and helpful when taking on roles to assist their sibling, such as by teaching or babysitting them. The current study found that siblings are willing to take on these new or extra roles, and that it makes their relationship with their sibling or family closer. Heller and Arnold (2010) found similar results, as the researchers suggest that siblings of individuals with a disability often take on a greater supportive role than in "typical" sibling dyads.

For some, shifting their role within the family may be a necessity. The findings of the current study are consistent with The Family Adjustment and Adaptation Response (FAAR) model (Patterson, 2002). The siblings report some hardships associated with having a sibling with Down syndrome, including the ignorance from others and worries about their sibling's wellbeing. During this time, the family must make adjustments to adapt to these situations and adjust their worldview. For some siblings, this means taking on a caregiving or advocacy role, learning from their sibling or about the condition, or not seeing their sibling as any different than someone without Down syndrome. As a result, siblings are better able to adapt to new situations.

There are many implications that may result from this study and other studies that focus on sibling experiences. Many participants discussed supports, and whether or not they found these supports helpful. Siblings talked about participating in "sib shops" and finding information online and through Down syndrome organizations in which their parents were a part of. One participant suggested a "how to" book, including how to care for their sibling as they get older. Furthermore, this study provides some insight into the demands of having a sibling with Down syndrome. Many studies focused primarily on the positives associated with having a brother or sister with Down syndrome, but some challenges were discussed in this study. Although the

siblings in this study felt that they were adequately able to handle the demands, people with Down syndrome may present with different levels of intellectual functioning and various behaviours. For instance, Stephanie discussed her brother's behavioural difficulties and how it affected their family's ability to do certain things, such as go on vacation; however, Brooke described her brother as gentle, loving, and always happy and discussed very few negative experiences. The literature discusses the Down syndrome advantage; however, this "advantage" may not be apparent in all families with a person with Down syndrome; therefore, it may be crucial to explore the demands in more depth to develop specific and targeted services for siblings and their families and to develop educational and informative programming for helping professionals and teachers in the area of disabilities and health conditions.

As caregiving may be a component to the relationship as the siblings age, additional research and supports should be available to siblings to help them with this transition. All participants in this study were female, which resulted in only presenting the "sister" perspective; therefore, it is strongly recommended that future studies also recruit brothers to be more representative of the population, as there may be differences in their experiences . Other demographic factors, such as urban or rural locations, socioeconomic status, and birth order were not explored. Additionally, further research may be warranted in the knowledge of Down syndrome by health care professionals or teaching staff, and with the input of siblings and families, training programs can be developed for these professionals to help them better serve people with Down syndrome and their families.

Conclusion

Siblings of individuals with Down syndrome maintain close relationships into adulthood. Many siblings discussed how their brother or sister with Down syndrome helped shape them into who they are, a revelation described with pride. However, they recognize the lack of knowledge and lack of supports available for siblings. As such, further research should explore the siblings' experiences, particularly with regards to their needs (e.g., support, education). Additionally, siblings discussed the lack of knowledge from helping and educational professionals; therefore, more research may be warranted on their knowledge of Down syndrome and their families, and educational programming, such as courses and formal training, should be available for this population. Although the current study supports the literature that siblings of those with Down syndrome have positive experiences, further focus on siblings can provide a better understanding of the sibling relationship, as well as the entire family, when a brother or sister has Down syndrome.

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"You do know that your brother's going to die…"

Experiences of Being a Sibling to Someone with Cystic Fibrosis

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"You do know that your brother's going to die…"

Experiences of Being a Sibling to Someone with Cystic Fibrosis

Cystic fibrosis is a fatal genetic condition that causes a build-up of mucus in the lungs (Cystic Fibrosis Canada, 2014). Cystic fibrosis can affect a number of organs, such as sinuses, pancreas, liver, and reproductive system (Ratjen & Döring, 2003). According to Cystic Fibrosis Canada (2014), 1 in ever 3,600 individuals born in Canada have cystic fibrosis, and it is common that individuals with cystic fibrosis experience persistent cough due to thick mucus in the lungs, as well as shortness of breath, frequent chest infections, excessive appetite, weight loss, and bowel abnormalities (Cystic Fibrosis Canada, 2014). As the mandatory treatment methods and therapies involve daily routines that require a significant amount of time, it often involves all members of the family, including parents, grandparents, and siblings (Foster et al., 2001; William, Mukhopadhyay, Dowell, & Coyle, 2007). This study aims to better understand the experiences of those who have a brother or sister with cystic fibrosis, focusing on the demands and capabilities, as outlined in the Family Adjustment and Adaptation Response (FAAR) Model.

Family Research

There is a dearth of literature on the experience of siblings of those with cystic fibrosis. There are some studies available on the parents' experiences, but much of the research is from nearly 30 years ago. Since then, there have been numerous advancements in the treatment of people with cystic fibrosis. Still, the available literature tends to focus on the parents' perspectives.

Janicke, Mitchell, and Stark (2005) reported predominantly negative experiences within families of children with cystic fibrosis, especially during mealtime, as someone with cystic fibrosis has specific nutritional needs to stay healthy. This observational study explored family functioning in school-aged children with cystic fibrosis during mealtime compared to families without a child with cystic fibrosis. Families of a child with cystic fibrosis scored lower in the areas of family functioning, affect management, interpersonal involvement, communication, and behavioural control. However, there were no differences between groups in task accomplishment and role allocation (Janicke et al., 2005). Patterson, McCubbin, and Warwick (1990) found that parents, and mothers in particular, will often neglect their own needs when they have a child with cystic fibrosis to care for. They are faced with worries that parents of children with other conditions (e.g., diabetes or intellectual disabilities) do not have, such as the fatal consequences of cystic fibrosis (Walker, Van Slyke, & Newbrough, 1992). Cowen and colleagues (1985) found that parents of a child with cystic fibrosis may feel more pressure to "do the right thing" by taking proper care of their child, have extra demands, and feel as if they constantly need to watch their child. As such, it is sometimes thought that mothers neglect their other children because their focus is on the child with cystic fibrosis. However, Quittner, Opipari, Regoli, Jacobson, and Eigen (1992) compared mothers of a child with cystic fibrosis to mothers of children without a chronic health condition and it was found that there was no significant difference between the groups in the amount of time spent with their husbands or other children.

Sibling Experiences

Although there is minimal research on families of those with cystic fibrosis, the majority of studies focuses on the parents' experiences. However, some studies have suggested that the

treatment process is stressful on the entire family. The person with cystic fibrosis's physiotherapy primarily relies on the mothers, but fathers, grandparents, and sibling are also involved (William et al., 2007). Through interviews with parents, siblings, and individuals with cystic fibrosis, Foster and colleagues (2001) found that the demanding treatments required constant parental involvement, which in turn, had a direct impact on the sibling as the parents sometimes relied on the siblings to assist with treatments and siblings report receiving less attention while their brother or sister's needs take priority. Similarly, Larocque (2006) found that siblings believed that they sometimes received less parental attention compared to their brother or sister with cystic fibrosis.

However, there are many positives associated with having a sibling with cystic fibrosis. Larocque (2006) found that all 10 adolescent siblings that were interviewed described their family as "normal" and their relationship with their sibling as "typical". Wennström and colleagues (2011) reported siblings of young adults with cystic fibrosis generally have similar self-concepts of self-esteem, skills, and social relationships as other young adults who do not have a sibling with a chronic health condition. Also, Havermans and colleagues (2010) stated that siblings of children with cystic fibrosis scored higher in quality of life measures compared to siblings of children without chronic health conditions.

