INFORMING THE DEVELOPMENT OF AN INTERNET-DELIVERED MENTAL HEALTH PROGRAM FOR YOUTH WITH CYSTIC FIBROSIS:
A QUALITATIVE STUDY

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By
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Hilary A. Power, candidate for the degree of Master of Arts in Clinical Psychology, has presented a thesis titled, *Informing the Development of an Internet-delivered Mental Health Program for Youth with Cystic Fibrosis: A Qualitative Study*, in an oral examination held on September 6, 2019. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

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Abstract

Youth with cystic fibrosis (CF) and their parent caregivers have been shown to experience elevated psychological symptoms. The need to address these issues through providing appropriate information and services to this population is evident. At present, there is no specific mental health program designed for youth with CF in Canada. The current study qualitatively examined the information and service needs of youth with CF. Participants \((n = 16)\) included five youth with CF \((M_{\text{age}} = 9.40, SD = 1.01)\), seven parent caregivers \((M_{\text{age}} = 36.43, SD = 3.46)\), and four CF health care professionals \((M_{\text{age}} = 44.00, SD = 10.46)\) recruited from CF clinics and chapters in Saskatchewan, Canada. Participants completed a brief demographic questionnaire. Semi-structured individual interviews were conducted with all participants. Thematic content analysis was used to analyze the data collected for each participant group. Four major themes were uncovered from youth participant responses: (1) challenges living with CF, (2) building independence, (3) coping, (4) bridging gaps in services. Six major themes were uncovered from parent participant responses: (1) emotional challenges (2) social challenges, (3) demanding treatments, (4) coping, (5) encouraging independence, and (6) improving services. Six major themes were uncovered from health care professional participant responses: (1) emotional challenges, (2) social challenges, (3) lifestyle restrictions, (4) developing independence, (5) barriers to care and managing CF, and (6) focusing on future mental health care. The findings highlight the many challenges experienced by youth with CF and their families. The results also draw attention to the importance of providing effective support in managing and coping with CF. Information gathered in the present study will be later used, in combination with the empirical
literature, to inform the development of an evidence-based, Internet-delivered mental health program for this population.

*Keywords*: Cystic fibrosis, psychopathology, children, adolescents, Internet intervention, mental health, qualitative design
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1.0 Chapter 1: Introduction

Cystic fibrosis (CF) is a progressive, fatal, genetic condition amongst children and young adults (Cystic Fibrosis Canada, 2018). CF impairs the function of many organs, with its greatest effects on the lungs and digestive system, resulting in persistent cough, thick mucus, and recurrent lung problems (Accurso, 2008). Aside from being one of the most difficult health conditions to manage (Quittner et al., 2014), adolescents with CF and their parent caregivers have been found to experience elevated symptoms of depression and anxiety (Bregnballe, Thastum, & Shiotz, 2007; Quittner et al., 2014; Smith, Modi, Quittner, & Wood, 2010), as well as impairments in quality of life (Riekert, Bartlett, Boyle, Krishnan, & Rand, 2007). The corresponding impact on functioning is concerning as psychological symptoms in individuals with CF and their parents has been associated with a variety of health variables such as decreased lung function (Goldbeck, Beiser, Hinz, Singer, & Quittner, 2010; Yohannes, Willgoss, Fatoye, Dip, & Webb, 2012), and increased hospitalizations and health care costs (Snell, Fernandes, Bujorneau, & Garcia, 2014). In the interest of addressing these issues, providing appropriate information and mental health services is necessary; however, currently there is no specific mental health program available for children and adolescents with cystic fibrosis.

The following thesis includes an overview of CF and research on the psychological functioning of children and adolescents with CF, as well as their parent caregivers. Additionally, the information and service needs of this population are considered with reference to specific recommendations that have been made in the current literature regarding the need for intervention. Common barriers associated with traditional mental health service delivery are explored and innovative methods to
navigate these barriers are suggested as a feasible intervention to address the needs of children and adolescents with CF. Furthermore, the research objectives, detailed methodology, statistical analyses, and results are discussed. A discussion of the study results, its limitations, and future directions are also presented.

1.1 Cystic Fibrosis

Cystic Fibrosis (CF) is a rare, life-limiting, fatal genetic disease. Approximately 1 in 3600 children in Canada are born with CF and over 4300 Canadians living with CF visit specialized CF clinics (Cystic Fibrosis Canada, 2018). The CF population in Canada has been steadily increasing, with a growth of 36.8% in the last twenty years (Cystic Fibrosis Canada, 2018). The Canadian Cystic Fibrosis Registry (CCFR) reported 124 individuals living with CF in Saskatchewan in 2017, 61 of those individuals being children and adolescents. Currently, there is no cure for CF (Cystic Fibrosis Canada, 2018). CF occurs when an individual inherits one abnormal gene from each parent (Cystic Fibrosis Canada, 2018). When two parents who are carriers have a child, there is a 25% chance the child will not have cystic fibrosis and will not be a carrier, a 25% chance the child will have cystic fibrosis, and a 50% chance the child will be a carrier (see Figure 1). Approximately one in 25 Canadians are carriers for an abnormal version of the gene responsible for CF (Cystic Fibrosis Canada, 2018).

1.1.1 Pathophysiology. CF is a complex and multisystem disease (Antoniou & Elston, 2016; Frizzell & Pilewski, 2004). The disease is an autosomal recessive condition caused by a genetic mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) protein (REF). More than 2000 CFTR mutations have been identified and create various degrees of CF severity (Cystic Fibrosis Canada, 2018). CF affects the body in
several ways, with the main effects being on the lungs and digestive system (Cystic Fibrosis Canada, 2018). A build-up of thick mucous causes severe respiratory issues, and mucous and protein accumulation in the digestive tract also result in difficulty digesting and absorbing nutrients from food (Antoniou & Elston, 2016; Cystic Fibrosis Canada, 2018; Hurt & Bilton, 2012). Although the majority of morbidity and mortality is associated with respiratory disease, other organs are also affected by CF including the pancreas, liver, intestines, and bones (Antoniou & Elston, 2016).

1.1.2 Symptom features and complications. CF affects several of the body’s systems. This disease causes dehydration of the respiratory epithelium and defective mucous clearance in the lungs, resulting in viscous secretions that are predisposed to bacterial colonization, airway inflammation, and recurrent infection (Antoniou & Elston, 2016; Frizzell & Pilewski, 2004). Other typical symptoms experienced by individuals with CF include persistent cough, shortness of breath, wheezing, frequent chest infections (e.g., pneumonia), bowel disturbances, weight loss or failure to gain weight, pancreatic insufficiency, deficiency of fat-soluble vitamins, salty tasting sweat, decreased fertility in women and infertility in men (Antoniou & Elston, 2016; Cystic Fibrosis Canada, 2018).

People living with CF often have exacerbations of the disease or experience complications caused by CF, such as an increase in symptoms of chronic lung infection, cough, and sputum production (Elbron, 2016; McCourt et al., 2015). Chronic lung infection and airway inflammation often lead to bronchiectasis, a disease enlargement of parts of the airways of the lungs, as well as progressive airflow obstruction in most individuals with CF (Antoniou & Elston, 2016; Hurt & Bilton, 2012; McCourt et al., 2015). Exacerbations and complications are associated with increased breathlessness,
Figure 1. Genetic breakdown of CF

- Carrier Father
- Carrier Mother

- Unaffected Child: 25%
- Child Carrier: 50%
- Child with CF: 25%
fatigue, and reduced exercise tolerance (McCourt et al., 2015; Stenbit & Flume, 2011). Other complications include difficulty digesting fats and proteins, malnutrition and vitamin deficiencies as a result of being unable to absorb nutrients, CF-related diabetes, and sinus infections (Cystic Fibrosis Canada, 2018). Effective treatment of exacerbations is critical, as increased frequency of exacerbations is associated with greater decline in lung function, reduced quality of life, and poor overall survival (de Boer et al., 2011; Stenbit & Flume, 2011; Waters et al., 2012).

1.1.3 Diagnosis. The diagnosis of CF is usually made by the identification of clinical symptoms suggestive of CF, positive family history of CF, positive newborn screening, sweat chloride tests, or genetic testing (Elborn, 2016; Hurt & Bilton, 2012; Filbrun, Lahiri, & Ren, 2016). The majority of cases of CF are diagnosed early in life by newborn screening (Antoniou & Elston, 2016). Data demonstrating the importance of early diagnosis led to efforts to develop newborn screening for CF (Filbrun et al., 2016). During the diagnosis process, blood is taken from a heel prick in newborns to search for markers of pancreatic injury indicative of CF (Antoniou & Elston, 2016). If concentrations of the marker are high, genetic testing and a sweat test are administered (Antoniou & Elston, 2016). The sweat test assesses CFTR dysfunction and involves measuring the amount of salt content present in the sweat (Antoniou & Elston, 2016). Two CFTR mutations combined with sweat test results that are positive and indicate that the sweat collected contains more salt than usual, supporting a diagnosis of CF (Antoniou & Elston, 2016; Cystic Fibrosis Canada, 2018).

In cases where individuals have not been diagnosed through newborn screening, the diagnosis of CF is made when a patient presents with clinical features and symptoms
suggestive of CF (Filbrun et al., 2016). The signs and symptoms a patient may present with vary widely, as CF affects multiple organ systems; however, some examples may include recurrent pneumonia or bronchitis, chronic cough, nasal polyps, fat soluble vitamin deficiencies, prolonged neonatal jaundice, salty tasting skin, and/or unexplained liver failure (Filbrun et al., 2016). Although newborn testing and sweat testing diagnose many cases of CF, there are still individuals who remain undiagnosed until later in childhood and adulthood (Filbrun et al., 2016).

1.1.4 Treatment. CF is complex and progressive, stressful to manage, and requires time-consuming treatments (Goldbeck, Fidika, Herle, & Quittner, 2014). At present, there is no cure for CF, however, due to medical advances, the life expectancy of individuals with this chronic disease has been increased and the large majority of children with CF survive into adulthood (Dodge, Lewis, Stanton, & Wilsher, 2007). In Canada, individuals with CF are living to a median age of 52.3 years (Cystic Fibrosis Canada, 2018). Despite this increase in life expectancy, CF continues to be one of the most difficult chronic health conditions to manage (Quittner, Alpern, & Blackwell, 2012) and long-term management of this disease has become an important focus (Goldbeck et al., 2014).

Coordinated CF care programs delivered by multidisciplinary teams including physicians, nurses, physiotherapists, dietitians, and psychologists are recognized to result in the most favourable outcomes for individuals with CF (Antoniou & Elston, 2016). Treatments that improve the clearance of mucus from the lungs and treat consequent infections, in combination with combatting pancreatic insufficiency and malabsorption of nutrients, have resulted in improvements in clinical outcomes and quality of life in
individuals with CF (Elborn, 2016). As the severity of symptoms and experience of CF differs from person-to-person, individualized and age-specific treatment programs are required (Elborn, 2016); however, the basis of treatment management for CF involves treatment of lung infections, optimization of nutritional status and management of CF-related complications such as CF-related diabetes (Antoniou & Elston, 2016). The management of respiratory disease, using chronic pulmonary drugs such as nebulized antibiotics and mucolytic agents, aim to prevent the onset of infections, maintain lung function, and prevent or reduce the frequency of pulmonary exacerbations. Studies have reported the benefits of chronic pulmonary drugs in improving lung function, reducing the frequency of exacerbations and improving quality of life in individuals living with CF (Fuchs et al., 1994). Other airway clearance techniques are also incorporated and are an integral part of treatment regimens, such as chest physiotherapy (Antoniou & Elston, 2016; Hurt & Bilton, 2012). Chest physiotherapy techniques may include active cycle breathing, autogenic drainage, and mechanical devices such as positive expiratory pressure (PEP) masks (Antoniou & Elston, 2016).

Pancreatic insufficiency, poor weight gain and deficiency of fat-soluble vitamins occurs in approximately 85% of individuals with CF (Antoniou & Elston, 2016). Additionally, low body mass index (BMI) is a poor prognostic indicator in CF. As a result, nutrition has become a target in treatment and maintaining a healthy BMI is an important aspect of disease management (Antoniou & Elston, 2016). Individuals who experience pancreatic insufficiency often require the incorporation of pancreatic enzymes, supplemental vitamins, and nutritional supplements in their treatment programs to optimize their nutritional status (Antoniou & Elston, 2016).
In addition to treatment interventions that are both complex and time-consuming, preventative practices have also been suggested to maintain health status and manage the disease. Person-to-person spread of respiratory pathogens is a danger to individuals with CF. Consequently, patients are managed in single rooms within CF care facilities and are advised not to socialize together (Hurt & Bilton, 2012). Many CF clinics implement strict isolation practices to ensure no person-to-person contact (Saiman et al., 2013; Schaffer, 2015). Although this reduces cross-infection, contributing to maintaining physical health in individuals with CF, the segregation and restriction of individuals results in a loss of peer support (Elborn, 2016; Ramsay et al., 2013).

The requirement of adherence to complex and demanding treatment regimens, that can take up to four hours per day to complete, is a difficult task and poses many challenges for individuals with CF and their caregivers (Abbott et al., 2015; DeLambo, Ievers-Landis, Drotar, & Quittner, 2004). Barriers to implementing treatment regimens have been identified and include the time-consuming nature of treatments, the unpalatability and side effects of particular treatments, poor family functioning, and child oppositional behaviour (Everhart, Fiese, Smyth, Borshuk & Anbar, 2014; Modi & Quittner, 2006; Santer, Ring, Yardley, Geraghty, & Wyke, 2014). Overcoming challenges associated with treatments and dealing with childhood resistance to treatments can be stressful and experienced as a burden for caregivers (Santer et al., 2014). Strict treatment adherence can interfere with other priorities, such as preserving family relationships, providing a “normal life” for the family, and promoting well-being (Santer et al., 2014). Additionally, adolescents may experience embarrassment in taking their treatment and claim it interferes with their social life (Llorente, Garcia, & Martin, 2008).
Although one of the goals of treatment is to improve quality of life, high treatment burden may heighten the risk of poor adherence, having a negative impact on health and well-being of individuals with CF (Ireland, 2003; Sawicki & Tiddens, 2012).

1.2 Chronic Illnesses and Psychological Functioning

Chronic illness has shown to be a risk factor for psychological problems (Bennett, 1994). Children, adolescents, and adults with chronic health conditions (e.g., congenital heart disease, neuroblastoma, acute lymphoblastic leukemia, degenerative neurological disease, Duchenne muscular dystrophy, asthma, diabetes, traumatic brain injury, fibromyalgia, epilepsy, spina bifida, sickle cell disease, metabolic diseases), as well as their parent caregivers, are at increased risk for psychopathology, including symptoms of depression and anxiety, and impairments in quality of life (Fauman et al., 2011; Hatzmann, Heymans, Ferrer-I-Carbonell, Van Pragg, & Grootenhuis, 2008; Moussavi, Chatterji, Verdes, & Tandon, 2007; Pinquart & Shen, 2011). Children and adolescents living with a chronic illness face difficulty related to their illness such as hospitalization, restrictions in activities, and stressors related to the course of their illness and the future (Compas, Jaser, Dunn, & Rodriguez, 2012; de Bruin, Sieh, Zijlstra, & Meijer, 2017; Pinquart & Shen, 2011). The presence of physical symptoms that accompany chronic illnesses, combined with the need for intensive treatment and disease management regimens, are likely to interfere with many aspects of daily life, such as maintaining peer relations and school attendance (Suris, Michaud, & Viner, 2004). Not surprisingly, with these interruptions in daily life, children and adolescents with chronic illnesses have been demonstrated, on average, to have higher levels of depressive symptoms compared with
their healthy peers, as well as reduced health-related quality of life (Alonso et al., 2004; Fortin et al., 2004; Pinquart & Shen, 2011).