Yet, it was also suggested that older siblings scored lower on self-esteem measures, and reported a higher impact than siblings younger than the individual with cystic fibrosis (Havermans et al., 2010). A study published in 1997 by Stawski, Auerbach, Barasch, Lerner, and Zimin also suggested that older siblings of chronically ill children were at a significantly higher risk for having internalizing problems. Although there are some negatives, overall, the literature

suggests that having a sibling with cystic fibrosis is a positive experience. However, the current literature tends to focus on children with cystic fibrosis and their families. With advancements in treatment methods, those with cystic fibrosis are living longer and may continue to require support from their family as they become adults. This study explores the experiences of siblings aged 16 and older, and provides a better understanding of the siblings' experiences and potential needs as their brother or sister with cystic fibrosis age.

Methodology

The current study is part of a larger project, exploring the sibling experiences of people who have a brother or sister with a chronic health condition or disability. A basic interpretive approach (Merriam, 2002) was used, consisting of semi-structured interviews. Interpretative phenomenological analysis (IPA; Eatough & Smith, 2017) was used for the analysis of interviews, as the goal of this study was to understand the overall experiences of being a sibling to someone with cystic fibrosis. The Family Adjustment and Adaptation Response (FAAR) model guided this study, and the development of the following research question: What are the experiences, including demands and capabilities, when being a sibling to someone with cystic fibrosis? The FAAR model focuses on the tasks that families perform to balance family demands (stressors) with family capabilities (coping behaviours; Patterson, 2002a, 2002b). When faced with a crisis, the family must employ coping behaviours and resources during the adjustment phase to help the family regain balance and return to the adaptation phase. Using this model, the interview questions were developed with the understanding that family members experience many hardships and daily hassles, but also use various resources to help cope in those situations.

Interviews

Twenty semi-structured questions were developed for a larger project, using a basic interpretive approach (Merriam, 2002), and provided an in-depth look into the experiences of siblings of those with cystic fibrosis, including the capabilities and the demands. These questions were designed to understand the sibling's overall experience, and focused on demands and capabilities, as discussed in the FAAR model (Patterson, 2002a, 2002b). Questions included "tell me about a typical day in your household?" or "how would you describe your sibling?." Prompts were used as needed.

Participants

Eight brothers and sisters of individuals with cystic fibrosis participated in this study. The ages of the participants ranged from 16 to 28 with a mean age of 21.8 (*SD*= 4.7). Five siblings were females and three were males. Seven participants were the biological siblings, and one was adopted. Four participants were older than their sibling, and four were younger. Participants' ages and general demographic information can be found in Table 3.

Participants were recruited through word of mouth, social media postings, and by contacting Cystic Fibrosis Chapters throughout Canada. Pseudonyms have been used to protect the participants' identity and privacy. It is important to note that Jason and Dylan are brothers, and Lucy and Kelsey are sisters; therefore, although eight siblings were interviewed, there were only six brothers or sisters with cystic fibrosis that were discussed. Additionally, at the time of the interviews, all individuals with cystic fibrosis were living, with the exception of Bree's sister, who had passed away approximately four years prior to the interview.

Table 3: Cystic Fibrosis Participant Characteristics

Pseudonym	Age	Gender of Sibling with cystic fibrosis	Age of Sibling with cystic fibrosis
Amanda	20	Female	15
Bree	28	Female	*Deceased*
Dylan	16	Male*	21*
Jason	18	Male*	21*
Kelsey	26	Male†	22†
Lucy	28	Male†	22†
Stacey	22	Male	20
Tony	16	Female	19

*†Denotes the same sibling, as Jason and Dylan are brothers with one brother with cystic fibrosis, and Lucy and Kelsey are siblings with one brother with cystic fibrosis.

Analysis

Interviews were audio recorded and transcribed verbatim, with the participants' consent. Interpretative Phenomenological Analysis (IPA; Eatough & Smith, 2017) was used to analyze the data in this study. IPA is the exploration of the participant's personal world by recognizing important or interesting statements the participant says (Smith & Osborn, 2008; Smith, Flowers, & Larkin, 2009). The transcriptions were read a number of times. Then, noteworthy or significant statements that the participant made were logged in the left-hand margin of the page. The transcripts were read again and emerging themes and connections were made throughout the data (Smith & Osborn, 2008). Based on these connections, themes and subthemes were developed.

Results

Siblings described their lived experiences of having a brother or sister with cystic fibrosis, including many capabilities, as well as demands. They often saw themselves as having a “typical" or “normal” relationship with their sibling, comparing their relationship to other sibling dyads where one individual does not have a chronic health condition. However, it was clear that their experiences included many factors that are not present in sibling relationships where one member does not have a chronic health condition, such as worries about health. These interviews were analyzed using IPA, and four main themes emerged, including Caregiving and Responsibilities, Worries, Improving Treatments and Increasing Supports, and Affecting the Sibling’s Own Future. Within these themes, siblings discussed the demands and stresses associated with having a brother or sister with cystic fibrosis and how their sibling’s chronic health condition influences their life, particularly the way they see the world around them. Lastly, siblings discussed their capabilities, such as coping behaviours and supports that were used to help manage these demands in times of distress.

Caregiving and Responsibilities

All participants reported taking on a caregiving role or felt responsible for their sibling in various ways. Individuals with cystic fibrosis require a lot of extra care that an individual without cystic fibrosis may not require. The extra care may include daily treatments such as physiotherapy, medication, and masks. Siblings recognized their roles in their sibling’s life, and often took on a caregiving position, a position that some siblings took on with pride, but others felt negatively about the additional responsibilities. Siblings felt that they needed to re-evaluate their position within the family and how it relates to their sibling by taking on these new

responsibilities and making adjustments in their lives to better suit the needs of their family. As these responsibilities may change over time depending on their sibling's health or changes in the family's dynamics, the sibling may need to go through repeated cycles of adjustment. Caregiving is further explored in two subthemes, "Recognizing their role as caregiver" and "Negative feelings towards taking on extra responsibilities."

Recognizing their role as caregiver. Participants discussed that they take care of their sibling, even if their sibling is older. For some, taking care of their sibling means helping with daily therapies, including patting their sibling's back as part of physiotherapy or administering medication. It may also include ensuring that their siblings are taking care of themselves. The siblings talked more about their role as caregiver as children and adolescents, but are not as actively involved in their siblings' care as they reach adulthood. However, they still recognized it as a potential responsibility.

Many siblings discussed helping their brother or sister with mandatory therapies. Amanda explained, "I learned how to do [physiotherapy] fairly early because when I would babysit her I would have to do it." Similarly, Kelsey stated that she sometimes felt responsible for her brother when she was a child and adolescent, adding that she often mixed his enzyme pills with applesauce to assist her parents in the caregiving process. Some siblings, such as Dylan, wanted to be more involved in their sibling's care. He stated, "I tried [to help] before but I just couldn't (laughs)… I would sit down when I tried doing [the physiotherapy] and I'd put in on his lower back and it was supposed to be higher on his back." He further indicated that he finds it hard not being involved in his brother's care.

All siblings also reported that they planned to continue acting as caregivers as time goes

on. Kelsey explained that she feels less responsible for her brother as he gets older, and understands that he can take care of himself. However, as his older sister, she still has some sense of a "protector" and caregiving role. Lucy has some worries about the future, particularly the overwhelming impact it may have on her life. She explained,

> I guess when I picture my life in the future, like I see myself having a family and um you kind of like wonder how you would be able to juggle all of that, like how you would be able to juggle caring for a sibling who's in the hospital potentially, potentially your aging parents, your own children, um, potentially your child you know that might have challenges themselves just based on family history, um, I guess it's maybe a little bit overwhelming.

However, when discussing caregiving roles, the focus was more so on their current or past responsibilities for their brother or sister, rather than the future. Despite the fact that these siblings take on extra responsibilities and a caregiving position for their brother or sister, it was often described with pride. But for some, there was sometimes annoyance involved with helping their sibling.

Negative feelings towards taking on extra responsibilities. Siblings often have to take on more responsibilities in their home, such as chores, compared to other brothers or sisters who do not have a family member with a chronic health condition. The family's focus is often on the care of the sibling with cystic fibrosis, which in turn, can take away attention and time from the brother or sister without a health condition and may cause some jealousy or frustration. Lucy explained that at family meals, her brother would be exempt for completing chores. She stated, "The expectation was always that the kids did the dishes, but [my brother] would be like 'oh, you

know, I'm really tired right now' and he would go upstairs, but it was conveniently every time we had to do the dishes." She and her sister sometimes felt frustration towards their brother in these situations where the family expected less of their brother with cystic fibrosis. Tony indicated that he is sometimes bothered by the fact that his sibling requires extra care, and how this care may include his involvement. He stated, "We're doing therapy twice a day, it's difficult. If my mom goes away, you know, I have to do it. It is, sometimes, it is kind of time consuming. But irritating." Although he expressed his irritation with helping his sibling, he also understands his family's dependence on him to help.

Lucy described having to take on the responsibility of educating her brother about cystic fibrosis. She described that her parents did not speak about the illness or the effects that it has on her brother. She explained, with some annoyance, that her parents had not provided her brother with "straight answers" about cystic fibrosis. She thinks that her family may have underestimated his understanding and his abilities. She suspected that her brother used the internet to find out more about his illness, and so she decided to take it upon herself to answer any questions that her brother had. She said,

> I don't know how I knew but I think I knew that he was looking that stuff up and so I just kind of said to him, you know, if you ever have any questions or you want to talk about something, feel free you can come talk to me about that or, you know, that kind of stuff… that was kind of how I felt protective for him with like the information surrounding [cystic fibrosis].

Lucy felt that it was her role as an older sibling to provide him with that information and be protective by being straightforward with her brother, because her parents were not. The information included the negative consequences of the illness, which can be a challenging, but necessary, conversation to have with a sibling.

Worries and Concerns

Worry was discussed in many contexts. Siblings discussed their fear of losing their sibling, due to potential future health problems, such as surgeries or life expectancy. Also, they were concerned that their brother or sister will not be able to do things in the future, such as meeting milestones, due to their cystic fibrosis. Siblings discussed how these demands affected their daily lives and how they viewed the world, as most siblings talked about their brother or sister dying at a young age, which may not be a thought for someone who does not have a sibling with cystic fibrosis. They reported feelings of hope that their sibling will have the same opportunities as an individual without a chronic health condition, but recognized that their illness may impact their ability to live a long life or have children. Two subthemes, "Health problems" and "Worries about siblings having 'typical' futures" provide a detailed understanding of this theme.

Health problems. Siblings discussed the worry that they experienced when their sibling was in the hospital. They also talked about their fears surrounding their sibling's failing health and life expectancy. Individuals with cystic fibrosis sometimes have prolonged hospital stays, may need emergency care or surgeries, and are more likely to die over thirty years before reaching the average life expectancy of a Canadian. According to Cystic Fibrosis Canada (2015), half of the individuals in Canada who passed away as a result of cystic fibrosis related symptoms

or complications in 2013 were under the age of 35. Other sources, such as Stephenson and colleagues (2017), state that the mean survival age of those with cystic fibrosis is as high as 48.5 years. The life expectancy of a person with cystic fibrosis is significantly lower than the average life expectancy in Canada, which is 81.9 years (Statistics Canada, 2017), indicating that a Canadian with cystic fibrosis may be more likely to have a shorter lifespan than a Canadian without cystic fibrosis. Failing health resulting in death was a worry discussed by all participants.

Dylan described a lot of fears that he has associated with his brother with cystic fibrosis, and noted that he does not have the same worries about his other brother without cystic fibrosis. He explained how he was "freaking out" during one situation where his brother was coughing up blood. He also said, "I hope he's got good health because I'm scared because a lot of people out here that have CF always die at 20, 19, and I'm just really glad that [my brother] has made it this far." Similarly, Jason talked about the life expectancy of someone with cystic fibrosis and how this is often on his mind, saying, "You do know that your brother's going to die or whatever but when will it happen…" As siblings get older, it is often a concern that one will lose their brother or sister in the coming years; however, with siblings of those with cystic fibrosis, the worry is more imminent and can be a reality. Bree, whose sister had recently passed away after two double lung transplants, described the difficulties of seeing her sister in pain. She said, "One of the most difficult parts were when she collapsed on the floor and you have to carry her to the hospital… It's really difficult to see her going through that." Bree, like other siblings, had trouble discussing these difficult situations and expressing the fear they had during these moments.

All siblings talked about their worries associated with their sibling's health and hospital visits, particularly how they fear that their sibling's health will decline. Dylan said, "whenever he

goes into the hospital, and then we just hope that he's in good health." Similarly, when asked what worries him, Tony stated, "that she has to stay [in the hospital] even longer, you know. For her it would suck because she has to be in there and she can't like leave." These fears are not typical in a sibling dyad when a chronic health condition is not present, and are a unique experience to brothers and sisters of people with conditions like cystic fibrosis. Along with their fears of failing health, siblings worry about their brother or sister's ability to lead a "normal" or "typical" life, such as graduating school, getting married, or having children.

Worries about siblings having "typical" futures. In addition to their fears about their sibling's health, they have many concerns about their brother or sister's ability to meet life milestones. They also fear that their sibling will be held back by their condition. The main concern expressed by most siblings was surrounding the life expectancy of people with cystic fibrosis. Jason, whose brother was 20 at the time of the interview, said "If he makes it to 30, I'll be absolutely amazed." This is a common fear and a reality for siblings of those with cystic fibrosis. For some siblings, there was a fear that their brother or sister would not meet "typical" milestones that some may not think twice about. Amanda discussed her worries about her sister's chance to get married and have children. Similarly, when discussing her hopes for the future, Kelsey recognized that her brother may not be able to do things in life that she and her sister without cystic fibrosis are able to do. She stated,

> I guess my hope would be that kind of health continues and that he, um, continues to take care of himself and is able to sort of live life to the fullest and, you know, meet all the milestones that my sister and I will be able to meet.

In addition, the brothers and sisters with cystic fibrosis are faced with other consequences of their illness, including sterility for men. Kelsey continued by saying, "although infertility is part of CF, but there are ways around that…but obviously there's an element of realism in there." Although siblings hope that their brother or sister are able to do the things that they would consider "typical" for those without cystic fibrosis, siblings explained that it may not be in their brother or sister's future.

Due to potential hospitalizations or failing health, siblings also worried about how cystic fibrosis can affect their brother or sister's ability to be autonomous. With numerous hospitalizations and possible lung transplants in the future, participants discussed how this could affect their sibling's life, and how in turn, this created worries for them. Lucy discussed the "unknowns" associated with her brother's health condition. She worries that her brother's illness will interfere with his ability to work or live on his own. She said,

> I even wonder sometimes if, I mean my parents are in a very stable financial position but you never know depending on if [my brother] can keep a job and my parents' health themselves, like if we're going to need to be some type of life financial support for him.

However, many siblings discussed the element of hope in their lives, and how they look forward to new advancements in care or how more education about the effects of cystic fibrosis should be available to other families of those with cystic fibrosis, or even those in the general public.

Improving Treatments and Increasing Supports

Participants talked about their hope for new therapies and advancements in the care of cystic fibrosis. For some siblings, hope is a coping mechanism (i.e., capability). They discussed

possible cures in the future, or what type of services would be helpful in alleviating stress and worry in siblings and families of people with cystic fibrosis. They also recognized the lack of knowledge from others, which has inspired some individuals (e.g., Bree) to become more involved in cystic fibrosis initiatives, or find solutions to combat these difficulties. This theme is further explored through two subthemes, "Hope for advancements in care" and "The need for more knowledge and support."