In addition to the effects of chronic illness on childhood and adolescent psychological functioning, parent caregivers of chronically ill children are also at risk for increased psychopathology. Parents of children and adolescents with chronic illnesses are often burdened with stressors about their child’s health as well as practical factors such as managing daily routines, relationships with other family members, balancing work schedules and possible financial problems (Cousino & Hazen, 2013; Waters et al., 2017). Studies have found that parent caregivers with children who have chronic illnesses have elevated symptoms of depression (Brown et al., 2006; Daoud, Dooley, & Gordon; 2004; Fauman et al., 2011; Hobdell, 2006), as well as a significantly lower health-related quality of life in areas such as sleep, social functioning, daily activities, and positive emotions (Brehaut et al., 2004; Hatzmann et al., 2008; Lawoko & Soares, 2003; Murphy, Christian, Caplin, & Young, 2007; Youssef, Murphy, Langseder, & Rosh, 2006). Lawoko and Soares (2002) discovered that parents of children with congenital heart disease reported distress (e.g., depression) and hopelessness at greater frequencies when compared with parents of healthy children. The distress severity of a significant proportion (i.e., 18-30%) of parents with children with congenital heart disease matched or surpassed levels observed in psychiatric outpatients, and these caregivers were at a high risk for suicide (Lawoko & Soares, 2002). Further, parents who experience stress have been demonstrated to be less able to manage their child’s illness effectively (Cousino & Hazen, 2013).
1.2.1 Psychological Functioning in Children and Adolescents with CF. An abundance of literature provides evidence of elevated psychopathology (e.g., depression and anxiety) in children and adolescents with CF and their parent caregivers (Bregnballe et al., 2007; Driscoll, Montag-Leifling, Acton, & Modi, 2009; Kostakou et al., 2014; Smith et al., 2010; Yohannes, et al., 2012). Quittner et al. (2014) conducted a large epidemiological study that assessed the prevalence of psychological symptoms, including depression and anxiety, in 6088 adolescents and adults with CF and 4102 parent caregivers. The results revealed elevations in anxiety symptoms in 22% of adolescents with CF, 32% of adults with CF, 48% of their mothers, and 36% of their fathers. Elevated depressive symptoms were present in 10% of the adolescents with CF, 19% of the adults with CF, 37% of their mothers, and 31% of their fathers. These elevations in psychological symptoms were two to three times higher when compared with community samples (Quittner et al., 2014). The findings also demonstrated high rates of comorbidity of depression and anxiety for individuals with CF and their parents (Quittner et al., 2014). Stodolak et al. (2018) replicated the results from Quittner et al. (2014) demonstrating the prevalence of depression and anxiety in youth with CF was 10%. Additionally, associations have been made between symptoms of depression and anxiety experienced by adolescents with CF and parent caregiver symptoms of depression and anxiety (Beiser & Goldbeck, 2011; Quittner et al., 2014).

While these increased psychological symptoms alone are alarming, the associated impairment in quality of life and impact on functioning is also concerning. For example, psychological symptoms in individuals with CF and their parent caregivers is linked to lower health-related quality of life (Riekert et al., 2007), social isolation (Jamieson et al.,
2014), decreased lung function (Ploessl, Pettit, & Donaldson, 2014), lower body mass index (Snell et al., 2014), increased severity of chest symptoms (Yohannes et al., 2012), worse treatment adherence (Bishay & Sawicki, 2016; Hilliard, Eakin, Borrelli, Green, & Riekert, 2015; Smith et al., 2010), more frequent hospitalizations, and increased healthcare costs (Snell et al., 2014). It is evident that several health variables are associated with psychological symptoms in this population and these collective findings highlight that it is necessary to address the psychological functioning of this population.

1.2.2 Psychosocial functioning in children and adolescents with CF. In addition to elevated rates of psychological symptoms, children and adolescents with CF experience several psychosocial challenges that may also impact health outcomes (Muther, Polineni, & Sawicki, 2018). CF is one of the most challenging pediatric illnesses for families to manage (Mitchell, Powers, Byars, Dickstein, & Stark, 2004). Child development in the context of living with a chronic disease can result in unique psychosocial challenges (Muther et al., 2018). Children and adolescents with CF have reported feelings of isolation from peers, as well as difficulty establishing friendships as a result of being absent from school due to hospitalizations and illness (Jamieson et al., 2014). Children and adolescents with CF also experience lifestyle restrictions such as avoiding environments that can cause increased health risks (Jamieson et al., 2014; Cammidge, Duff, Latchford, & Etherington, 2016). These restrictions contribute to increased feelings of loneliness and difficulty relating to experiences of their peers (Jamieson et al., 2014). Adherence to strict treatment routines may also impact the psychological health of children and adolescents with CF, as well as their families (Muther et al., 2018). The burden of managing treatment routines may cause stress and
impact family functioning (Muther et al., 2018). Understanding the psychosocial challenges of children and adolescents with CF and their families, and integrating preventative approaches to mitigate risk factors to improve the mental health and wellbeing of those impacted by CF may be important.

1.3 Information and Service Needs

Based on the aforementioned prevalence rates of psychological symptoms in children and adolescents with CF and their parent caregivers, as well as the many psychosocial challenges they experience, there is need for mental health programs designed to address these symptoms and cope with these challenges. Prior to designing such programs, it is necessary to understand the information and service needs of children and adolescents with CF. Engaging patients with CF and parents early in the development of prevention and intervention programs may enable services to be tailored appropriately based on their needs (Everhart, Molitor, Wentx, Schmidt, & Schechter, 2019). Bregnballe et al. (2007) suggest that young children may not be informed well enough about their disease. The uncertainty, lack of knowledge, and lack of coping skills in young people with CF may be related to the psychological issues and distress they face (Anton-Paduraru, Ciubara, & Miftode, 2015; Bregnballe et al., 2007). Further, adherence to some CF treatments has been associated with disease knowledge. Disease knowledge has been shown to be suboptimal in adolescents with CF, and may be a potential explanation for poor adherence (Faint, Staton, Stick, Foster, & Schultz, 2016). Moreover, Everhart et al. (2019) found that parents of children with CF expressed interest in receiving more information and services related to helping their child manage their CF independently, cope with feelings of isolation or abnormality related to having CF, and manage their
stress, anxiety and mood. An important step to relieve anxiety, optimize treatment adherence, and improve disease management is possibly providing CF-related information, as well as information on effective coping strategies for children and adolescents with CF.

The International Committee on Mental Health in CF (ICMH) has developed recommendations for the identification and treatment of mental health risk factors in CF Centers internationally (Quittner et al., 2016). Recommendations include incorporating mental health screening annually, as well as offering education and preventative, supportive interventions to develop effective coping and disease management skills during all routine care for all individuals with CF and their parent caregivers (Quittner et al., 2016). It is suggested that for all individuals with CF that experience symptoms of depression and anxiety, there should be a flexible model of clinical intervention developed and implemented in close collaboration with patients, caregivers, CF healthcare providers, and mental health specialists.

1.4 Barriers in Traditional Methods of Mental Health Service Delivery

Designing and promoting a consistent and comprehensive approach to the assessment of and intervention for mental health needs of children and adolescents with CF and their parent caregivers would be ideal; however, there are numerous barriers to traditional mental health services (i.e., face-to-face, in clinic) that interfere with effective service delivery. For example, there may be a lack of resources to provide the proposed care and consequently, the resources that do exist may be underutilized (Beiser & Goldbeck, 2011). Other barriers also exist, including living in a rural setting that requires substantial travel to access care (Fidika et al., 2015; Ritterband & Palermo, 2009), limited
qualified mental health professionals available to provide treatment (Weisz, Hawley, & Jensen-Doss, 2004), financial restrictions and time conflicts (March, Spence, & Donovan, 2009). With regard to social support, traditional, face-to-face, disease-related support groups are curtailed in individuals with CF due to infection control (Saiman et al., 2013). While support groups are often recommended for individuals with chronic illnesses, infection prevention and control guidelines prevent that type of face-to-face intervention (Saiman et al., 2013).

A study by Salloum, Johnco, Lewin, McBride, and Storch (2016) highlighted the previously mentioned common barriers to treatment access and participation among anxious children who participated in a computer-assisted cognitive behavioural therapy (CBT) program. Their findings demonstrated that barriers to accessing effective treatments and barriers that affect participation in treatments can delay or prevent individuals who are in need of mental health care from receiving appropriate services. The results stressed the importance of providing accessible, time-efficient, engaging, and cost-effective methods of mental health service delivery to ensure that individuals receive the care they require.

1.5 Internet-delivered Mental Health Programs

Due to the barriers in traditional methods of mental health service delivery, novel forms of service delivery, such as Internet-based education and treatment, have been proposed as being worthy of investigation (Fidika et al., 2015). There is evidence to support the effectiveness of Internet-based psychological intervention programs for individuals with chronic illnesses. Results from meta-analytic and systematic reviews have shown that CBT delivered online has been effective in addressing concerning
symptoms and behaviours (e.g., anxiety, mood, compliance), and well-received as treatment for children and adolescents with various physical and psychiatric conditions (e.g., asthma, chronic pain, headache, encopresis, traumatic brain injury, obesity, anxiety disorders; Rooksby, Elouafkaoui, Humphris, Clarkson, & Freeman, 2015; Stinson, Wilson, Gill, Yamada, & Holt, 2009; Vigerland et al., 2016).

Numerous studies have investigated the effectiveness of Internet-delivered psychological interventions for children and adolescents with various chronic health conditions. For example, Palermo et al. (2016) conducted a large multicenter randomized controlled trial (RCT) in the United States and Canada examining the effectiveness of Internet-delivered CBT (iCBT) for pediatric chronic pain. The treatment condition demonstrated significantly greater reductions in children’s perceived difficulty in completing daily activities because of pain, as well as reductions in depression and anxiety symptoms associated with pain, compared to the control group. Further, the intervention was effective in improving sleep quality and reducing parent depression and anxiety symptoms. Another study showed iCBT was an effective intervention for improving child adjustment and self-management/compliance following traumatic brain injury (Wade, Carey, & Wolfe, 2006). Additionally, Internet-based education programs for individuals with asthma that are integrated into standardized patient management programs have been demonstrated to improve health outcomes, decrease the burden of disease, and decrease the utilization of healthcare services (Runge, Lecheler, Horn, Tews, & Schaefer, 2006). More recently, Douma, Scholten, Maurice-Stam, and Grootenhuis (2018) developed an online program with the goal of preventing and/or reducing psychosocial problems in adolescents with chronic health conditions through teaching
active coping skills using CBT techniques and are currently evaluating the programs’ effectiveness in a series of randomized-controlled trials (RCT). An abundance of evidence supports the effectiveness of Internet-based treatments for health conditions, suggesting the feasibility of implementing these evidence-based approaches for wide dissemination to specific populations.

There is also evidence to support Internet-delivered programs in treating childhood psychological conditions. Studies investigating the effectiveness of computerized CBT in children and adolescents have found this intervention to result in reductions in emotional symptoms, such as anxiety (Attwood, Meadows, Stallard, & Richardson, 2012). One RCT evaluated the effectiveness of Internet-delivered cognitive CBT (iCBT) for children with anxiety disorders (Vigerland et al., 2016). The results demonstrated significant reductions in clinician severity ratings of anxiety for the treatment group with a large between-group effect size when compared with the waitlist control group at post-treatment. They also found that 50% of children in the treatment group no longer met criteria for their principal diagnosis at the three-month follow up assessment, and parent-reported child anxiety was significantly lower in the treatment group (Vigerland et al., 2016). These results suggest Internet-delivered methods of mental health service delivery, such as iCBT, are effective in reducing childhood psychopathology symptoms.

With respect to CF specifically, researchers in other areas of care, such as physiotherapy, are investigating the emerging area of Internet-delivered treatments and possibilities to increase access to care through developing online programs (Lang, Wilson, Stockton, Russell, & Johnston, 2019). Within the area of psychological
programs, Fidika et al. (2015) developed and evaluated a web-based psychological support program (WEP-CARE), incorporating principals of CBT, for severely distressed parent caregivers of children with CF in Germany. The results showed that caregivers’ symptoms of anxiety decreased significantly between pre- and post-intervention. They also demonstrated reductions in fear of disease progression and improved quality of life. Although these results are promising, to date there are no interactive, Internet-delivered programs designed for mental health service delivery for children and adolescents with CF. Considering children and adolescents with CF face different challenges related to their illness than their parent caregivers such as social isolation, stigma, and fears related to disclosure of their illness, the need for an intervention tailored to the specific needs of children and adolescents is imperative (Jamieson et al., 2014).

An Internet-delivery method of mental health program for individuals with CF is a viable and appealing option as the Internet is widely accessible to Canadian children, adolescents, and parent caregivers. This form of delivery would also eliminate the need to travel to a CF clinic or health facility and reduce health care costs, making the program more accessible (Hedman, Ljotsson, & Lindefors, 2012). Further, offering a service using the Internet provides a potential opportunity to create a social support component for children and adolescents with CF that would be otherwise unavailable in a face-to-face format. Prior to designing and implementing this type of program however, it is necessary to gain insight into what components children and adolescents with CF and their parent caregivers would perceive as beneficial inclusions in the program, as well as to determine their perceptions of receiving mental health services via the Internet.

1.6 Rationale for a Qualitative Approach
A qualitative approach was employed in the current study. The rationale for employing a qualitative approach and the previous usage of a qualitative approach for the development of an existing Internet-based program for chronic pain in children will be explored (Stinson et al., 2013; Stinson et al., 2014; Stinson et al., 2016). The benefits of employing a qualitative approach to examine the experiences of individuals with CF will also be discussed.

1.6.1 Qualitative design. Previous research has indicated that in-depth insights into people’s beliefs and attitudes can be gained through qualitative research (Jamieson et al., 2014). Several studies have used qualitative research designs to inform Internet-based therapy (e.g., Berry, Bucci, & Lobban, 2017; Eysenbach et al., 2016; Garmy, Berg, & Clausson, 2015; Stinson et al., 2013; Stinson et al., 2014; Stinson et al., 2016). Such designs have shown to be informative in capturing the experiences of individuals who will participate in the program, identifying components that are useful to include in the program, examining attitudes toward receiving services via the Internet, identifying potential barriers and facilitators to interventions, and indicating considerations for increasing engagement and acceptability of programs (Berry et al., 2017; Eysenbach et al., 2016; Garmy et al., 2015).

Specifically, an Internet-based program for adolescents and young adults with chronic pain, iCanCope with Pain, used qualitative methods to inform the development of the program (Stinson et al., 2013; Stinson et al., 2014; Stinson et al., 2016). This Internet-delivered chronic pain self-management program was designed through several phases. The first phase consisted of two qualitative studies that explored the information and service needs of adolescents and young adults with chronic pain to inform the
development of the program (Stinson et al., 2013; Stinson et al., 2014). Stinson et al. (2013) reported that by using a qualitative design, patients and providers are directly involved in the planning and design of new intervention tools. Involving the users of the intervention early in the process of development ensures that the intervention is relevant and useful to the specific population (Stinson et al., 2014). The next phase of the project involved the development of a prototype of the iCanCope with Pain program in accordance with the information obtained in phase one. The prototype for the program included components on symptom self-monitoring, goal setting with respect to improving functioning, coping techniques, peer-based social support, and pain education (Stinson et al., 2014). The third phase of the project is currently being completed as a pilot RCT to evaluate the program’s effectiveness and participant satisfaction (Stinson et al., 2016). Finally, the program will be refined based on the findings from the pilot study and will be further evaluated in a second RCT that will be conducted in the fourth phase of this research (Stinson et al., 2016).

Jamieson et al. (2014) suggest that more qualitative research should be conducted on the topic of the psychological functioning and needs of individuals with CF. A limited number of qualitative studies have been conducted in Canada that focus on children and adolescents with CF. Previous studies in Canada have explored social support (Ellerton, Stewart, Ritchie, & Hirth, 1996), transition to adult care (Moola & Norman, 2011), physical therapy (Moola, Faulkner, & Schneiderman, 2012), and parental support (Bregnballe et al., 2011) related to CF. Other CF-related qualitative studies outside of Canada conducted thus far have mainly explored the transition to adult care (Boyle, Farukhi, & Nosky, 2001; Brumfiled & Lansbury, 2004; Palmer & Boisen, 2000; Al-
Yateem, 2012), support from family and friends (Graetz, Shute, & Sawyer, 2000), growing up with CF (Admi, 1996; Christian & D’Auria, 1997; D’Auria, Christian & Richardson, 1997), quality of life (Henry, Aussage, Grosskopf, & Goehrs, 2003), stress and coping responses (Patton, Ventura, & Savedra, 1986), psychosocial impact (Bywater, 1981; Hafetz & Miller, 2010; Russo, Donnelly, & Reid, 2006), and adjustment difficulties related to treatments (Foster et al., 2001). Many of these studies were conducted over seven years ago. Completing updated qualitative research is necessary to reflect the current status of experiences, challenges, and needs of children and adolescents with CF. Moreover, several of these studies have only included adolescents and young adults (ranging between ages 12 to 43 years) and lack participation and inclusion of younger children, parents, and health care providers. To-date, no studies have qualitatively investigated the challenges, information and service needs, and perceptions of receiving an Internet-delivered mental health program for children and adolescents with CF.

The current study will employ a qualitative research design (Sandelowski, 2000). Qualitative studies can be used to provide a comprehensive summary of data in the everyday terms of those events (Sandelowski, 2000). They are the method of choice when straight description of phenomena are desired, as is the case in the current study (Sandelowski, 2000). Qualitative research methods enable health researchers to explore questions surrounding barriers and facilitators to change, challenges individuals face, and the reasons for success or failure of particular interventions (Starks & Trinidad, 2007). They have been demonstrated to be valuable in making specific recommendations for future programs, generating information that adds contextual meaning to findings, as well
as allowing for a description of a disease experience beyond the data gained in quantitative methods (Toye, Williamson, Williams, Fairbank, & Lamb, 2016). Qualitative methods can also allow researchers to understand participants better and ensure that time and money is not wasted in trials of programs that may otherwise fail (Toye et al., 2016).

The current study followed the design utilized in developing the Internet-delivered program for chronic pain (Stinson et al., 2013; Stinson et al., 2014; Stinson et al., 2016). It included a series of semi-structured, open-ended interviews with the goal of providing an in-depth, qualitative exploration of the information and service needs of children and adolescents with CF that will be used to inform the development of an Internet-delivered program for this population. A qualitative investigation that includes direct input from children and adolescents with CF, their parent caregivers, and health care professionals, was anticipated to provide valuable information about the specific information and service needs of this population, as well as their views regarding service provision via the Internet.

1.7 Research Objectives

The purpose of the present study was to explore the information and service needs of children and adolescents with CF from the perspective of children and adolescents with CF, their parent caregivers, and health care professionals. To remain consistent, the term youth will be used moving forward to describe children and adolescents within the study. Although there was no participation from adolescents (13-18 years) in the current study, health care professionals and parents described adolescent experiences and thus the term youth will be used. When participants differentiate between experiences of children
(7-12 years) and experiences of adolescents, these terms will be used to clarify the specific group being described. There were five primary research objectives: To investigate (1) what type of information about CF youth with CF need; (2) what challenges youth with CF; (3) what types of services youth with CF; (4) what are the perceived benefits/drawbacks of obtaining service via the Internet; (5) what components should be included in an interactive, Internet-delivered mental health program for youth with CF. The information obtained from this initial study, coupled with existing empirical literature on CF, mental health disorders in youth with chronic illnesses, and the delivery of psychological treatments for youth via the Internet, will be used in the next step of this research to guide the development of an evidence-based, interactive, Internet-delivered mental health program for youth with CF.
2.0 Chapter 2: Methods

2.1 Epistemological Assumptions

Qualitative research is a discovery-based approach that has a goal of understanding and articulating the meaning of people’s experiences (Hadjistravopoulos & Smythe, 2000). Generally, qualitative research takes people’s experiences from their own perspectives rather than according to a universal framework (Hadjistravopoulos & Smythe, 2000). These goals are consistent with a view that psychological and social realities are socially constructed and situated in actual practice (Hadjistravopoulos & Smythe, 2000).

The current study was approached from a social-constructivist position. A social-constructivist paradigm provides the primary foundation for qualitative research methods (Ponterotto, 2005). The constructivist or interpretative position from this vantage point emerges from an interpretative, open-ended, and contextualized perspective of reality (Guba & Lincoln, 1994). Thus, within this paradigm, reality is recognized as being subjective and therefore different persons can have different perspectives on what truth is (Rubin & Rubin, 2005). From this perspective, reality is constructed by individuals and multiple realities can exist. Realities are social and experientially based, specific to the individual in nature, and their form is dependent on the individual persons or groups that possess the constructions (Guba & Lincoln, 1994). In order to organize and explain these constructions or realities that participants hold, the goal for the social-constructivist researcher is to understand the lived experiences from the point of view of those who lived it, and to construct an amalgamation of knowledge that is more coherent,
sophisticated, and informed than before (Guba & Lincoln, 1994; Ponterotto, 2005; Schwandt, 1994; Schwandt, 2000).

The researcher plays a central and active role in order to construct the amalgamation of knowledge (Ponterotto, 2005). Schwandt (2000) described that the meaning behind the realities and constructions of individuals is recognized and uncovered through deep reflection. The variable and personal features of social constructions suggest that these can only be stimulated and refined by the interaction between the researcher and participants in a course of interactive dialogue and interpretation (Guba & Lincoln, 1994; Ponterotto, 2005; Schwandt, 2000). Thus, the researcher facilitates the process of amalgamation of knowledge through interaction with participants where the findings are co-created as the investigation proceeds (Guba & Lincoln, 1994). Given that the current study follows a qualitative framework, I acknowledge that my involvement will necessarily contribute to shaping the realities and social constructions on which I report. The social-constructivist paradigm emphasizes a transactional and subjective stance that maintains that the interaction between researcher and participant is key in capturing and explaining the lived experiences of the participants (Ponterotto, 2005). It has been asserted that “knowledge” must be considered through individual, institutional, and sociocultural lenses (Henwood & Pidgeon, 2003). Thus, researchers are able to generate interpretations and conclusions without compromising the obtained data. Integrity can be preserved through recognizing the epistemological assumptions, and disclosing the subjectivity existing in this research.

2.2 Saturation
The principle of saturation in qualitative research has been defined in several ways (Saunders et al., 2017). From a broad perspective, it is commonly taken to indicate that from the data collection and analyses that have been completed; further data collection and/or analyses are unnecessary (Saunders et al., 2017). Several perspectives exist on how to determine when saturation is reached in qualitative research (Saunders et al., 2017). Saturation has been referred to as the point in research when the same themes are recurring and no new insights are being given by additional sources of data (Bowen, 2008). Additionally, saturation is described as the point when there is enough data to ensure that all research questions can be answered (Bowen, 2008). The depth and quality of data in qualitative research is considered more important than the quantity of data (Burmeister & Aitken, 2012). Saturation involves the inclusion of all variations in responses, not just the frequency of the occurrence of responses (Morse, 1995). When no new perspectives are emerging from the data, it is likely that saturation has been reached. It has been recommended that listing the major research objectives and comparing against the interview data and field notes is useful in ensuring all research questions have been answered sufficiently (Brod, Tesler, & Christensen, 2009). In this way, qualitative researchers should combine data collection and analysis, rather than considering them separate stages of the research process (Bryman, 2012). Saunders et al. (2017) suggested that saturation should be operationalized in a way that is consistent with the research questions and theoretical framework adopted. There is great variation in what number of participants is necessary to reach saturation, however, Guest, Bunce, and Johnson (2006) suggest that saturation for a qualitative research study is achieved with 10-12 participants. In the current study, it was anticipated that 5 youth (7-18 years old), 5 parent
caregivers, and 3 CF health care professionals would be required to reach saturation. Although the goal was to include representation of children and adolescents between ages 7 and 18 years old, given the base rate of children and adolescents in Saskatchewan is 61, there may not be an even distribution of child and adolescent participants (Cystic Fibrosis Canada, 2018).

The current study utilized the guidelines discussed to determine saturation. Saturation was considered across the entire sample, as well as within each separate group of participants included in the study. Saturation was monitored continuously throughout participant recruitment. Data collection and analysis were considered a fluid process rather than a linear process whereby analyses were completed as data were collected and results were compared against the research questions to determine whether the research questions were sufficiently answered (Bryman, 2012; Brod et al., 2009). Following interviews with 5 youth participants, 7 parent participants, and 4 health care professional participants, saturation was achieved. Saturation was apparent for several reasons after the 16th interview. New data were interpreted as redundant of the data already collected (Guest et al., 2006; Grady, 1998). For example, during the interview process, the same comments were made repeatedly. Similarly, during the coding process, it was observed that although there were several instances of the same codes, no new codes were being generated in the data (Urquhart, 2016). Moreover, additional data were not leading to new emergent themes (Birks & Mills, 2015; Olshansky, 2015; Uraquart, 2016). The research questions were answered sufficiently from the perspective of youth with CF, parent caregivers, and health care professionals. Saturation also became apparent as major themes that emerged from each participant group began to overlap across the entire
sample. As nothing new was apparent in the data from each participant perspective, the research questions were being answered, and the objectives of the study were achieved with the information gathered, data collection was discontinued (Francis et al., 2010; Sandelowski, 2008).

2.3 Part One (Youth with CF)

2.3.1 Part One design. Part One of this study involved the examination of the research questions from the perspective of youth with CF. Demographic forms (see Appendix A) were completed by parent caregivers on behalf of youth with CF. Qualitative semi-structured interviews (see Appendix B) were completed to answer the five research objectives of the study from the perspective of youth with CF: (1) What type of information about CF do youth with CF need?; (2) What challenges do youth with CF face?; (3) What types of services do youth with CF need?; (4) What are the perceived benefits and/or drawbacks of obtaining service via the Internet?; and (5) What components should be included in an interactive, Internet-delivered mental health program for youth with CF?

2.3.2 Part One participant recruitment. Youth with CF were recruited from CF Clinics and CF Chapters in Saskatchewan. Informational posters were posted in the CF clinics and information handouts were provided by the CF Nurse coordinator to potentially interested parents and youth (See Appendix C). Additionally, the research investigator was present in a separate room during CF clinic days for youth with CF and their parent caregivers to ask further questions about the study or to sign up to participate. Informational sessions about the study were delivered to CF Chapters in Saskatchewan.
At these sessions Chapter members (i.e., parent caregivers) had the opportunity to ask questions about the study and were given informational posters.

Youth were considered eligible to participate if they were between the ages of 7 and 18 years old, had a CF diagnosis, and could speak and read English. Youth with CF were excluded if they had a severe cognitive impairment or a major comorbid medical or psychiatric illness, as this may have impeded their abilities to participate in the interview process required by the study.

2.4 Part Two (Parent Caregivers)

2.4.1 Part Two design. Part Two of this study involved the examination of the research questions from the perspective of parent caregivers of youth with CF. Demographic forms (see Appendix D) were completed by parent caregivers. Qualitative semi-structured interviews (see Appendix E) were completed to answer the five research objectives of the study from the perspective of parent caregivers: (1) What type of information about CF do youth with CF need?; (2) What challenges do youth with CF face?; (3) What types of services do youth with CF need?; (4) What are the perceived benefits and/or drawbacks of obtaining service via the Internet?; and (5) What components should be included in an interactive, Internet-delivered mental health program for youth with CF?

2.4.2 Part Two participant recruitment. Parent caregivers of youth with CF were recruited from CF Clinics and CF Chapters in Saskatchewan. Informational posters were posted in the CF clinics and information handouts were provided by the CF Nurse coordinator to potentially interested parents and youth (See Appendix C). Additionally, the research investigator was present in a separate room during CF clinics for parent
caregivers to ask further questions about the study or to sign up to participate. Informational sessions about the study were delivered to CF Chapters in Saskatchewan. At these sessions Chapter members (i.e., parent caregivers) had the opportunity to ask questions about the study and were given informational posters. All parent caregivers were eligible to participate if they were able to speak and read English. In the case where two parent caregivers from the same household wished to participate in the study, they were both considered eligible for participation.

2.5 Part Three (Health Care Professionals)

2.5.1 Part Three design. Part Three of this study involved the examination of the research questions from the perspective of health care professionals that work with youth and adolescents with CF. Demographic forms (see Appendix F) were completed. Qualitative semi-structured interviews (see Appendix G) were completed to answer the five research objectives of the study from the perspective of health care professionals: (1) What type of information about CF do youth with CF need?; (2) What challenges do youth with CF face?; (3) What types of services do youth with CF need?; (4) What are the perceived benefits and/or drawbacks of obtaining service via the Internet?; and (5) What components should be included in an interactive, Internet-delivered mental health program for youth with CF?