Hope for advancements in care. Siblings talked about new technology and how care has evolved over the years. They discussed their hope that it will continue to improve. Dylan recognized that there is a need for new equipment to make daily treatments easier for the individual with cystic fibrosis and their families. When discussing his involvement in his brother's care, Dylan said, "I have thought of making inventions for [my brother]," and talking about the possibility of making a board that would make physiotherapy easier. Amanda also discussed the recent advancements in care and how she hopes that it will improve as her sister gets older. She said, "There's always new treatments… There are just advancements so fast and she is only 15 right now so there's still lots [to come]." Although there are possibilities such as failing health or death associated with cystic fibrosis, the siblings were hopeful that treatments will improve in the coming years that can help their sibling.

Jason discussed his family's spiritual beliefs, including using or not using certain medical interventions for an ill loved one, and how they have impacted his extended family's views of treatment options for his brother. However, he stated that his brother's health comes first in his family, and they are willing to explore treatment methods that others with similar beliefs may not

agree with. He noted that he and his brothers are open to new treatments, saying, "One thing I'd like to see is, um, stem cell research go further."

Currently, there is no "cure" for cystic fibrosis, but in the past thirty years, there have been significant advancements in the care of those with cystic fibrosis, as demonstrated by its increased life expectancy and an estimate that 10.3% of Canadians with cystic fibrosis receive lung transplants (Stephenson et al., 2017). With new advancements, individuals with cystic fibrosis have more opportunity to lead longer lives, which in turn, may significantly decrease the fear that siblings experience in regards to their loved one's life expectancy and health. However, many siblings discussed that they were not exposed to much information on their brother or sister's condition. Their families did not discuss their sibling's health condition at home and they were not kept informed by their sibling's medical team. For many siblings, they relied on resources such as the internet to learn about cystic fibrosis. As such, the siblings recognized that more support and knowledge, particularly from healthcare professionals should be accessible to siblings and those in their community who are interested in knowing more about cystic fibrosis.

The need for more support and knowledge. All siblings talked about lack of understanding from others, and the need for more supports for the entire family. Jason expressed his frustration towards medical professionals who did not talk to the siblings about his brother's condition. The lack of information for siblings impacted his, and other siblings', understanding of the condition, as well as their confidence to support their brother or sister with cystic fibrosis. He said, "Ventolin was never explained to us [by the doctors]. I don't know, maybe it was explained to [my brother], but not to us you know. Obviously they didn't feel any need to explain

it to us." Other siblings shared the frustration of being "left out" or overlooked. Kelsey described how she and her sister would go to their brother's appointments, and yet, no one ever asked how they were doing or feeling about their brother's condition. She further explained how cystic fibrosis was often not discussed in their home, and how talking to someone involved in her brother's care may have been helpful for her and her sister. When asked what she would have wanted from the medical team, she said,

> In the team [at the hospital], having someone to explain to us, kind of, what the disease was about and you know, talk through some of the challenges we might face at an age-appropriate level I think would have been helpful because like I said, there was a lot of taboo in our house growing up and I think having somewhere where we could discuss it openly when we were younger would have been helpful.

Amanda wants others to know more about cystic fibrosis. As a nursing student, she observes the lack of understanding from others, and how many believe cystic fibrosis is a "death sentence." She stated that it is not, and her sister is a "normal kid." Jason also discussed the lack of understanding from others. He explained how his family planned cystic fibrosis fundraisers at his school, but he still felt that others were not making the effort to learn more. He said, "people would just go out of their way for a person with cancer but, you know, my brother is sort of forgot about." Similar statements were made by Jason and other participants when discussing the need for more knowledge.

A major source of information and support in Canada are nationwide Cystic Fibrosis Chapters. Amanda discussed going to cystic fibrosis family social events, saying "[the events]

were really nice to have, and I mean all the parents would come and they would talk about different things that were going on and so. But it was always really fun." However, due to the possibility of spreading infections between those with cystic fibrosis, there are fewer social events available for families. Bree has become very involved in organizations focused on cystic fibrosis. She said, "I'm very passionate about moving forward with the cystic fibrosis chapter here in [my city]," continuing that there were no such supports when she was younger. She discussed how she stepped up to start this chapter after her sister passed away, and is hoping that it can provide more supports for other families affected by cystic fibrosis in her community. Even after her sister's passing, Bree has worked hard to preserve her sister's memory and has made advocacy a big part of her life. Bree, like most participants, discussed how having a sibling with cystic fibrosis affected their own future, including their careers or health choices.

Affecting the Sibling's Own Future

Siblings discussed how having a brother or sister with cystic fibrosis has directly affected their lives and future, including their own health and career choices. Relating to the FAAR model, the siblings adjusted their view on their identity or sense of purpose as a result of having a sibling with cystic fibrosis. Some participants disclosed their willingness to give their sibling a lung. They also considered the genetic component of cystic fibrosis and how that may affect their children or future families. Caregiving was talked about as a possibility in the future, which was previously discussed in the Caregiving and Responsibilities section. Discussion of subthemes, "Career choices" and "Personal health and genetics" will provide a better understanding of how having a brother or sister with cystic fibrosis affects the sibling's future.

Career choices. Having a sibling with cystic fibrosis influenced some participants' future career choices and moving to homes that are in close proximity to their sibling. Two siblings in particular, Amanda and Kelsey, chose to enter the healthcare field. Although they did not directly attribute these decisions to their sibling's condition, they noted that it was a contributing factor. Amanda said, "People ask me why [I study nursing] and then I always say, 'well I've been around hospitals forever, even when I was young, and when I was with my sister. And so I'm comfortable there.'" Similarly, Kelsey discussed that her brother's interactions with healthcare professionals inspired her to go into medicine. However, she felt a lot of pressure from her family to specialize in respirology and cystic fibrosis. She stated, "at a certain point I kind of had to take a step back and say like, you know, it's a little bit to close to home because I think dealing with that on a daily basis would be really hard."

For other participants, they chose career paths or education opportunities that were closer to their family and sibling with cystic fibrosis. In fact, many of the participants in this study either lived with their parents and sibling, or chose to live within a two-hour commute of their sibling. In families of children without cystic fibrosis, a person's decision of where to live or go to school may not be so influenced by their brother or sister. However, in families where a sibling has cystic fibrosis, this was an important factor in their career or living choices, as well as choices related to their own personal health.

Personal health and genetics. Many siblings talked about their own personal health and how their sibling influences their own future healthcare decisions. Siblings of someone with cystic fibrosis have the potential to be a donor if a lung transplant is required. Providing one's

brother or sister with an organ to save their life can be a terrifying experience, but can also bring on feelings of responsibility and acceptance. Siblings also discussed the genetic component of cystic fibrosis, and how their own children may be affected.

Amanda sometimes experienced guilt for smoking cigarettes. She stated, "I've got fairly healthy lungs and here I am like doing this on purpose pretty much where [my sister] has no choice and [her lungs] are wrecked. And what if someday she may need a transplant and I'm doing this to mine, and so that's a big thing." Jason also talked about his efforts to stay away from people who smoke because "I've got to keep my lungs healthy in case [my brother] needs one." If a person has a brother or sister without a health condition, they may not consider how taking care of their own bodies and health can affect their sibling. However, the participants in this study know that keeping their own bodies healthy could improve their chance of being able to donate a lung, a procedure that can greatly improve their sibling's health.

Interestingly, some siblings talked about the possibility of having their own children with cystic fibrosis. Jason explained, "I always worry about growing up as parents, you know, what kind of parent will I become if I have a kid with CF…Will I be able to handle it?" He recognized his parents' struggles with having a son with cystic fibrosis, and is aware that there is a possibility that he carries the gene that causes cystic fibrosis. Not only do these siblings worry about their brother or sister's health and wellbeing, they understand the genetic component of cystic fibrosis and how it may affect their own children or other family members in the future. Lucy stated, "I've seen what it's like with my brother and my parents and like I guess just seeing having that in the family and seeing [my brother] go through it, like you wouldn't want that for

your brother, you wouldn't want that for anyone, you wouldn't want that for your own child." However, she continues that it would not affect her decision to have children. Other individuals who may carry the gene but do not have siblings with cystic fibrosis might not be as prepared for their child's care, compared to someone that has grown up with a brother or sister living with this condition.