2.5.2 Part Three participant recruitment. An information session was delivered to CF health care professionals (i.e., physicians, nurses, dieticians, physiotherapists, and social workers) at the CF clinic in Regina, Saskatchewan. At this session, the study was presented, and health care professionals had the opportunity to ask questions. Health care professionals who were interested in participating in the study gave their contact
information (email and telephone number) to the research investigators to be contacted to schedule a time for participation. Health care professionals were then contacted via an informational email (See Appendix H) or phone by the research investigator to schedule a time to complete the study. Health care professionals working in the CF clinics in Saskatchewan were eligible to participate if they had been working with CF for a minimum of 1 year according to self-report.

2.6 Materials

2.6.1 Demographics. For youth, the demographic questionnaire inquired about age, self-identified gender, education level, and ethnicity, as well as information specific to their health, cystic fibrosis, and treatments they received. The questionnaire also inquired about any mental health concerns and interventions that the youth may have received (See Appendix A). Parents were asked to complete the demographics questionnaire for their child. For parent caregivers, information was obtained concerning their age, self-identified gender, education level, self-identified ethnicity, relationship status, employment status, family size, household income, and any health conditions or treatments they had (See Appendix D). Health care professionals were asked about their self-identified gender, age, education level, self-identified ethnicity, what type of healthcare professionals they were, how many years they had been working with patients with CF, employment status, relationship status, household income and current living situation (See Appendix F).

2.6.2 Interview guides. The interview questions were informed by the research objectives and the existing literature (Stinson et al., 2013, 2014), combined with the clinical experience of the researcher. Interview questions included general introductory
questions about informational and service needs, as well as more specific questions that allowed the participants to elaborate on their own personal experiences. Further, questions concerning the perceived benefits and/or drawbacks of receiving a mental health service via the Internet were included. Participants were also specifically asked about the potential components that should be included in an Internet-delivered mental health program for youth with CF (See Appendices B, E, and G). As the interviews were semi-structured, in some cases the questions were re-worded, re-organized, or slightly altered depending on the direction of conversation between the research coordinator and participants. Additionally, follow-up questions were asked in order to encourage the participants’ responses, as well as to clarify or allow them to elaborate on their previously given response. Interviewing techniques such as establishing rapport, active listening, using relaxed body language, and using developmentally appropriate language were also employed (Morgan, 1997).

2.7 Procedure

2.7.1 Screening. Potential participants interested in becoming involved with the study contacted the research coordinator via email or phone. The research coordinator informed interested participants of what the study would entail and the requirements of participation in the study, including the benefits and risks of participation. Participants were advised that participation in the study was completely voluntary and were given information surrounding confidentiality. The research coordinator also requested permission to audio-record the interview and explained the confidentiality of all documents and audio-recordings. The research coordinator scheduled a convenient time and location for individuals to participate in the study.
2.7.2 Consent. On the day of study participation, written participant informed consent was obtained from parent (See Appendix I), and health care professional (See Appendix J) participants. Parent caregivers provided written consent on behalf of their child and youth provided verbal assent (See Appendix K). Participants were reminded of information about the study, its voluntary nature, withdrawal without penalty, the risks and benefits of participation, and a description of their involvement. The open-ended or discovery-based methodology and nature of the questions posed to participants that is generally used in qualitative research often results in spontaneity as new research questions emerge during the process of gathering data (Hadjistavropoulos & Smythe, 2001). Smythe and Murray (2000) argue that these unexpected conversational directions that are likely to emerge in open-ended interviews can complicate the informed consent process as the research questions may bring up issues that the researcher and participant were not prepared to discuss. Consequently, participants may disclose sensitive information and psychological themes that they may not have anticipated or wished to reveal. To address this potential ethical issue within the structure of qualitative research, Munhall (1989) suggested that consent in qualitative interviews should be an ongoing process, referred to as ‘process consent’. It is recommended that the consent to participating in qualitative research should be a mutually negotiated process between the researcher and participant that is ongoing throughout the study, rather than simply signing the consent form prior to participating (Smythe & Murray, 2000). In order to assure adherence of the recommendations for the consent process in qualitative research, consent was not limited to the initial signing of the consent form or the initial verbal
assent, but was instead considered continual and collaborative throughout participation in the study.

Following the consent procedure, participants were asked if they had any questions or concerns about their study or their involvement. Participants were reminded that participation is entirely voluntary. They were also provided information to contact the primary investigator or supervisor at any time if they had further questions. They were also invited to contact the primary investigator or supervisor about the results of the study after the study had been completed.

2.7.3 Interview. Parent caregivers, and healthcare professionals completed a brief paper-and-pencil questionnaire to obtain basic demographic information. Parents completed a demographic questionnaire on behalf of their child. Individual interviews were conducted by the research coordinator as opposed to focus group format to follow infection prevention and control guidelines that preclude peer-to-peer exposure to reduce the transmission and acquisition of CF pathogens (Saiman et al., 2013). Parent caregivers were allowed to be present during the individual youth interviews when requested by the youth or parent caregiver. Individual interviews were also conducted with parent caregivers and health care professionals. Interviews ranged from 30 to 90 minutes in length. All interviews were audio-taped and field notes were made during the interviews. The audio-recorded interviews were transcribed verbatim. Based on the type of qualitative analysis being used (i.e., thematic content analysis), attention was placed on accurately representing the content of the interview responses when transcribing. The way in which content was communicated such as accents or involuntary vocalisations not a focus (Oliver et al., 2005). Participants were reimbursed for their travel costs to and
from the interview. All participants were offered a $25.00 cash honorarium for their participation in the study.
3.0 Chapter 3: Data Analysis

3.1 Qualitative Analysis

3.1.1 Theoretical approach. Qualitative content analysis is the strategy of choice in qualitative descriptive studies (Sandelowski, 2000). Thematic content analysis was used to analyze all interview audio-recording transcripts, allowing for important themes from the information gathered during semi-structured interviews to emerge (Sandelowski, 2000). Thematic content analysis is described as a research method for the interpretation of the content of textual data through a process of systematically classifying, coding, and identifying patterns or themes (Hsiah & Shannon, 2005). This type of analysis of verbal data focuses on summarizing the important informational content of the data (Athelaide, 1987; Morgan, 1993). The overall goal of thematic content analysis is to understand the lived experiences of participants and to produce rich thematic descriptions about these experiences (Starks & Trinidad, 2007). The expected result of qualitative descriptive analyses is a straight-forward, organized, and descriptive summary of the informational contents of the data gathered (Sandelowski, 2000).

3.1.2 Steps to analysis. The transcripts were verified against the audiotapes and imported into a qualitative analysis software program, NVivo 12. This program is designed to facilitate organization, coding, and retrieving data in qualitative methods. The field notes made during the interviews were also transcribed and included in data analysis. A thematic content analysis method was used to analyze the interviews. In this method, the focus is placed on accurately encapsulating the content of the responses given during the interview (Oliver et al., 2005). The way in which the content is communicated (e.g., nuances of language, accents, involuntary vocalizations, etc.) is not
a focus (Oliver et al., 2005). Thematic content analysis was conducted independently by two members of the research team to deduce the main themes in participants’ responses (Miles & Huberman, 1994; Morse & Field, 2005). Disagreements in the identification of themes was handled through consensus of the two researchers analyzing the data.

The six phases of thematic analysis (Braun & Clarke, 2006) were conducted. The first step of thematic analysis involved becoming familiar with the data and recognizing initial ideas. This was completed by listening to the recording, reading and re-reading the transcripts several times, and making notes of any initial ideas (e.g., codes, themes). Second, the entire data set was systematically coded by two independent coders (i.e., myself and a research assistant) while collating data relevant to each code. Each transcript was carefully read and each segment of data was given a name to represent what was important about that segment of data. A list of codes was created to be later organized and combined to generate themes and subthemes. The third phase involved organizing the codes into potential themes. Fourth, the themes were reviewed in relation to the codes and the entire data set. Quotes for each theme were reviewed to determine if they formed a pattern. If no pattern was forming or if quotes were misplace, themes were re-worked, refined, or discarded. The fifth step involved an ongoing analysis to identify and refine the specific details of each theme in relation to the overall story, as well as to create clear definitions and names to encompass each theme. Themes were examined in relation to capturing the meaning of the entire data set. During the sixth phase, examples of each theme were selected that were of importance and were related to the results of the research objectives (Braun & Clarke, 2006). Finally, the results of the analysis were related back to the initial research objectives and relevant literature. The goal of these
qualitative analyses was to create themes that reflected the experiences of participants gathered through the interviews. The themes that emerged from this analysis ultimately served in attaining the research objectives of the study (Braun & Clarke, 2006).

**3.1.3 Rigour and trustworthiness.** Qualitative analytic methods are inherently subjective as the researcher is the instrument for the analysis (Starks & Trinidad, 2007). In these analyses, the research team makes judgments pertaining to the coding, categorizing, decontextualizing and recontextualizing of the data (Starks & Trinidad, 2007). As a result, it is necessary to utilize techniques to monitor, document, and evaluate the analysis and it is ultimately the researcher’s role to assure rigour and trustworthiness throughout this process (Starks & Trinidad, 2007).

There are several techniques used in qualitative research to help ensure the rigour and trustworthiness of results. For example, reflexivity is a process employed by researchers to ensure credibility of qualitative research findings (Creswell & Miller, 2000). This procedure requires researchers to recognize and self-disclose their beliefs, assumptions, and biases (Creswell & Miller, 2000). It is important that researchers acknowledge and report their beliefs, values, and biases early in the research process as they may shape their interpretation of the data. A “bracketing” technique, where they recognize and set aside their prior knowledge and assumptions of the research questions under investigation, may be employed alongside reflexivity (Gearing, 2004). The goal of “bracketing” is to ensure the data is being approach with an open mind (Gearing, 2004). I acknowledged my own biases as a researcher in the early stages of this project before the research had commenced. For example, biases that I recognized in myself included my personal attachment to the research project and the value I see in potential implications
this project could have, as well as my personal beliefs that valuable information will come from the participants in accordance with what I have learned from previous research. I also held biases that participants would perceive the Internet-delivered intervention as being acceptable and would view it as beneficial based on the literature that Internet methods of delivery have been demonstrated to be effective. Additionally, coming from a clinical psychology student perspective, having the goal of helping individuals with mental health needs and having expectations of the needs of this specific population is another bias.

Consulting with colleagues and writing memos are additional reflexive practices that allow the researcher to ensure the rigour and trustworthiness of results (Cutliffe, 2003; Finlay, 2002). Writing memos throughout the analysis can aid the researcher to examine how their ideas change as they become more involved with the data (Cutliffe, 2003; Finlay, 2002). Memos also provide documentation of the analyst’s thoughts throughout the data analysis process. This procedure is a concrete method to document the emerging impressions and interpretations of the data, and how further engaging in the data may shape the interpretations and understanding of initial assumptions (Cutliffe, 2000). Throughout the study, a field journal was kept with the purpose of keeping an ongoing account and reflection of researcher beliefs, biases and assumptions. This journal was consulted throughout the analyses and is included in the reporting of results where relevant.

A fourth procedure used by researchers to ensure validity of their results is triangulation (Creswell & Miller, 2000). This technique refers to when researchers search for converging evidence among multiple sources of information to form categories in a
qualitative study (Creswell & Miller, 2000). Researchers employ triangulation by systematically organizing the data to find themes and eliminate overlapping areas. In order to accumulate confirmatory evidence, qualitative researchers often triangulate evidence from multiple methods (e.g., transcripts of interviews and field notes) to form the themes, a method that was employed in the current study (Creswell & Miller, 2000). In the current study, audio-recorded interviews and field notes were transcribed and used in the data analysis. Data were collected from multiple participant groups (i.e., youth with CF, parent caregivers, CF health care professionals) to gain perspectives from multiple sources with the goal of answering the research questions. Participant groups were analyzed separately, followed by collapsing results across participant groups to accumulate converging evidence among multiple sources for each research objective.

Another procedure qualitative researchers also routinely engage in is the search for disconfirming evidence (Miles & Huberman, 1994). This process involves the researchers first establishing the themes in a study and then purposefully searching for evidence that confirms or disconfirms these themes (Creswell & Miller, 2000). This technique relies on examining the multiple and complex perspectives that may emerge within a theme. Although this is a difficult procedure, as investigators have an inclination toward finding confirming evidence to support their preliminary assumptions and themes, a search for both confirming and disconfirming evidence strengthens the credibility to the derived themes and supports the overall validity of the results (Creswell & Miller, 2000). This study employed a purposeful search for contradictory evidence after preliminary themes were established.
Finally, Lincoln and Guba (1985) suggest that member check procedures are a critical technique for establishing the credibility in a study. This consists of having the participants in the study review and appraise the data and interpretations of the data so that they can give additional input to whether the information is credible (Creswell & Miller, 2000). During this stage, the researcher asks participants if the themes are realistic and accurately reflect their experience, as well as if there is sufficient evidence to support the study’s conclusions (Creswell & Miller, 2000). This also gives participants an opportunity to clarify or elaborate further on the final results. In the current study, participants were contacted after the study’s completion and provided an opportunity to review the final results and interpretation of responses provided by participants. At that time, they were able to clarify, qualify, or otherwise add to the final results.

3.2 Quantitative Analysis

The quantitative data collected (i.e., demographic information) was analyzed using IBM SPSS Statistics-Version 24 and summarized as means and standard deviations for continuous data and frequencies for categorical data. The goals of the quantitative analyses were to strengthen and inform the qualitative analyses. Descriptive statistics was an addition to the qualitative data gained through the semi-structured interviews, and furthers our understanding of the demographics of the particular population within this study.
4.0 Chapter 4: Part One (Youth with CF)

4.1 Introduction

Acquiring the perspective of youth living with CF is critical to fully understand the challenges faced by youth with CF and their families. Youth with CF provide a direct perspective of the challenges they face and their experiences. With the goal of informing the development of an Internet-delivered mental health program specifically for youth with CF, gathering opinions on the interest and feasibility of the program from individuals who may eventually engage in the program is key. This chapter will examine youth perspectives of what challenges they face associated with living with CF and what information and services they need. Specifically, youth knowledge and experiences will be demonstrated with the goal of answering the research questions.

4.2 Summary of Participants

With the goal of maintaining participants’ anonymity, I have decided to provide collective descriptive information on youth demographics. I have also decided to assign each participant a number and will refer to them using the assigned number. The sample included five youth with CF, four females and one male. Participants ranged in age from 8 to 11 years old ($M_{age} = 9.40$, $SD = 1.01$). In terms of ethnicity, all participants self-identified as Caucasian. The Body Mass Index (BMI) of participants ranged from 17.00 to 23.80 ($M = 19.78$, $SD = 2.88$). Forced Expiratory Volume (FEV1%) as a percentage ranged from 87% to 98% ($M = 91.00$, $SD = 4.30$). No participants reported having hemoptysis or pneumothorax in the last six months. No participants were currently receiving intravenous antibiotics. Participants also reported they were not on the waiting list for a lung transplant. Three participants reported a current mental health condition.
Mental health conditions reported included Attention Deficit Hyperactivity Disorder (ADHD) and anxiety. Two participants were taking medication for the treatment of a mental health condition, and one participant indicated they were receiving psychotherapy for a mental health condition.