Discussion

The aim of this study was to explore the overall experiences of being a sibling to someone with cystic fibrosis, as siblings are often overlooked within the literature. Particularly, research focuses on siblings of children with cystic fibrosis and few studies look at the sibling relationship into adulthood. All sibling dyads, with or without a chronic health condition, changes over time. The FAAR model discusses the need to re-adjust when necessary and when faced with changes or a crisis. As individuals with cystic fibrosis are living longer, understanding the adult sibling relationship is crucial when examining sibling experiences. The findings of this study suggest that siblings see their brother or sister with cystic fibrosis as if they did not have a chronic health condition, often seeing past their sibling's illness; however, they face many demands and capabilities that siblings of someone without cystic fibrosis may not experience. Nevertheless, all siblings reported their experiences as positive. These positive experiences are also reported in studies by Havermans and colleagues (2010) and Larocque (2006).

The participating siblings in this study reported caregiving duties in some way. For instance, many siblings discussed helping with treatments and daily therapies, which some viewed as a demand. It was suggested by the siblings that their brother or sister's treatment included various responsibilities and can be stressful for the entire family, which was also found

in a study by William and colleagues (2007). Although some siblings spoke of their responsibilities with pride, others found these duties annoying.

All siblings discussed worry in some way, which can be viewed as another demand. They have concerns about their sibling's future health and the possibility of hospitalizations and death. According to Cystic Fibrosis Canada (2015), half of the individuals in Canada that passed away as a result cystic fibrosis related symptoms or complications in 2013 were under the age of 35. The average age of living siblings with cystic fibrosis in this study is 19.4. As such, fears about health and death are realities for the participating siblings and their families. Larocque (2006) also discussed worries about their sibling's future health, as well as worries about their sibling having a "typical future." Siblings attribute meanings to these situations, and some have employed various coping behaviours to help manage these stresses.

Siblings also considered various supports that they would like to have to make their experiences more positive. For instance, they all talked about hopes for advancements in care and therapies for their sibling. Additionally, they reported needing more support and knowledge from others. O'Haver and colleagues (2010) reported that 75% of siblings in their study had never spoken to their brother or sister's health care professionals. Siblings in the current study also discussed wanting to be more involved in their loved one's medical appointments, including an age-appropriate explanation about cystic fibrosis or their sibling's overall health.

Lastly, most siblings explored how their experiences of having a brother or sister with cystic fibrosis has influenced their own personal decisions. These personal choices include career paths or personal habits (i.e., smoking), and how the genetic component of cystic fibrosis may

affect their own children, a consideration that is not present in sibling dyads that does not include a chronic health condition such as cystic fibrosis.

This study presented various strengths and limitations. Interviewing the siblings directly is a strength of this study, as it provided them with an opportunity to openly discuss their own personal experiences, rather than obtaining this information through other sources such as parents. Additionally, the study was guided by the theoretical model, the FAAR model (Patterson & Garwick, 1994), which provided structure to the research project and ensured dependability and quality of data collection and interpretation (Shenton, 2004). The FAAR Model offers a way to view family dynamics and family relationships, particularly when faced with various stressors. Interview questions were developed to explore the specific demands and capabilities of having a sibling with cystic fibrosis, while understanding meanings and the sibling's worldview. Siblings discussed facing crises within their families, especially when their brother or sister was hospitalized or became very ill. When faced with these demands, many used various coping behaviours (capabilities), such as talking about the illness or being involved in their sibling's care, to counteract these stressors.

Although the methods were rigorous, there are some limitations to the study. Participant recruitment was mostly through support groups such as cystic fibrosis chapters throughout Canada. In some cases, chapter presidents did not respond to recruitment attempts, were not interested in passing on the study's information, or indicated that their chapter had very few participants or that the families involved did not have other children without a health condition. As cystic fibrosis is a genetic condition, some of the interested participants also had cystic fibrosis. However, the goal of this study was to explore the experiences of siblings who do not

also have the condition, as their experiences would be different compared to a brother or sister who also has cystic fibrosis. Future research should also explore additional demographic factors, such as birth order and location relative to available community resources. Studies by Havermans and colleagues (2010) and Stawski and colleagues (1992) suggested that older siblings of those with cystic fibrosis experience more internalizing problems than younger siblings; however, this was not explored further in the current study. Socioeconomic status can also be a factor in future studies, as treatments can be expensive and often require travelling to other cities to see specialists. Therefore, siblings from families of different socioeconomic status may have different experiences.

The results of this study have numerous implications, especially in providing support for siblings of individuals with cystic fibrosis. Siblings particularly discussed how they want to know more about cystic fibrosis and be able to discuss it openly with healthcare providers and their families. The results of this study may help healthcare providers on how to involve the family as a whole when providing treatment to the sibling with cystic fibrosis. As the sibling experience is often overlooked, this study stresses the importance of sibling involvement and including the entire family when a member has a chronic health condition like cystic fibrosis. Additionally, this study focused on siblings aged 16 and older as adult sibling dyads are not explored as often as children siblingship.

As many siblings are involved in their brother or sister's treatments, information should be provided to them about the various treatment methods, and they should have an opportunity to discuss their concerns or accomplishments with other siblings through support groups or organizations, either online or in person. Lastly, this study provides a better understanding of the

relationship between siblings when one has cystic fibrosis and the other does not, which will aid in the development of resources for the family.

Conclusion

Siblings of those with cystic fibrosis report close relationships, but recognize that their experiences may be different than in sibling relationships where one person does not have a chronic health condition. Most siblings discussed their caregiving responsibilities with pride, though some recognized that they are sometimes annoyed or feel that their parents pay more attention to their siblings. There are many worries associated with having a life-threatening illness such as cystic fibrosis, but have many hopes for the future such as medical advancements and better therapy options. When appropriate capabilities, such as having hope, are applied in situations of stress and worry (demands), the sibling is making adjustments to restore balanced functioning within the sibling and family relationship (Patterson, 1988). This study adds to the current literature available on sibling experiences of those with cystic fibrosis, their relationship, and may help provide a better understanding on what supports and services should be available for siblings. Additionally, as people with cystic fibrosis have access to advancements in treatments and are living longer, this study brings insight into the adult sibling relationship, which to the author's knowledge, has not been explored.

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Chapter Four: Conclusion

The current manuscript-based thesis adds to the literature of being a sibling to someone with a chronic health condition, specifically Down syndrome and cystic fibrosis. Two research articles are included in this thesis; one that focuses on the overall experiences of having a brother or sister with Down syndrome, and another that aims to better understand the experiences of having a sibling with cystic fibrosis. In this chapter, similarities and differences are discussed. In addition, the findings of these studies are related back to the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988) and the larger project. Lastly, ensuring the quality of qualitative research, considerations for future research, knowledge translation, and clinical implications are also explored.

4.1 Summary of Findings

Within this manuscript-based thesis, two articles were developed, exploring the lived experiences of being a sibling to someone with Down syndrome or cystic fibrosis. Although very different health conditions, having a family member with Down syndrome or cystic fibrosis affects the family's dynamics and worldview, and siblings shared some similar experiences. Furthermore, Down syndrome and cystic fibrosis are both lifelong conditions that are can be diagnosed shortly after birth. Symptoms of Down syndrome include intellectual and psychological effects, but can also include many physical difficulties, including heart and lung defects, thyroid abnormalities, and stunted growth, (Mitchell & Ziegler, 2013). Thus, Down syndrome is often referred to as a "disability" rather than a chronic health condition. As a result, Down syndrome and cystic fibrosis are often not seen as comparable conditions within the

literature, and to the author's knowledge, no other study has compared the experiences of siblings of someone with Down syndrome and siblings of individuals with cystic fibrosis.

The first research question, "What are the experiences, including demands and capabilities, when being a sibling to someone with a chronic health condition?" was explored within the two articles (see Chapter 2 and Chapter 3). The second research question, "How are the experiences different and similar between siblings of individuals with Down syndrome and cystic fibrosis?" will be explored within this section.

The first article, "He's kind of shaped me into who I am today": Experiences of Being a Sibling to an Individual with Down syndrome, is an exploratory study that focuses on the experiences of having a brother or sister with Down syndrome. The experiences of siblings are often overlooked (Stoneman, 2005), as the literature focuses on the experiences of primary caregivers or parents. The literature suggests that having a sibling with Down syndrome is a generally positive experience, and that siblings believe that they are better people because of their loved one with Down syndrome (Skotko et al., 2011; Skotko et al., 2016). Interviews consisting of twenty semi-structured questions were completed with seven siblings of individuals with Down syndrome.

Results showed that siblings often saw their sibling as "normal" and looked past their condition. They also viewed their family as having "typical" relationships that they compared to families without a member with Down syndrome. The FAAR model explains that family members make situational and global or worldview meaning of their loved one's health condition. These meanings influence how they approach demands and uplifting experiences. Within social models, disabilities in particular are viewed as impairments that are "non-standard"

or not seen in the majority of individuals (Goering, 2015). As a result, many view disabilities or health conditions with a negative view because they may believe that these individuals are "lacking" in some way (e.g., impaired speech, non-functional organs, missing limbs). However, these "impairments" may or may not be met with a negative evaluation by the individual with a disability or their families (Goering, 2015). The siblings in this study evaluated their brother or sister with Down syndrome as "normal" or "typical," and made a point of discussing this throughout the interviews, perhaps in part because of the lingering biases and social views of Down syndrome.

Siblings recognized the lack of understanding from others, including those within society who may underestimate their brother or sister. They also discussed the ignorance of various healthcare and teaching professionals, and how they sometimes needed to take on an advocacy role in these situations. Consequently, the siblings interviewed described personal growth and being better people because of their sibling with Down syndrome, similar to the findings of Skotko and colleagues (2011, 2016). They also experience a shift in roles within the family to better suit their sibling's needs. This relates back to the FAAR model (Patterson, 1988), as adjustments had to be made within the family in order to maintain balance between the family's demands and capabilities. For example, when faced with demands, such as their parents aging, participants employed capabilities to adjust. For some siblings, there was a shifting of roles in the family and they took on caregiving responsibilities or found available resources such as group homes or healthcare providers to aid the family in these "crises." As such, the family's balance returns and they are in the adaptation phase.

The second article, titled "You do know that your brother's going to die…" Experiences of Being a Sibling to Someone with Cystic Fibrosis", explored the experiences of having a sibling with cystic fibrosis. Similar to the methods of the first article, semi-structured interviews were completed with eight siblings of someone with cystic fibrosis. The twenty interview questions were developed using a basic interpretive approach (Merriam, 2002), and the data were analyzed using Interpretative Phenomenological Analysis (IPA; Eatough & Smith, 2017; Smith & Osborn, 2008; Smith et al., 2009). The experiences of siblings of those with cystic fibrosis included hassles, as well as uplifting situations. Many siblings took on responsibilities, such as helping their brother or sister with daily therapies, with pride, though some found it annoying and time-consuming. Foster and colleagues (2001) also found that therapies involved the entire family, and noted that some siblings felt that their parents focused primarily on that sibling's health and treatments. Additionally, siblings have worries that brothers or sisters of those without health conditions may not have, particularly related to their sibling's failing health. They described feeling scared for their sibling's future, and felt constant concern for their sibling. Siblings in the current study have hope for the future and discussed various needs, including advancements in care. Finally, having a sibling with cystic fibrosis affected their own personal decisions about their health or career choices. As cystic fibrosis is genetic, there are concerns about their own future children's wellbeing, a worry that is not typically present in sibling dyads where a chronic health condition is not present.

There are various similarities between the findings of these two articles. Siblings in both groups often take on additional responsibilities or roles within their family that their friends who do not have a sibling with a health condition would not have. Additionally, there are numerous

worries and negative feelings as a result of having a sibling with a chronic health condition. Lastly, all participants discussed supports, or lack of supports, for siblings of individuals with Down syndrome or cystic fibrosis. These similarities, as well as differences between sibling groups, are further described below.

4.1.1 Roles within the Family. Siblings in both the Down syndrome and cystic fibrosis groups described their roles within the family, and the additional responsibilities that they have as a result of having a brother or sister with a chronic health condition. All siblings discussed taking on a caregiving role in some respect. For those with a sibling with Down syndrome, this caregiving role included being involved in their sibling's care, such as working with healthcare providers or helping their sibling plan for their future. Additionally, siblings of individuals with Down syndrome often became the "voice" of their sibling when their brother or sister is unable to express their needs. They also described their roles as a "protector." Although it may be stressful at times, siblings generally discussed these roles with pride. Similarly, siblings of those with cystic fibrosis reported being involved in their sibling's care by attending appointments and helping with daily therapies. Most siblings were happy to be involved in their brother or sister's care, though some found it "annoying." Siblings in the cystic fibrosis group also described taking on a role as their sibling's protector. However, these roles differed. Many of the siblings in the cystic fibrosis group had more responsibilities for their sibling's care in the past, and these responsibilities lessened as their sibling got older and became more autonomous. Alternatively, those in the Down syndrome sibling group described more responsibilities as they got older and as their parents, their sibling's primary caregivers, aged. Although siblings of individuals with

Down syndrome and siblings of those with cystic fibrosis took on caregiving responsibilities within the family, the type and extent of the role differed between groups and across the lifespan.

4.1.2 Worries and Negative Feelings. All participants expressed worries associated with their sibling's condition. As the average life expectancy is lower for individuals with these chronic health conditions when compared to the general population (Cystic Fibrosis Canada, 2015; Kliegman et al., 2015; Statistics Canada, 2017), siblings recognized that their sibling might die before them. This was especially a concern for those with a brother or sister with cystic fibrosis, and their negative feelings and worries are primarily about their sibling's failing health and impending death. Although siblings in the Down syndrome group were also concerned with their sibling's failing health, their worries were more related to their sibling's ability to be autonomous. For instance, participants who have a sibling with Down syndrome were more concerned about where their brother or sister will live, if they will be able to take care of themselves, and who will take care of them on a daily basis. These concerns were not as prevalent within the cystic fibrosis group, though some siblings were concerned that their brother or sister would not be able to get married or have children due to the life expectancy and symptoms associated with cystic fibrosis. Unfortunately, some siblings do not feel that they have the support or knowledge to deal with these difficulties.

4.1.3 Supports. Lastly, siblings discussed various supports and lack thereof. Most siblings of those with Down syndrome explained that their families were very open with discussing Down syndrome and being involved in their sibling's care. However, many siblings of individuals with cystic fibrosis expressed that their families did not speak about their sibling's condition or the consequences of their illness as openly as they would have liked. Siblings in

both groups felt that others were not knowledgeable about their sibling's condition, and some wanted to be able to speak to their brother or sister's healthcare professionals. Additionally, there are various organizations, including Down syndrome support groups or cystic fibrosis "chapters" throughout Canada; however, siblings explained that they are generally focused on providing support and services for their parents and there are minimal opportunities for siblings to get involved to gain knowledge. Some siblings chose to obtain their own knowledge and support, particularly through their own research or by choosing career paths that are related to their sibling's condition, such as a career in the medical field or social services, or they chose to live close to their sibling to be more involved in his or her life. Overall, siblings of those with cystic fibrosis and Down syndrome discussed wanting more support to help them deal with the stresses associated with their sibling's condition.

4.2 Relation to the FAAR Model and the Larger Project

The Family Adjustment and Adaptation Response (FAAR) Model is used to better understand how a family maintains balance in times of adversity by using resources and coping behaviours (Patterson, 1988; Patterson & Garwick, 1994, 1998). The findings of the current study were interpreted using the FAAR model to better understand the sibling experience.