4.3 Summary of Themes

Thematic content analysis uncovered four major themes from the semi-structured interviews: (1) challenges living with CF; (2) building independence; (3) coping; and (4) bridging gaps in services. Subthemes were identified under each major theme and will be described. Direct quotes are included to provide support for themes and subthemes. As our sample included young children with CF, some youth did not elaborate extensively on their experiences. Parents were often present during the interviews to help prompt their child to answer questions and clarify responses from their child. In cases where parents clarified youth reports, direct quotes from parents are included to further illustrate youth experiences. The themes and subthemes are listed in Table 1. The complete schematic theme for youth perceptions is represented in Figure 2. The thematic scheme for youth perceptions is represented by a funnel in which information presented by youth concerning their challenges, experiences, and opinions on services all inform the development and improvement of services.

4.4 Challenges Living With CF

Youth described various challenges they face associated with living with CF. Three main subthemes emerged in this topic area. Youth expressed a variety of emotions related to living with a chronic illness. Challenges with communicating about CF and maintaining social connections were explained. Finally, youth described one of the main
Table 1.

Summary of Themes from Part One.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
</table>
| **Challenges Living with CF** | 1. Emotional challenges  
2. Social challenges  
3. Treatment challenges         |
| **Building Independence**     | 1. Learning to manage CF  
2. Accepting responsibility  
3. Mechanisms for learning     |
| **Coping**                    | 1. Focusing on positives  
2. Learning to cope from others |
| **Bridging Gaps in Services** | 1. Barriers to access  
2. Informing future care       |
**Figure 2.** Representation of themes from youth with CF.
challenges of living with CF is maintaining a rigorous treatment regimen.

**4.4.1 Emotional challenges.** In the first subtheme, youth with CF expressed several emotions they experience related to having a chronic illness. Many emotions experienced by participants were emotions related to their disease outcomes, as well as emotions related to having to undergo various procedures at the hospital. Participants shared their experiences with emotions such as feeling *worried, mad, sad, scared,* and *happy.* Participants described worrying about the progression of their disease, and also about testing procedures (e.g., pulmonary function tests, bloodwork) and medical procedures (e.g., surgery, intravenous antibiotics, insertion of catheters). Youth with CF also elaborated on feelings of sadness about being admitted to the hospital and having to undergo medical procedures. One participant discussed feeling upset during the transition from receiving physiotherapy from parents to having to independently use a pep device. The increasing responsibility of youth with CF was described as a major challenge. Emotional experiences of youth with CF were mainly described as being health-related.

*Well when I first started doing my pep it was really hard, because I was doing physio before that and so I started crying when I was doing it. And sometimes I feel like it is unfair, and wonder what it would be like to have a normal life.*

*(Youth 3)*

Youth 1 shared their feelings about hospitalization:

*There have been times when we have talked about staying in the hospital for a week or so and I started crying because I don’t like something bad to happen.*

*(Youth Participant 1)*
4.4.2 Social challenges. The second subtheme focused on social challenges youth experience associated with living with CF. Youth described having different requirements and restrictions compared to other youth without CF. For example, participants described having to go to the doctor and undergo various health-related procedures as things they have to do that their peers do not. As a result of their differing lifestyle, participants described feeling different from their peers. Some participants expressed that this had no impact on their friendships with peers, whereas others described “feeling left out” and missing out on activities that their peers or family may be participating in.

Sometimes in gym it’s harder to keep up with everyone else from running, because I’m always so out of breath really early. So, yeah sometimes I feel sad because I get left out in a lot of things and its harder to do things. I can’t do certain things...Sometimes when my friends are out playing, I have to stay inside and do my treatments and I can’t go outside right away. So, it kind of makes me feel left out kind of. (Youth 1)

Youth 3 also shared their experience of missing out on activities:

Well, say like my friends are going to come over but then sometimes I like had to go to the hospital or something...And sometimes we have to cancel on mom’s group for house church [spiritual group meeting at house], or taekwondo because we’ve had to go to the hospital in Saskatoon. And it is like a while from here.

Similarly, Youth 5 described the impact completing time-consuming treatments to manage CF has on their social and academic life:
It affects it [life] significantly because I have to do a tonne of treatments so it’s hard to go see friends and everything like that. I miss a lot of school and then I get behind.

In addition to feeling different from their peers and missing out on activities, youth with CF described being isolated from other people with CF. Participants explained the lack of connections they have with other individuals with CF.

Well, we can’t really [connect with other people with CF]. I can’t go to them [other people with CF] because there is a six-foot rule... I don’t really know anyone with CF. (Youth 3)

Finally, participants described their experiences interacting with other people about CF including their doctors and nurses, family, friends, and teachers. Participants had varying perspectives on interacting with their doctors and nurses about CF. Some participants described this experience as feeling comfortable, because their doctors and nurses know them and have knowledge about CF, whereas others described it as being difficult. One participant described communicating with doctors as difficult and sometimes not knowing what to say. Another participant expressed talking to doctors made them feel better because they know they are there to help.

Kind of in the middle. Maybe a little uncomfortable but it isn’t bad to talk to them. (Youth 4)

Most participants described speaking with their parents about CF is comfortable and helps them “feel better”. Youth 5 elaborated on different feelings associated with speaking with their parents about CF:
I feel many different ways like sometimes I feel sad when things are tough, supported when they are there for me in the tough times, frustrated because I get in trouble when I’m not doing my stuff properly. (Youth Participant 5)

In contrast to participants that felt comfortable communicating with their family about CF, youth with CF reported little communication with their siblings about CF and that communicating with siblings can be uncomfortable. Youth 2 described certain aspects of CF that are more embarrassing to discuss with their siblings. Parent of Youth 2 elaborated on the discussion:

But it can be gross sometimes [talking about CF with siblings]. It can be a little bit embarrassing sometimes too. Because of the CF sometimes you get tummy aches. And you get lots of air in your tummy.

Youth with CF expressed being comfortable communicating with their friends about CF. Participants reported that when their friends ask questions about CF it feels good to talk about CF and makes them feel like their friends care about them. One participant described feeling “normal” talking to friends about CF and feeling accepted by their peers. Many participants described incorporating a lesson about CF in their health class at school with the help of their parents, and that this helped their friends to understand their experience with CF.

It’s good [talking to friends about CF]. I don’t feel scared to talk to them.

Sometimes they have questions and stuff like that, that are harder to answer, but I find a way to answer them... Like a harder one is like “What is the feeling of it when you have CF?” That is a really hard one to answer. (Youth 1)
Participants also explained how it feels to communicate with their teachers about CF. Some participants described not sharing with their teachers about CF. Participants described communicating with their teachers as somewhat uncomfortable and that talking about it with teachers made them “feel different”. Youth 4 shared not feeling comfortable talking with their teacher about CF as they reported not sharing their CF treatment routine they complete at home with their teachers and classmates. Some participants felt they would be singled out by making their CF a topic of discussion and felt best to limit communication about their CF at school.

4.4.3 Treatment challenges. In the third subtheme, youth participants described their demanding treatment regimen. Youth explained that completing treatments accounts for a large portion of their day. Participants described having to complete treatments, such as physiotherapy, in the morning before school, in the middle of the day, and in the evening. Participants described their demanding treatment routine as interfering with other things they would rather be spending their time doing, and that they often miss out on activities and opportunities because of the time spent managing CF. Treatments were also described as a requirement and not an option, and therefore take priority to other activities. Youth 3 shared:

*I feel like I am wasting a whole bunch of time of my day just doing my treatments and stuff like that... I have to do a lot of treatments, at least five a day... I think when I counted the minutes it was about 120 minutes.*

Similarly, parent of Youth 2 elaborated on feelings associated with the time-consuming nature of treatments:
It takes a little bit of time. And it is boring. Sometimes we don’t always want to do it. Sometimes it’s tough because you are really hungry first thing in the morning and you really want to eat right away. And sometimes you want to stay sleeping longer.

In addition to treatments completed at home, participants discussed other requirements for managing CF including having to make several visits to the hospital, attending doctor’s appointments, and having to undergo various health procedures (e.g., bloodwork, surgeries, needles).

I have had to go to the doctor lots. I needed a few surgeries and many hospital stays. It has been pretty hard because I have had to get lots of needles and stuff...

Having to go to the hospital a lot and not really being able to do some things. I have to eat a tonne. Needles and going into surgery. (Youth 5)

4.5 Building Independence

The second major theme that was generated from youth participant responses included youth experiences building independence in managing their CF. Three subthemes were uncovered. Youth described learning to manage their CF and information they considered to be important in learning to manage their CF independently. Participants also described accepting responsibility in managing their CF and elaborated on struggles they encountered with being more independent and having more responsibilities. Finally, youth discussed how they learn about CF and how to manage it, as well as specific people that play an important role in teaching them about CF.
4.5.1 Learning to manage CF. In the first subtheme, participants described their experiences learning about CF and how to manage CF. They discussed information they need to manage their CF independently and to deal with having CF. Participants reported needing to know general information about what CF is and how it affects their body. Each person experiences CF differently, and youth described needing to know what aspects of CF they have. Understanding how it affects their body was described as being important for understanding the mechanisms of how their treatments and medication work.

Well, if I didn’t know that I didn’t have digestive problems and that the pills help, then I probably wouldn’t have been taking them. (Youth 3)

Additionally, parent of Youth 4 described it would be beneficial for youth to know signs and symptoms of when they are feeling increasingly sick. Although Youth 4 did not feel competent in understanding signs and symptoms of feeling sick, Youth 4 agreed with their parent that this would be helpful information to learn:

It would probably be important to know some signs of maybe when you are getting a cold, to know what those look like so you can decide if you are going to do an extra treatment that day, or if you are going to your doctor, right?...You don’t know how to, but I think as you get older, right? Even too, if you tell mom, “Hey Mom, I’m not feeling good” then mom can make you an appointment, but you have to recognize how you are feeling.

In addition to understanding how CF affects the body, youth described needing to understand their treatments. For example, understanding rationale for completing treatments, what each treatment helps with, and how to complete treatments was
described as being important. Participants described needing to know medication and
treatment names, how to complete treatments, when to do them, and what order to do
them in. Youth also described needing to understand how to calculate the appropriate
dosage for their medications. Youth described the abundance of information they need to
know and described their current knowledge of treatments and how to complete them.

*I need to know how to do my treatments and how CF affects me and what my
medications are for and my doses. I need to do my treatments, pills, try and stay
positive, and need to do tube feed so I can gain weight. (Youth 5)*

Finally, youth mentioned the importance of acknowledging the stress that
accompanies managing and dealing with CF. Participants described needing to
understand their limits and pace themselves when managing their CF. Through describing
their responsibilities in managing CF, they highlighted that it is important to
acknowledge their own limits. Participants emphasized the importance of understanding
what their body needs and how much their body can handle, as well as recognizing when
they might be stressed and need to take a break. For example, Youth 1 stated:

*It’s important to know that you can only do so much.*

Additionally, parent of Youth 2 stated:

*She knows how much she needs... You know when you need rest and when it is
time to chill out for a while. She is pretty in-tune.*

**4.5.2 Accepting responsibility.** In the second subtheme within the topic of
building independence, participants described taking on the responsibility of managing
their own treatment. Youth explained having more responsibilities as they get older and
having to be more independent in managing their CF. Parents allow their children to
manage tasks that children are capable of completing independently. For example, youth described taking their own medications at school and using strategies such as having an organized pill container in their lunch box to help them with this responsibility. Youth also explained that exercising as part of their treatment routine is something that they can do independently. One participant described being involved in dance lessons and gymnastics as something that contributes to managing her CF that she can do independently without help from parents. Further, creating fun strategies to complete treatments independently was also discussed. For example, one participant described jumping on the trampoline as a way to complete physiotherapy. Youth also described the challenges of having increased responsibilities. Participants described the abundance of information they are required to know and amount of treatments they are required to do to manage CF in combination with other life activities such as going to school and maintaining friendships can be overwhelming. Youth 1 explained that although it is easier to manage CF now that she is older, having more responsibilities is challenging:

Well, it [managing CF] kind of got easier...but I have more responsibilities now.

Like I have to remember to take my pills on my own. And it is really hard to remember. And to do the proper amount of treatments.

Participants elaborated on specific treatments they struggle to complete independently. Some participants described treatments that are unpalatable, such as sinus rinses, are more difficult to complete independently and require more help and encouragement from parents. Specifically, participants described the transition from having parents help with physiotherapy to using the pep device to clear their lungs as a
challenge. Treatments that are more challenging may require extra help from parents and may be more difficult to do independently. When describing treatments Youth 3 shared:

Some of them aren’t just machines, like one of them is not electronic so it is hard. It is called a Pep. I breathe into this little thing, and the blue thing has to stay in between the lines for four seconds.

Additionally, parent of Youth 2 elaborated on their experience transitioning to the pep device:

The physiotherapist teaches you how to use your pep mask. And that is something you could do on your own. But that is not pushed very much at our house. We made a thing. “Oh yeah, we are going to get better with the pep mask”, at last clinic. And we are coming up to our next clinic, and we haven’t gotten better with the pep mask. But that is not *Youth 2*, that is mom and dad and the sterilizing in between. Sometimes it is just easier to do the physio, right?

Finally, experiencing attention difficulties (i.e., Attention Deficit Hyperactivity Disorder) was described as a barrier to managing treatments independently. Experiencing attention difficulties may add an extra responsibility of remembering to take medication, and may elicit the need for more reminders from parents, preventing youth from self-managing certain tasks. When asked about barriers that get in the way of managing CF, Youth 5 shared:

Sometimes I get distracted because I forget my ADHD pills. (Youth 5)

4.5.3 Mechanisms for learning. In the final subtheme, participants described how they learn to manage CF and the people in their lives that contribute to helping them learn to manage CF. Youth described their parent caregivers being the primary
individuals that help them learn about CF and how to manage CF. Participants described their parents teaching them about CF and treatments, as well as helping them complete treatments. Youth also described health care professionals as playing an important role in helping them learn to manage CF. Participants described gradually learning about CF over the years and health care providers helping them increase their knowledge about CF. One participant described the CF Nurse Coordinator at their clinic giving them short tests on what CF is and asking questions about CF to them to test their knowledge. Finally, learning about CF through reading was also discussed. Youth participants described reading books about CF as being helpful to their learning.

Well, the doctors, they told me a lot about it. And my parents have told me a lot about it. And, yeah, I kind of just...when I was younger, I used to learn about it a lot. So, now that I am older, I know more about it and I'm still learning. (Youth 1)

Through books, and the nurse teaching me and eavesdropping on mom's conversations with the nurse. I talk it out with mom and friends or the nurse. I learned from the nurse over many years. (Youth 5)

4.6 Coping

In the third major theme, youth discussed a variety of ways they cope with their CF. Two subthemes emerged from youth responses including focusing on positives and learning to cope from others. Youth reported focusing on the positive aspects of their life and creating positive opportunities as one way they cope with challenges and difficult emotions they experience related to having CF. Youth also emphasized the importance of
individuals in their life that teach them how to deal with emotions and provide social support in coping with CF.