The FAAR model is based on a family's ability to be resilient when faced with stress (Patterson, 2002a), where a family must adjust and adapt when facing a crisis. The components of the FAAR model also apply to siblings, and as such, the current study explored the stressors and adversities that siblings experience when having a sibling with a chronic health condition, and how they employ coping strategies and supports to restore balance and maintain healthy family relationships. Throughout this study, siblings described many experiences that they

viewed as positive or uplifting. They shared stories of how growing up with their sibling contributed to their close relationship or how it has positive implications on their behaviour or choices. However, siblings also discussed numerous stressors and demands associated with having a brother or sister with a chronic health condition. These demands include treatment-related stresses, the sibling's symptoms and impairments, the sibling's health, as well as changes in the family, such as the sibling's autonomy or change of needs as they get older. Various capabilities and "adjustments" were examined. Siblings discussed a number of supports, including discussing the condition with family, friends, or healthcare professionals when available. Some siblings were also involved in health organizations and have met other families of those with Down syndrome or cystic fibrosis. These supports helped the siblings, and family as a whole, cope in times of stress. Additionally, siblings often sought out additional information and knowledge about their brother or sister's condition. For some, being involved in their sibling's care and being open and honest with their family about their sibling's condition was also helpful. Many siblings took on new roles within the family, including being their sibling's voice, caregiver, or protector, to maintain balance within the family dynamics. Overall, it was found that siblings that had more support from others and were more involved in their sibling's care had closer relationships to their brother or sister with a chronic health condition, and felt that their family was generally more cohesive. However, not all siblings were able to obtain balanced functioning due to lack of capabilities, including support from family, friends, and helping professionals, unsure of how to deal with the lack of understanding from others, or feeling that they do not have an opportunity to discuss their concerns with others. These findings parallel the FAAR model, as families who employ capabilities in times of distress are able to

restore balance within their family dynamics and are able to adapt to these negative situations. There are some limitations of using the FAAR model with siblings. According to the Family Systems theory, from which the FAAR model evolved, one must study each family member's relationship to every other family member, and understand the various components within the context of the family (Becvar & Becvar, 2018). As this study focuses on the siblings' experiences, it may be argued that the FAAR model is not an appropriate theoretical model when examining the experiences of siblings. However, as the literature expands to include more studies on sibling experiences, the entire family system will be better understood.

The findings in this study contribute to the aforementioned larger project. The larger project focuses on the experiences of siblings when they have a brother or sister with a chronic health condition or disability, including Fetal Alcohol Spectrum Disorder, Autism Spectrum Disorder, Down syndrome, and cystic fibrosis. All of the listed conditions are life-long and have no "cure," and affect the entire family as a whole. The larger project uses a mixed-methods approach (Johnson & Onwuegbuzie, 2004) that includes a semi-structured interview and two questionnaires. The questionnaires used in the larger project include Sibling Inventory of Behaviour Scale (SIBS; Schaefer & Edgerton, 1981; Hetherington et al., 1999) and The Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2006).

The current study contributed to the larger project by incorporating further data on siblings of those with Down syndrome, and introducing a new group of siblings, those with a brother or sister with cystic fibrosis. This study focused primarily on the qualitative interviews, rather than incorporating a mixed-methods approach.

4.3 Ensuring the Quality of Qualitative Research

Ensuring quality and trustworthiness when conducting qualitative research is crucial. According to Merriam (1998), trustworthiness is how well a particular study does what it is supposed to do. There are four components to ensure trustworthiness in qualitative research: credibility, transferability, dependability, and confirmability (Guba, 1981; Shenton, 2004). In an attempt to warrant all four components of trustworthiness, multiple strategies were employed. These strategies include frequent peer reviews, member checks, and extensive audit trails.

Credibility is often compared to internal validity in quantitative research (Guba, 1981; Shenton, 2004). The researcher is often seen as an "instrument" in qualitative research (Guba & Lincoln, 1981; Denzin & Lincoln, 2017), which may lead to bias. Therefore, transparency is essential. As such, a reflexivity section is often recommended where the researcher articulates their biases and self-reflects (Denzin & Lincoln, 2005; Toma, 2006). A reflexivity section was included in the first chapter of this document (see section 1.7), which explored the author's personal and professional experiences that may have influenced the interpretation of the research. Furthermore, Interpretative Phenomenological Analysis (IPA; Eatough & Smith, 2017; Johnson & Osborn, 2008; Smith et al., 2009), a well-established qualitative analysis method, was used in this study, providing further credibility.

Peer reviews, including reviewing data and interpretations with colleagues involved in the larger project, as well as the author's supervisor, were critical components of maintaining credibility. Frequent contact with the author's supervisor was made to ensure that the interpretations were not biased, and that the analysis was valid. Additionally, preliminary results and analyses were presented to peers involved in the larger project, as well as fellow academics

at research conferences, and input and scrutiny of the results were welcomed. Member checks were also employed. According to Guba and Lincoln (1989), member checks may be one of the most important components to ensure credibility in qualitative research. The author often checked with participants during and after the interview to ensure that the information was understood as the sibling intended.

Transferability, or external validity, is how well the findings of a study can be applied to other situations (Merriam, 1998; Shenton, 2004). Throughout this study, the author obtained extensive background data to help establish the context of this study, which included immersing oneself within the available literature, attending conferences on the topics of qualitative research and chronic health conditions, and becoming familiar with available resources for families of an individual with Down syndrome and cystic fibrosis. Furthermore, extensive details surrounding chronic health conditions, their families, and the current study have been provided, which aids readers in understanding the relevant background information necessary for this study.

Qualitative research's reliability is assessed through its dependability (Guba, 1981; Shenton, 2004). To ensure dependability, Shenton (2004) recommends that study's procedures be outlined for readers. These procedures, including the research design, the details in relation to gathering data, and reflection on the process, are outlined within chapter 1 to chapter 4. In addition, this study was guided by a theoretical orientation, the FAAR model (Patterson, 1988). The FAAR model was used when developing the interview questions and guided the research questions, analysis, and reporting of data.

Lastly, audit trails were used to ensure the confirmability, or objectivity. Audit trails allow others to follow the course of the research (Shenton, 2004), as the researcher includes notes of

decisions or processes throughout the analysis (Smith et al., 2009). Audit trails also contribute to a study's credibility and dependability (Tuckett, 2005). As the final interpretations may be significantly different from the raw data, audit trails may provide a better understanding as to how a researcher arrived at a conclusion. Therefore, an audit trail, including handwritten notes and numerous drafts, was maintained throughout the course of this study.

4.4 Considerations and Recommendations for Future Research

Qualitative methods were employed with rigor throughout this study; however, there are still considerations to be made regarding the two articles. Furthermore, suggestions for future research will also be explored in this section.

A main limitation within this study is related to issues with recruitment. Participants were recruited by contacting health organizations and requesting that the information related to the study be passed on to its members. As a result, some siblings may have presented a bias when discussing available supports, as they were already involved in local organizations. Unfortunately, many organizations were unwilling to provide their members with information on this study, and some did not respond to the author's emails or phone calls. Participants were also recruited through social media advertisements and word of mouth. Many siblings were not willing to complete interviews or withdrew their interest. Furthermore, this research project was first designed as a mixed-methods study, including an interview and two questionnaires. The quantitative results of the questionnaires would further triangulate the results, but many participants did not complete the questionnaires, even with reminders. Therefore, this study focused on the qualitative data obtained.