4.6.1 Focusing on positives. In the first subtheme, youth described coping with CF by focusing on positive aspects of their life and finding hope. One participant described not thinking about the challenging aspects of CF and that thinking about the difficulties associated with the condition is difficult. Other participants explained that knowing there are treatments that can help manage their CF is comforting. Understanding that they may be able to access effective treatments if their condition worsens was described as helpful with coping with the uncertainty of their disease progression. Youth also expressed having a positive mindset helps them cope. Further, some participants described finding hope through faith and religion as an important coping mechanism.

In addition to a positive mindset, youth described creating positive opportunities as a helpful aspect of living with CF. For example, youth described major fundraising initiatives they have led with their families for CF and the opportunities it has gave them. Youth also described taking advantage of opportunities from various charity foundations as something that helped them cope.

*But sometimes during, when you have CF, there is the good things about it too. Where, like I was a part of this foundation called Children’s Wish and I got to meet the cast of Fuller House! Just because I had CF. (Youth 1)*

4.6.2 Learning to cope from others. In the second subtheme, participants explained another helpful way they cope with CF is through sharing with others and learning how to cope from other people. Youth discussed talking with their parents as a helpful coping mechanism when having difficult feelings associated with CF. They
reported mainly learning about emotions and how to deal with emotions from their parents. Health care providers were also mentioned as people that teach them about emotions and how to cope with CF. Further, participants found it helpful to know there are other people with CF that have similar experiences and hearing about other people with CF is helpful. In addition to relating to others with CF, relating to other people with other chronic health conditions was discussed as helpful when dealing with CF and emotions associated with having CF.

I’ve heard about other people with CF... And I have a friend who has Lyme Disease. And it is easy to talk to her, because she kind of understand what I am going through...Then there is my friends. And there is also a girl named *friend’s name* and she has eczema. (Youth 3)

4.7 Bridging Gaps in Services

In the final major theme, Bridging Gaps in Services, two subthemes emerged from participant responses. Youth discussed the services they receive currently, aspects that they consider to be missing from services, and barriers to accessing treatments or help with managing their CF. Additionally, youth shared their opinions on receiving a mental health program delivered via the Internet and components they believe should be included in a mental health program for youth with CF.

4.7.1 Barriers to access. In the first subtheme, participants identified barriers to accessing services or treatments that help them manage or deal with CF. Some participants could not identify or did not report any barriers to accessing services of treatments. In contrast, other participants described barriers they experienced in attempting to access services or treatments to help manage CF. Participants
acknowledged one barrier in accessing psychological services is the lack of consistency of professionals available at the clinic to provide psychological services. One participant reported that there is often a social worker available, however there is only sometimes a psychiatrist available at the CF clinic. Another barrier identified to accessing certain treatments was the opinions of health care professionals about treatments. It was reported that there are differing opinions and a lack of consistency among health care professionals and CF clinics about treatments and whether they will prescribe certain treatments. Participants that attend a clinic where a treatment is discouraged based on health care professional opinions may be prevented from accessing the treatment.

Another major barrier identified to accessing treatments to help manage CF were financial barriers. Participants explained newer treatments that may be effective as difficult to access due to cost. For example, one medication, Orkambi, that is used to treat CF is expensive and often not covered under health insurance. Although this may improve the quality of life of individuals with CF, few people are able to access Orkambi based on its high cost. Another treatment that was identified as difficult to access was the high-frequency chest wall oscillation vest that helps individuals with CF clear their airways. In addition to being expensive, inconsistencies in health care professional attitudes towards the effectiveness of this treatment has prevented some who have wanted to use the vest from accessing it. Youth 2 expressed interest in accessing the airway clearance vest. Parent of Youth 2 elaborated on their experience attempting to access the vest:

_What about the thing, like with the vest… (Youth 2)_
She has been talking about the vest incessantly. And the doctor is not a fan and he
doesn’t encourage it because the physio is working really well. It’s just, she has
seen it and she wants it. There is another little girl that is around her age that has
one, that just got one. And it is not really a common thing in Canada. And I guess
it is getting more common, but the company that developed the vest wasn’t…I
think there is no real science behind it. I think it was just, it would have to fit
exactly perfectly right, and I think it is not efficient. That is probably what it is.
Like you are needing to target certain areas... Well with the vest, we are trying to
say we don’t need it, it is almost $20,000... (Parent of Youth 2)

Similarly, Youth 1 explained the difficult process of accessing the vest treatment,
as well as the difficulty accessing Orkambi medication:

So, my vest. It hasn’t come yet, but we had to phone...we had to put in an
application and sign a bunch of paperwork and there is a lot of stuff. And there is
this medicine called Orkambi. We haven’t got it yet, but it’s really hard to get it
covered in Saskatchewan. And we talked to a lot of the government and stuff, but
it hasn’t...They made an exception for a few people, but that is if their lung
function has dropped down like 20% in one week, and that is like A LOT.

4.7.2 Informing future care. In the second subtheme, participants discussed
services that they feel they need and their opinions on participating in an Internet-
delivered mental health program. Participants described attending clinic and receiving
services from a multidisciplinary team as being helpful. When describing services at the
CF clinic, participants focused on the physical aspects of services they receive. For
example, Youth 1 described the process of attending clinic for them:
All I really do is just talk to some doctors like check my weight, check my breathing...my blood pressure. And I do a throat swab.

Youth 5 described their experience accessing psychological services and expressed they would like to continue to have a psychiatrist at the clinic:

I had hard feelings and went to a psychologist to help learn how to deal with those emotions. Now I see a psychiatrist.

In alignment with a suggestion for continued psychological services, participants expressed openness to trying a mental health program delivered via the Internet and openness to the program being monitored by a health care professional. Youth also expressed openness and excitement when presented with the idea of connecting with other youth with CF through an Internet-delivered program. Youth elaborated on factors that would motivate and prevent them from participating in an Internet-delivered mental health program. One motivating factor identified included the use of rewards or a “point-system” to encourage participation. The ability to learn new information about CF was also identified as a motivating factor. Youth 2 shared that one way to make the program fun would be “That I could learn different things that I never knew”. Factors identified that would prevent program use included if there was bullying on the program or no monitoring by a health care professional, as well as if participation the program was time-consuming.

Finally, youth shared their ideas on components that should be included in an Internet-delivered mental health program. Participants shared the desire to learn more about CF and their treatments. For example, Youth 2 expressed wanting to know more about how CF affects their body and about how medications help with CF. Participants
suggested including games and having a cartoon character deliver the information as ways to make the program fun and interactive. Youth also emphasized their interest in connecting with other youth with CF as an important component of the program. Sharing treatment strategies was suggested as a potential component, such as sharing food recipes and sharing ways to make completing treatments less boring and more palatable. Finally, including crisis line information was proposed.

*Probably having something fun in there, like not just boring facts... Maybe there is kind of like those math kind of games, that like if you’re doing a game or whatever, then before you can get to a certain place it stops you and you have to read a paragraph or something before you can move on* (Youth 1)

*Well, just to know that they like, know what I am going through... maybe a FaceTiming thing so you could have a private conversation with another person... Maybe like you could send little things kind of like texts or emails.*

(Youth 3)

4.8 Discussion

Part One provides an in-depth understanding of the challenges faced by and information and service needs of youth with CF. Gaining the direct perspective of youth with CF is a valuable addition to the existing literature and is essential in informing and improving the future mental health care for this group. I will explore the results of reports from youth with CF within the context of the overall research objectives. Further, I will relate the results to the existing literature and discuss how the results contribute to our current understanding of the challenges youth face living with CF and what information
and services they require. Implications of the results in informing an Internet-delivered mental health program will also be described.

4.8.1 Challenges. The first research objective involved understanding what types of challenges youth with CF and their parent caregivers face. Youth identified several challenges they face related to living with CF including emotional, social, and treatment challenges. Youth expressed various emotions they experience related to CF. Specifically, health- and hospital-related emotions were the most common types of emotions described by participants in the current study. Youth expressed feeling worried about their disease outcomes. Further, emotions such as worry and sadness associated with being hospitalized or undergoing health procedures were expressed. Youth also expressed feeling upset by the increasing demands and responsibilities of managing their CF independently as they grow older. The current results are consistent with previous qualitative investigations that suggest youth experience several emotions associated with living with CF (Jamieson et al., 2014). Previous studies have demonstrated the challenge of living with the unpredictability of CF and worrying about physical effects of the illness for youth with CF and their families (Cayse, 1994; Hayes & Savage, 2008; McNeill, 2004). Additionally, being hospitalized or tolerating health testing and procedures has been identified as a source of difficulty for some youth with CF because of anxiety, concern with health status and well-being, or unfamiliarity with the procedures (Ward, Brinkman, Slifer, & Paranjape, 2010). The current study adds to the existing research by providing the direct perspectives of youth with CF and how they experience emotions related to living with CF. Whereas many studies focus solely on older youth with CF (i.e., adolescents), the sample of the current study included younger ages of youth with
CF. By including younger ages in the sample, the study provides novel information on emotions that this group experiences and demonstrates that difficult emotions, such as worry and sadness, may develop at a young age.

In addition to the emotional challenges faced by youth with CF, participants elaborated on several social challenges they face. Youth with CF described having different expectations and responsibilities that their healthy peers do not share. Consequently, youth with CF feel different and may have difficulty relating to their healthy peers. Moreover, participants described missing out on activities and school to attend appointments and manage their CF, creating feelings of being left out. Youth with CF also described the experience of being isolated from other youth with CF as a challenge. The current findings are consistent with previous studies that have highlighted similar psychosocial challenges of youth with CF (Jamieson et al., 2014). Understanding the psychosocial challenges of youth with CF is important in considering how to address these challenges in terms of prevention and intervention approaches.

Finally, the demands of treatments and the impact of maintaining a rigorous treatment routine on the lives of youth with CF and their families was identified as a major challenge. Youth with CF described treatments as demanding and time-consuming. As youth spend a large portion of their time completing treatments, they often miss out on activities they would rather be participating in. Further, this places extra restrictions on family lifestyle and activities. The challenge of completing treatments for youth with CF described is consistent with previous studies (Barker & Quittner, 2016; Jamieson et al., 2014). The current study adds to the existing literature by providing direct descriptions of the aspects of life youth feel are most impacted by their treatment routine.
4.8.2 Type of information needed. The second research objective of the current study was to understand what type of information youth with CF and their parents need. Youth with CF reported needing information about CF and how CF affects their body. Participants also reported wanting information about their treatments and medications. Previous research has suggested the importance of youth with CF gaining disease and treatment knowledge as it is associated with treatment adherence (Faint et al., 2016). Youth described varying strategies they use to make time spent doing treatments less tedious and boring and expressed wanting more information about different strategies that other youth with CF employ. Youth also acknowledged the stress of managing their CF and that it is important to understand their limits mentally. Current findings suggest that youth may need more information about coping with stress and accepting emotions related to living with CF. As youth with CF reported learning information and gaining responsibility gradually, youth should learn the information needed gradually and in a developmentally appropriate way. Participants reported their parents are often the primary people that teach them about CF, how to manage their CF, and how to cope. As such, it is important for parents to have a good understanding of CF, treatments, and effective coping strategies to pass the information onto their children and model appropriate health behaviours.

4.8.3 Type of services needed. The third research objective involved identifying services youth and their parents need to help manage their CF and to deal with the challenges associated with having CF. Based on the ages of the youth in the current study’s sample, perspectives and descriptions of services needed were limited; however, youth were able to described some barriers to accessing services that may direct the type
of services needed in the future. Youth reported a lack of consistency in mental health professionals available to deliver psychological services at the CF clinic. Ensuring consistent mental health services are available for youth with CF may be an important consideration for improving future services. Further, youth identified financial barriers to accessing certain treatments and medications that they desired. Considering the barriers to accessing services youth with CF and their families face is important in directing future care. Additionally, understanding the challenges youth with CF face, as described earlier, is important to inform appropriate and effective care tailored to their specific needs.

4.8.4 Benefits and drawbacks of service via Internet. The fourth research objective involved gaining insight on the perceived benefits and drawbacks of receiving a mental health program via the Internet. Youth participants expressed openness to trying an Internet-delivered mental health program. Participants shared a desire to learn new information about CF and how to cope with CF. Potential drawbacks of the program were also identified including the potential for bullying on the Internet. Monitoring of the program by a health professional may be an essential component to ensure the safety of users of the program. Further, youth mentioned a drawback may be if the program was time-consuming. As youth with CF are already busy with managing a treatment routine engaging in an additional program may be difficult. Ensuring the program is not overly time-consuming may be an important consideration to maximize youth participation. Further, some participants expressed struggling with attention difficulties and that this impacts management of their condition. This is consistent with previous research that has demonstrated the prevalence of ADHD is substantially higher in youth with CF than the
general population (Cohen-Cymberknough et al., 2018). Youth with comorbid CF and ADHD have demonstrated worse adherence and outcomes compared to those with CF and without ADHD (Cohen-Cymberknough et al., 2018; Georgiopoulos, & Hua, 2011; Spitzer, Legare, Patel, Toselli, & Livingston, 2018). Keeping the modules of an Internet-delivered mental health program short may also be important when considering attentional difficulties experienced by youth.

4.8.5 Components of program. The final research objective involved determining what components should be included in an Internet-delivered mental health program for youth with CF. Youth provided their opinions on what information and components they considered as important to include should an Internet-delivered mental health program be developed. Participants suggested including new information about CF and treatments. Based on the reports of attentional difficulties of youth with CF, another potential component of the program may involve including a task-reminder option and scheduling resource for completing treatments. Sharing information about treatment strategies with other youth with CF may be a beneficial inclusion in the program. These findings are consistent with existing literature that suggests the use of technology for tracking of treatment completion, access to information, and online support about treatment strategies (Bishay & Sawicki, 2016). Youth with CF reported that they learn to deal with emotions by learning and sharing with their parents. Incorporating ways to engage their parents in the program may be important as they are modelling coping for their children. Participants provided valuable information on ways they currently cope with their CF, such as hearing from other individuals that live with chronic illness. Building on their current coping mechanism by incorporating ways for youth to connect
with other youth with CF may be helpful. Participants expressed interest in connecting with other youth with CF. Further, youth provided suggestions to make the program engaging and motivating such as including a rewards system, having a cartoon character deliver the information, and incorporating games. Incorporating a character to deliver the information has been successfully used in an Internet-delivered preoperative, preparation program for children (Wright, Raazi, & Walker, 2017). Information on youth strengths and needs, their coping strategies, and the feedback provided will be used to inform the development of an Internet-delivered program.
5.0 Chapter 5: Part Two (Parents)

5.1 Introduction

Part Two of the current study involved examining the perspective of parent caregivers of youth with CF. Parents can provide descriptions of the experiences and challenges they observe in their child with CF. It is important to gather information from parents as they can corroborate and elaborate on challenges that their children may have difficulty speaking about. Parents also provide important feedback on the interest and feasibility of an Internet-delivered mental health program for youth with CF, as well as the necessary components and safety features of the program. This chapter will describe parent perspectives of what challenges they perceive youth with CF face and what information and services they need. Parent knowledge and experiences will be demonstrated with the goal of achieving the research objectives.

5.2 Summary of Participants

With the goal of maintaining participants’ anonymity, I have decided to provide collective descriptive information on parent demographics. I have also decided to assign each participant a number and will refer to them using the assigned number.

Demographic characteristics for parent participants are summarized in Table 2. The sample included seven parents, five females and two males. Participants ranged in age from 30 to 41 years old ($M_{\text{age}} = 36.43, SD = 3.46$). All participants self-identified as Caucasian. In terms of family characteristics, six participants indicated they were married, and one participant indicated they were divorced and re-married. Family sizes ranged from three to five people. Six participants reported living in an urban setting and one in a rural setting. One participant reported an existing health condition and three
participants reported at least one existing mental health condition. Mental health conditions reported included ADHD ($n = 1; 14.29\%$), anxiety ($n = 1; 14.29\%$), and depression ($n = 2; 28.57\%$). Four participants reported receiving mental health interventions including psychiatric medication or psychotherapy.
Table 2.

Demographic characteristics of parent sample.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Parent (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Grade 12</td>
<td>2 (28.57%)</td>
</tr>
<tr>
<td>Some university</td>
<td>2 (28.57%)</td>
</tr>
<tr>
<td>University diploma</td>
<td>2 (28.57%)</td>
</tr>
<tr>
<td>University degree</td>
<td>1 (14.29%)</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
</tr>
<tr>
<td>Self-employed</td>
<td>1 (14.29%)</td>
</tr>
<tr>
<td>Part-time</td>
<td>3 (42.86%)</td>
</tr>
<tr>
<td>Full-time</td>
<td>2 (28.57%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (14.29%)</td>
</tr>
<tr>
<td><strong>Household income</strong></td>
<td></td>
</tr>
<tr>
<td>$50,000-$99,999</td>
<td>3 (42.86%)</td>
</tr>
<tr>
<td>$100,000-$499,999</td>
<td>4 (57.14%)</td>
</tr>
</tbody>
</table>
5.3 Summary of Themes

Thematic content analysis uncovered six major themes: (1) emotional challenges; (2) social challenges; (3) demanding treatments; (4) coping; (5) encouraging independence; and (6) improving services. Subthemes were identified under each major theme and will be described. Direct quotes are incorporated to provide support for themes and subthemes. Themes and subthemes are listed in Table 3. The complete thematic scheme for parent perceptions is illustrated in Figure 3. The thematic scheme for parent perceptions is represented by a funnel in which information presented by parents concerning youth challenges, experiences, and opinions on services all inform the development and improvement of services for youth with CF.
Table 3.

Summary of Themes from Part Two.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional Challenges</strong></td>
<td>1. Feeling envy</td>
</tr>
<tr>
<td></td>
<td>2. Feeling worried</td>
</tr>
<tr>
<td></td>
<td>3. Feeling confused</td>
</tr>
<tr>
<td></td>
<td>4. Differentiating emotions</td>
</tr>
<tr>
<td><strong>Social Challenges</strong></td>
<td>1. Feeling different</td>
</tr>
<tr>
<td></td>
<td>2. Communicating about CF</td>
</tr>
<tr>
<td></td>
<td>3. Feeling self-conscious</td>
</tr>
<tr>
<td><strong>Demanding Treatments</strong></td>
<td>1. Treatments interfering with daily life</td>
</tr>
<tr>
<td></td>
<td>2. Treatments as not optional</td>
</tr>
<tr>
<td><strong>Coping</strong></td>
<td>1. Learning from and sharing with parents</td>
</tr>
<tr>
<td></td>
<td>2. Finding the positives</td>
</tr>
<tr>
<td><strong>Encouraging Independence</strong></td>
<td>1. Understanding CF</td>
</tr>
<tr>
<td></td>
<td>2. Increasing responsibility</td>
</tr>
<tr>
<td></td>
<td>3. Struggles with independence and managing CF</td>
</tr>
<tr>
<td><strong>Improving Services</strong></td>
<td>1. Services needed</td>
</tr>
<tr>
<td></td>
<td>2. Needing social support</td>
</tr>
<tr>
<td></td>
<td>3. Barriers to access</td>
</tr>
<tr>
<td></td>
<td>4. Informing novel approach</td>
</tr>
</tbody>
</table>
**Figure 3.** Representation of themes from parents.
5.4 Emotional Challenges

The first major theme uncovered from parent participant responses included a variety of emotional challenges that youth with CF experience related to their illness. Parents reported their children experience several emotions such as worry, frustration, anger, sadness, disappointment, confusion, and isolation related to having CF. More specifically, envy, worry, confusion, and differentiating between emotions were elaborated on by participants.

5.4.1 Feeling envy. In the first subtheme, parents explained that youth with CF feel emotions towards the restrictions placed on their lives due to having CF. Youth were described as feeling emotions such as envy and confusion as to why they cannot do certain things their healthy peers can. Youth with CF have extra responsibilities that their healthy peers do not. Parents explained that most healthy youth are able to be carefree and focus on being a kid. In contrast, youth with CF are tasked with the time-consuming management of their illness, requiring them to be more conscientious, and restricting them from participating in certain activities. Parents expressed that although there is a sense of normalcy to living with CF as they do not know differently, youth can observe the lifestyle of their healthy peers and desire to have a similar lifestyle. Parent 1 shared:

Most kids are able to just kind of doing whatever they want when they want and that is the beautiful part about being a kid. But she, morning and night and, depending on her health level, after school, has to just always have the regime.

Similarly, Parent 7 shared:
Anxiety, anger, a little bit of envy of other people. It is hard for him to see, you know, his little brother being able to do whatever he wants when his is tethered to his nebulizer, right?

5.4.2 Feeling worried. In the second subtheme, participants described youth with CF worrying about their disease outcomes. Parents explained that as their children learn more about the nature of a progressive disease, they experience greater worries. For example, Parent 7 described their child having difficulty concentrating in school due to worrying about their lung function dropping. Parents explained that because they are young, youth lack a complete understanding of the meaning of having a progressive disease; however, as their knowledge about their disease increases, the feelings of worry also increase. Parent 4 stated:

_I think she is worried. The older she gets, the more she understands what the possible outcome is._

Additionally, experiencing fear of dying was an emotional challenge that youth experience emphasized by parents. Youth with CF must deal with uncertainty about their disease prognosis. Participants described that during instances where youth are experiencing complications related to their CF, undergoing procedures, or are hospitalized worrying about death and their prognosis is amplified.

_She has a lot of fear, fear to die. (Parent 6)_

5.4.3 Feeling confused. In the third subtheme, parents highlighted the difficulty youth have understanding why they have CF. Feelings of confusion were also experienced in relation to completing treatments. As youth with CF do not necessarily feel sick, it can be difficult to understand why they have to consistently adhere to their
treatments regardless of how they are feeling. Parents also explained that completing treatments does not always result in a positive outcome. Youth may be confused why they are completing treatments if they cannot directly observe the reward associated with adhering to their routine strictly. Parent Participant 6 explained:

*A lot of self-loathing, so she’s only 9, so a lot of like ‘Why me? Why me?’. Also, a lot of confusion, just with her having to do CF tune-ups and stuff, like she is not actually sick nor is she feeling sick but then the doctors tell her “Well we need to go for a tune-up”. So, it doesn’t really make sense and there is all this effort and there is no tangible reward. You know, you go to the gym, you work out, you lose weight, that is a tangible reward. But with CF, you know, you don’t know the other side of it. All that treatment, you don’t necessarily know, “Would like be as healthy if I did it differently or didn’t do it?”.*

5.4.4 Differentiating emotions. Finally, a struggle encountered by parents was differentiating between emotions associated with having CF and emotions that are associated with being a child. As youth get older, parents experience increasing challenges differentiating between emotions related to growing up and emotions related to having a chronic illness. Understanding that youth with CF have extra responsibilities and different life circumstances, parents expressed the challenge of ensuring their child is coping with emotions associated with their illness, as well as other emotions. *Worry* was highlighted as a common emotion experienced by parents when attempting to ensure their child is coping appropriately with difficult emotions. Further, parents explained hearing experiences of older youth with CF experiencing depression and anxiety related to CF and consequently, may be more sensitive to the potential emotional challenges their
youth may be dealing with and how they are coping with these challenges. Parent 1 expressed:

*I sometimes find it hard as a parent to know whether it is just ‘growing up’ kind of feelings or whether its feelings related to chronic illness... A question I would say to myself is “Would she be saying this as just a regular eleven-year-old? Does a regular eleven-year-old say this? Or does this like have something to do underlying with CF? Or am I making too much of this and this is just a regular girl thing?”. And it’s fine and it is what it is, but there is that added level of worry. You just want to like extra make-sure that she is okay knowing that there is a whole other compartment that she is dealing with that most kids aren’t.*

5.5 Social Challenges

The second major theme focused on social challenges that youth with CF face. Parents elaborated on the difficulties youth experience socially due to having CF. Three subthemes were identified. Parents highlighted specific challenges such as youth with CF feeling different from their healthy peers, difficulties communicating about CF, as well as feelings of self-consciousness.

5.5.1 Feeling different. In the first subtheme, parents explained that one social challenge youth with CF face is feeling different from their healthy peers and siblings. Participants explained the differing expectations and responsibilities youth with CF have that their healthy peers and siblings do not share. Youth with CF are required to comply to a rigorous treatment routine that often interferes with their daily life. Parents described their children having to grow up much quicker as a result of their extra responsibilities. Moreover, youth with CF spend an abundant amount of time managing and thinking...
about CF compared to just being a kid. Parent 4 shared one example of the difference between youth living with CF and those without CF:

*Just the fact that the way you are, just being able to, like other kids just snack on this when you are at a party or a birthday party, just snack on chips throughout the whole time. Well no, you gotta make sure, okay if you’re going to eat, you gotta take the enzymes with the food, you can’t just graze.*

Similarly, Parent 6 elaborated on the challenge of having extra responsibilities that healthy youth do not share. Consequently, this may make it difficult for youth with CF to relate and build relationships with their peers.

*CF brings on a heavy sense of responsibility at such a young age and it is hard for her to build true relationships with others her age because the disease is forcing her to grow up faster, so she feels like her and her classmates don’t quite have the same expectations of them. And you know, they get to do all of this stuff, but we have to limit what kind of weekday activities we have because we have to do treatment in the evening. So, I think it is hard for her to find common ground with them, as a result of the level of responsibility that it takes in just staying healthy. (Parent 6)*

In addition to feeling different based on the extra demands and responsibilities youth with CF have, youth with CF often experience lifestyle restrictions that their peers do not. For example, being isolated from friends when they are sick to prevent infections are necessary measures for youth with CF. Parent 5 shared:

*The restrictions at times with her accessibility to friends and things like that, when she is sick or her friends are sick then... And she knows that, and she is*
fairly accepting of it, she has had to do it since day one, but it is more of a challenge. This winter I think there was about five weeks where she didn’t see her best friend. That wasn’t great.

Similarly, Parent 3 described other situations or experiences that youth with CF may have to avoid in order to maintain their health. Parents expressed a certain level of caution and hesitancy around participating in more risky activities and explained often their children are frustrated by not being able to participate in other activities their healthy peers participate in. Parents also expressed that as youth get older, the differences between them and their peers become more apparent, making it increasingly challenging.

We really don’t want to send her over to her one friend’s house because she’s got reptiles… The doctor had told us not to have reptiles as pets and I’m thinking “Yeah, E. coli and all of the things that she can pick up”. And like her brothers can go in hot tubs, she can’t go near a hot tub. And like digging in the dirt in the yard, she can’t just wander around all free, she has to put a mask on. And even then, if her dad is tearing up the garden, I’m like having a freak-attack because of all the stuff that she can catch, really bad bacteria in the lungs, and she knows that… It is those instances, where she has to be a little bit different, I think that it’ll affect her. (Parent 3)

5.5.2 Communicating about CF. In the second subtheme within the social challenges experienced by youth with CF, parent participants shared their perspectives of youth experiences communicating about CF to people in their lives. Participants described the experience of youth with CF communicating to different groups of people including their doctors and nurses, family, friends, and teachers. Parents shared different
experiences of their youth communicating about CF to their doctors and nurses. Feeling comfortable communicating about CF to health care professionals appears to depend on various factors such as personality of youth, how well youth know their doctors and nurses, as well as the topic of conversation. Youth that have a more outgoing personality and have a consistent CF team that they are comfortable with may be more open to discussing their CF. For example, Parent 3 shared:

*It is usually when she’s gotta get the pokes that she is a little bit more shut down.*

*When it is time to get the throat swab she doesn’t like that. But the doctor will ask her questions and she is pretty chatty with him for the most part. I think we’ve built kind of like a good relationship there. But that has taken years, she has always been really outgoing so that hasn’t been hard for her.*

Further, Parent 1 explained that having a consistent team of health care professionals contributed to their youth feeling comfortable having discussions about CF:

*I think she is comfortable. She’s had pretty much, I mean, some different people, but a lot of them are quite the same. I think honestly the piece that makes it the most comfortable is that the CF Nurse Coordinator has been the same person for the whole time that she’s been a part of the clinic.* (Parent Participant 1)

Parents also explained it being difficult for youth to find the appropriate language to express their needs to their doctors and nurses. Parent 6 expressed the difficulty their youth has communicating with doctors and nurses when something is confusing or scary.

*She has completely shut down and not wanted to talk about it whenever there is something that scares her or she is confused by. So she doesn’t understand why the doctor is suggesting she take an antibiotic, and she is confused and that*
frustrates her, and as a result she just shuts down and not want to think about it, which I think is a pretty natural reaction for someone at such a young age.

Parents expressed their youth being comfortable communicating to their family about their illness. One challenging aspect of communication about CF identified by parents was discussing the harsher aspects of CF with their youth. Parents expressed difficulty determining when is the appropriate time to have discussions about topics of life expectancy with their youth. Participants described being worried about how their youth would find out about sensitive issues related to having CF. Participants emphasized the timing of these conversations in a developmentally appropriate way is important, however expressed feeling uncertain about what age is appropriate to begin communicating about these topics.

Whatever I know, I try to let her know. The one thing that I am not so open with, and I am kind of being, I am just waiting to see where things go, I’m not trying not to introduce this to her, but the understanding of a progressive disease and what that means. And not wanting her to find out, how it is a life-limiting disease, by going on the computer after having talked to a friend and finding that out. But at the same time, I don’t want to be putting a cloud over the top of her that she is not looking for too. That would be the one thing that is difficult. (Parent 5)

Similarly, Parent Participant 3 pondered about the timing of conversations about life-expectancy, and how much information to give to their child:

I think there is a lot more talking we have to do. Because I think we just go through our day-to-day and it is like routine. We don’t really stop to think, like how much does she know? Does she know everything that she needs to? Does she
want to know more? She was expressing that she wanted to know more... but how much more? I don’t want to be... I don’t want her to be completely in the dark, but I don’t want to go “Oh yeah, by the way, the life expectancy is...”. We don’t want... those realities are a little bit too harsh right now.