Another consideration is the demographics, including age, gender, and location of participating siblings. In the first article that focuses on the Down syndrome group, all siblings interviewed were females, which resulted in only presenting the "sister" perspective. It is strongly recommended that future studies recruit both sisters and brothers as participants, as a brother may bring a different perspective. Additionally, having male and female participants would be more representative of the population. Additionally, the location of the siblings, such as urban or rural communities, was not explored. Some siblings discussed lack of supports in their "small towns," but as this was not a focus of the study, it was not thoroughly investigated. Additional research may be warranted to compare siblings that live in more urban locations and those who live in rural areas. Further demographic information, such as socioeconomic status may also be a factor of interest in future research, as it may contribute to the resources available to families, such as respite services, specialists not covered by provincial healthcare insurance, or travel expenses to see healthcare professionals.

4.5 Knowledge Translation

Knowledge Translation (KT) is the synthesis, dissemination, exchange, and ethically-sound application of knowledge. The goal of KT is to improve the health of Canadians by strengthening the healthcare system by providing effective healthcare services (Canadian Institutes of Health Research, 2015; Fredericks, Martorella, & Catallo, 2015). As research is crucial for the development of healthcare services, the findings of this research will be shared with knowledge users through various methods, including publication and presentations.

The outcomes of the current study is relevant among various fields, including but not limited to clinical psychology, nursing, social work, education, and pediatrics. Therefore,

individuals involved in these areas should work as an interdisciplinary team to provide resources and supports for siblings of those with chronic health conditions within various settings, including schools, clinics, and support groups. Dissemination of results within these settings can assist in recognizing needs for siblings, and either developing or improving available supports. The results of this study can then be shared with families and siblings of individuals with health conditions, through their healthcare professionals or community resources. Additionally, the present research will be published in peer-reviewed academic journals, which will add to the available research on families of people with chronic health conditions

4.6 Clinical Implications

Siblings in the current study described numerous demands and capabilities associated with having a brother or sister with Down syndrome or cystic fibrosis. For those who do not have a brother or sister with a chronic health condition, these experiences are very different from the sibling experience in typically-developing sibling dyads. As various supports and services for siblings may be developed by a professional who does not have lived experiences similar to the participating siblings in this study, research such as the current study is crucial for developing the most appropriate supports or develop educational programs for these helping professionals to learn more about chronic health conditions such as Down syndrome or cystic fibrosis.

Many siblings interviewed discussed not having someone to speak to about their experiences, and some felt that it was helpful when they were able to talk about their concerns or their sibling's condition openly and honestly. Particularly, siblings struggled with various life transitions, such as their sibling's failing health, their sibling's ability to take care of themselves, or what will happen when their parents (the sibling's primary caregivers) can no longer care for

their brother or sister. Therefore, supports including social support groups and professionals specializing in one-on-one support is a major clinical implication of this study. Some siblings wanted an opportunity to discuss their concerns with other siblings experiencing the same difficulties. Although there are peer support groups for siblings (e.g. "Ship-shops"), the siblings that participated in these groups felt that the programs were not adequate in addressing the siblings' worries. The available resources and supports may need to be evaluated to ensure that it is meeting the specific needs of the siblings involved, such as discussions on future caregiving, coping with the failing health or death of a sibling, and where to find additional support if needed. Mentorship opportunities can also be developed as in-person or online programs to ensure accessibility for all siblings.

By better understanding the sibling relationship when an individual has a chronic health condition, a clinician will be better able to tailor supports. As the stresses of having a sibling with a health condition can be stressful, it may manifest into other difficulties including anxiety or depression, feelings of guilt, or even grief if the sibling becomes increasingly ill or perishes.

Additionally, healthcare professionals and clinicians should offer family-focused services, such as family therapy. A concern by some siblings, especially those in the cystic fibrosis group, is that their parents or families do not like discussing their sibling's condition. However, this may prove difficult for some families, as siblings worry about their parents (Larocque, 2006) and may not want to add to their parents' responsibilities by worrying about them. Nevertheless, siblings talked about improving communication within their family and how they believe this would help them cope with difficulties associated with their sibling's health condition. By providing services for the entire family, it can promote cohesiveness and

understanding within the family unit, which may also address the psychological impact that siblings and their families may experience as a result of the stress associated with their sibling's condition.

Lastly, training programs and educational efforts can be developed using the results of this study. Various programs can be developed for the families of those with a chronic health condition, but also for those involved in the individual's care (i.e., healthcare professionals, teaching staff), as well as the general public. As the sibling's needs are often overlooked, it is crucial that brothers and sisters of those with chronic health conditions are consulted during the development of these programs. Some siblings discussed a lack of knowledge not only in the general public about their sibling's condition, but also by those who are meant to help their families. Healthcare professionals may face barriers when working with families of someone with a chronic health condition, as they need to be proficient in family-centred care practices, in addition to patient- or client-centred care. Kuo and colleagues (2012) stated that the principles of family-centred care should be recognized and implemented by nurses when caring for a patient. Nurses, doctors, and other helping professionals should be able to access additional training as needed to be better equipped when working with someone with a chronic health condition and their family. By offering training and general information to the public about individuals with chronic health conditions, including their symptoms, needs, and the role of the family in their care, it will better bridge the knowledge gap that many siblings described in their interviews.

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Appendix A: Laurentian University Research Ethics Board Approval

APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS
Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New X / Modifications to project / Time extension

Name of Principal Investigator and school/department	Krystina Tyandovski with Shelley Watson, supervisor, Psychology
Title of Project	Sibling experiences in families of a child with a disability: Down Syndrome, Cystic Fibrosis and Cerebral Palsy
REB file number	**2016-01-13**
Date of original approval of project	February 26, 2016
Date of approval of project modifications or extension *(if applicable)*	
Final/Interim report due on: *(You may request an extension)*	February, 2017
Conditions placed on project	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the

study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PHD, Chair, *Laurentian University Research Ethics Board*

Appendix B: Study Recruitment Flyer

"Sibling Experiences in Families of a Child with a Disability: Down Syndrome and Cystic Fibrosis"

Are you the sibling of a child with Down syndrome or cystic fibrosis?
Are you a parent of a child with Down syndrome or cystic fibrosis who has a brother or sister without one of these conditions?
Would you like to tell your story or have them tell theirs?

If so, please contact Kristina Trandovski, BASc at ktrandovski@laurentian.ca orShelley Watson, Ph.D. at 705-675-1151 X4223 (or toll free 1-800-461-4030) swatson@laurentian.ca for more information.

Birth and adoptive siblings are invited to participate.

Kristina Trandovski, BASc
Department of Psychology
Laurentian University
935 Ramsey Lake Road
Sudbury, ON, Canada
P3E 2C6

Appendix C: Interview Guide

1. How old are you?
2. How many siblings do you have?
3. How old are they?
4. How old is (insert name of sibling with chronic health condition)?
5. Did your sibling grow-up in the same home as you?
6. Was your sibling adopted?
7. How did you find out that your sibling has Down syndrome/cystic fibrosis?
8. How would you describe (insert name of sibling with chronic health condition)?
9. What is it like to be (insert name of sibling with chronic health condition)'s sibling?
10. Tell me about a typical day in your household.
11. What is a favourite memory you have with him/her?
12. What are some of your favourite activities to do with (insert name of sibling with chronic health condition)?
13. What is the best part of being a sibling to (insert name of sibling with chronic health condition)?
14. What are some difficult parts of being a sibling to (insert name of sibling with chronic health condition)?
    a. What helps you handle the difficult parts (insert name of sibling with chronic health condition)?
    b. How often do you engage in these activities?
15. How do other children/classmates act towards you and your sibling?
    a. How do you react to this?
16. How do you see the future for your sibling?

   a. What do you worry about?

   b. When you worry, how do you cope?

   c. Who do you talk to when you are worried?

17. How do you see your future?

   a. What role do you think you will play in your sibling's future?

18. Are there any supports you would like or is there anything that would help you in your relationship with your sibling (insert name of sibling with chronic health condition)

19. If you could speak to others who have a brother or sister with Down syndrome/cystic fibrosis, what would you tell them?

20. Is there anything else you think I should know about your relationship with your sibling?