Parents also described how youth experience communicating to their friends about CF. Participants had varying perspectives about how their youth feel communicating about their CF to friends. Some participants believed their youth limit communication about CF with their friends to avoid being different.

*I honestly don’t think he talks about it very much to his friends. Yeah, when he is with his friends, he just wants to have fun and you know, if he brings it up it’s like an “Oh okay sounds good” and then they carry on. Cause he just wants to be a kid when he is with his friends.* (Parent 7)

Many participants described youth being very open and feeling comfortable talking about CF with their friends. Parent 5 described their youth being open to share with friends they are comfortable with; however, this has changed with age and they have become more private over time. Similarly, Parent 4 shared that their youth feels comfortable speaking with their friends about CF, but that this may evolve and become more difficult with age:

*I think most of her friends pretty much know what is going on. I don’t think it bothers her too much around her friends, it’s just maybe the older she gets it is going to be harder.*

Finally, participants described how youth with CF feel communicating with their teachers about CF. Many participants reported initiating a classroom educational session
about CF with their teacher and classmates. Parents explained having a classroom
discussion about CF as being helpful in creating a sense of normalcy around the topic of
CF. Youth were believed to feel positive about sharing information about their CF to
their classmates and answering questions about CF. Parent 6 shared:

*It depends on the response. So, I’ve seen her really excited to talk about her CF with others who don’t look at her with pity or sadness when she starts to talk about it. I go in to her class to talk about CF and she is always really excited for them to learn and understand more. I think the reason she is excited there is because she has sometimes struggled to make full on bonds with them as there is just a difference in their lives and that is a way for them to understand her more. But I think it makes her feel included.*

5.5.3 **Feeling self-conscious.** In the third subtheme, participants described youth feeling self-conscious about CF and some of the visible aspects of CF. One participant described their youth feeling self-conscious about going swimming as others would see their button, port, and g-tube. Another participant described their youth feeling increasingly self-conscious and embarrassed with age. Youth may attempt to hide certain noticeable aspects of their condition to avoid appearing different from others. Parent 3 explained different physical symptoms associated with CF that contribute to feelings of self-consciousness:

*Definitely with her, her tummy aches she gets, like the gas, and her brothers kind of poke at her about how she smells. And I think that probably bothers her. I know she doesn’t say it all of the time, but I think she tucks some things away that she doesn’t talk about....*
When she has to wear a mask, she doesn’t like that. We went to an Easter function and my cousin’s little guy, he just finished his last chemotherapy session, he had a brain tumour. And she had the sniffles and we asked her to wear a mask and she was mortified. She didn’t want to because it’s kind of like... I mean, in the hospitals it is fine, but outside of hospitals...

5.6 Demanding Treatment Routine

The third major theme uncovered from parent participant responses included the challenges of adhering to a demanding treatment routine. Two subthemes were identified. Parents described the time-consuming nature and responsibility of completing treatments impacts daily life of youth with CF. Additionally, parents shared their perspective about the demand of completing treatments and the idea that treatments are not optional.

5.6.1 Treatments interfering with daily life. In the first subtheme, participants described the time-consuming treatments youth with CF are required to complete and the impact their treatments have on their daily life. Parents explained several aspects of their life as being impacted by having to adhere to a strict medical regime. For example, Parent Participant 2 described their youth having to get up earlier in the morning to do treatments and often being late for school as a result. Parents also described youth missing out on activities and opportunities due to the requirements of adhering to their treatments. Family activities and lifestyle were identified as being impacted by treatment routines. Parent 7 shared their challenges managing treatments within the context of their daily lives:

It is very challenging for him though. He struggles a lot with opportunities that he misses when he is having to do his treatments or his hospital stays. I think it is a
heavy responsibility for him to bear... It affects our family activities because we are always having to plan around, you know, oh we can’t just go out for supper because we need two hours to do his treatments. So, it affects how our family works as well, and I wish we could have a little bit more of that freedom.

Self-managing treatment routines was described as placing an extra level of responsibility on youth with CF. Youth with CF are often expected to be independent in tasks such as remembering to take their medications at school. Parent participants elaborated on the challenge of creating a routine, and how changes in the routine, such as increasing disease-related complications, makes maintaining treatment routines more challenging. Parent 1 shared:

As she gets older, she has definitely had more complications with lung function, and PFTs dropping and sickness, and just a lot of digestive issues and stuff. And then they try new medications and try different things, so just when you kind of feel like you are getting into your rhythm of what already feels like a lot, doing like two hours to three hours of treatments, then you get like a sickness or a bug or something else comes in and they want to try something new and it just feels like a whole lot more. One little tweak in the routine can feel like a mountain because it just feels like a whole lot more to manage when you are already...feeling like you are running a tight operation here of medical care.

5.6.2 Treatments as not optional. In the second subtheme, participants explained the non-negotiable nature of treatment routines for youth with CF. Completing treatments is essential to maintain health status for youth with CF. Parents explained that although treatments are time-consuming and sometimes unpalatable, treatments are not optional.
Parents emphasized the challenge this creates for their youth putting in an abundant amount of effort to complete their treatments to maintain their health status, but not necessarily improving their health status. Parent 6 explained the experience of their youth dealing with the demanding nature of treatments:

*Effort with no tangible reward. So never being able to stop or compromise on treatment, regardless of how you are feeling. If anything, the weaker and sicker you are the more energy is required from you to do treatment. So there is no compromise on it... So it is not like “Oh well what if I just did my pulmozyme today and did my treatment at night?” or whatever. There is just like no compromise in it. Like you go onto a strict diet and there is always a cheat day, you know, there is always that Sunday where you can have those Doritos and that ice cream. But with her treatment there is no cheat days, there is no compromise, there is no adjustment, and because it is a progressive disease all that usually happens is that those treatments become more intense, more of them, and they take longer. So it is hard growing up knowing that the older you get, the actual more work you are having to put in to take care of this disease, and then still finding time to take care of being a kid, and homework and all the other, and making friends and all of that. So, I don’t think there is any that she is more engaged in simply because they are all related back to a demand and not an option. (Parent Participant 6)*

In addition to emphasizing the demands of treatments for youth with CF, parents expressed the difficulty of adhering to treatments for youth when their mood is low or when they are feeling physically sick. A struggle highlighted by parents was finding a
balance between enforcing their treatment routine to better their physical health and allowing for occasional treatment non-compliance to help them improve their mental health. Parent 1 explained their experience and challenges with the demanding nature of treatments:

She definitely has days where she feels down, and she has days where she just doesn’t want to do her treatments. Or if she is like actually sick, I mean, she always has CF, but when she’s like sick with something else like a cold or a flu, like just not feeling good, those treatments are REALLY hard. It is like asking someone to exercise when they’re sick. Like nobody wants to do it, and most people wouldn’t do it, they would take a break, but this is something that really you can’t take a break from. So that I would say, the times when she feels the most down, when she just like, more than, and as a parent it is a constant back and forth of “Do I just let her not do them today? Do we just not do them right now?” And then feeling like, you’re then allowing that to be like, “Okay well then when she asks, we just won’t do them.” ... It is always this sort of balancing act, you just want to figure out, “Physically this is going to help you be better, but mentally is she in a place where it would be better to just say, ‘Okay we’re not going to do this treatment right now, we are just going to do something else right now’?” And like try to like help bring her mental state to a happier place. That’s the juggle. Yeah, it is very hard to balance.

5.7 Coping

The fourth major theme emerging from parent participant responses focused on the topic of how youth cope with the difficult emotions associated with living with CF.
Parents provided two main ways youth with CF cope with their emotions, forming the two subthemes within this topic. First, parents described youth cope with CF by learning to deal with emotions from their parents and expressing their emotions to their parents. Second, parents described focusing on the positive aspects of life and creating opportunities as a coping strategy.

5.7.1 Learning from and sharing with parents. In the first subtheme, parent participants discussed that youth with CF learn to cope with the emotions they experience primarily through sharing with others. Parents explained that by expressing their emotions to those they feel comfortable with, such as their parents, youth with CF are able to cope with difficult situations related to having CF. Parents highlighted the importance of creating an open environment and encouraging youth to share how they are feeling. Participants believed that sharing with their parents is one of the main coping strategies youth with CF employ. Further, parents explained that how parents deal with their emotions is associated with how youth deal with their emotions. Parent 6 suggested the importance of parents learning how to effectively cope. Parents that demonstrate effective coping promote the use of appropriate coping strategies in their youth. Parent 1 shared their child’s experience coping through sharing with parents:

*Non-related to CF, and her having some anxiety issues, like that is just her tendency, not specific to CF, but she has seen night and day what can happen when you talk about the feelings. And how addressing and dealing with things can make things so much better... And just feeling like we are creating a safe environment here. That there are no wrong things to say, ever. Whatever you need to do, you just do.*
In addition to sharing and learning from their parents, youth with CF learn to cope with emotions through reading books about others coping with difficult situations. Participants described using tools, such as books, to demonstrate how others cope with difficult situations in life. Learning how to cope with situations and emotions unrelated to living with CF were also emphasized as being helpful. Building general coping strategies for dealing with emotions can be used in all life situations, including difficult experiences related to CF. Parent 7 described how their use of reading with their child contributed to learning about coping:

*He talks to his dad and me very openly about what he is struggling with and what he thinks we need to change. And just things that he is frustrated with, even if we can’t change it, he will just say like “Ugh this is so frustrating.” Sometimes just talking about it helps it be less frustrating... We usually open up the bible and do a bit of reading there, because there is every emotion that you could have experiences in there. It really is good for him to see that you know, people who don’t have this disease also experience these things, and they were able to overcome it, right? So, we try to not just make it CF related, we will talk about other people with other things, and how it might not be exactly what he is going through, but he can relate to other people, he is never truly alone, right?*

5.7.2 Finding the positives. In the second subtheme, participants discussed focusing on the positive aspects of life and creating positive opportunities as a way youth cope with CF. Parents described encouraging youth to accept difficult situations and emotions, as well as to find positive ways to spend their time. Many participants described being involved in fundraising initiatives in support of CF and that youth often
take leadership roles in these initiatives. Parents expressed being involved in positive initiatives related to CF as a helpful way of coping for the entire family. Becoming a leader and taking ownership of an activity or initiative fosters confidence in youth with CF and gives them something to focus their energy on aside from managing their CF. Parent 1 explained:

She really is just very open to advocating for CF and I mean, I’ve tried to encourage her in that. I make the opportunities happen so that she can do that, but she very willingly wants to be a part of it. So, it has really been, like that for me feels more positive, and I think for her that feels more positive too… She loves public speaking. I don’t think she would have had all of the platforms that she has had to do all of these things by this age had she not had CF… So it’s been kind of neat that the things she really likes to do anyways, like there’s been ways to incorporate that positively for her. (Parent 1)

Participants also added that finding supportive communities to join, such as spiritual communities, as being helpful in coping with difficult situations. Forming associations with communities was described as being helpful in providing social support, encouragement, and hope to youth with CF and their families. Parent 5 shared:

Our spiritual community that we have, that is a huge thing for her too, that support. (Parent 5)

5.8 Encouraging Independence

The fifth major theme generated from parent responses focused on encouraging independence in youth with CF. Three subthemes emerged. Parents reported the importance of youth understanding CF and understanding treatments. Participants
discussed how youth learn about their CF and treatments and how their responsibilities
increase with age. Finally, parents explained challenges associated with youth self-
managing their CF.

5.8.1 Understanding CF. In the first subtheme, parents suggested that to feel
comfortable managing CF independently youth need to have knowledge about their
disease. Participants explained information about CF should be delivered to youth in a
developmentally appropriate manner. As youth get older, they increasingly learn more
about CF. There are many variations in the way CF presents across individuals, youth
with CF need to understand what aspects of the condition they have. Parents believed that
through gaining disease knowledge youth will understand why their medications and
treatments are necessary and what they help with, contributing to building their
independence in managing their condition. Parent 6 stated:

...Then obviously [need to know] what is wrong with her body in the way, and
wrong in as positive of a way it can be, what is deviated about her body that
makes these medications and treatments essential. I think in understanding those
that is how she is going to become independent within doing her medications and
within doing her treatments.

In addition to having a developmentally appropriate understanding of CF, parents
emphasized the importance of youth understanding their treatments. Participants provided
eamples of information youth should know about their treatments such as knowing the
ames of medications and treatments, when medications and treatments need to be
completed, and medication dosages. Participants also highlighted the importance of
understanding rationale for why they need to complete their treatments. Parents explained
the lack of tangible reward of completing treatments makes it difficult for youth to understand the importance of maintaining a consistent treatment routine. Educating and reminding youth of the long-term benefits of completing treatments was described as being necessary for youth to be motivated to manage their CF on their own. Parents reported that understanding the value completing treatments has in the long-term contribute to youth being motivated to consistently self-manage their CF. Parent 1 and Parent 6 shared:

\[ \text{We always want her to understand why she is doing what she is doing... So, we want her to know that, and without her being scared into it, but have her having that understanding that often, being diligent with your treatments, and in all of the things that you are being instructed to do by your clinic equals being healthier. Because those things kind of go hand in hand. If you decide you don’t want to do your treatments, you can, but you will most likely get sick, and that will lead to a lot of other things. (Parent 1)} \]

\[ \text{I think she needs to understand the value of each medication and each treatment, what each treatment and medication has and the impact it has on her life. She also needs to understand that it is a long-term result and that the efforts made today can’t be measured between treatment to treatment, and that also ties into again that tangible reward, where it is a long-term result, not a short-term one. (Parent 6)} \]

5.8.2 Increasing responsibility. In the second subtheme, participants explained how youth learn about CF and gradually take more responsibility in managing their CF
independently. Parents explained that information about managing CF is provided initially by health care professionals at the CF clinic and is reiterated and reinforced by parents. Participants described health care professionals keep youth involved in conversations and encourage them to advocate for themselves. Health care professionals also ensure youth are involved in decision-making processes. One helpful tool used by health care professionals to increase youth knowledge about CF are age-appropriate questionnaires about CF and managing CF. As youth get older, they are encouraged to learn more about CF and managing their disease. Parent 1 stated:

*And they are all just really good about talking with them on their level and they treat them, even though we are in the room, they treat them like they are the patient and they, conversation is always directed towards them, not to us in the room. And we get asked upon if a question is needed to be answered that she doesn’t know, but yeah, they make it really good. And they try like, by the age of fifteen, already they go independently to clinic, in order to help them transition to the adult CF clinic.*

Similarly, Parent 4 explained the importance of youth involvement in their own health care in preparing for being independent in the future:

*Keep her involved with everything. When we are talking to the doctor, get her involved, even though she is only 8. If something is happening to her, explain what is happening and what do you need to do to fix it, why you’re taking this new medication or why you have to do this new therapy. Just keep her involved... By the time she is older, and she has to take care of it on her own, I think she will be*
well educated by then, between clinics and everything. There is no worries about that I don’t think. (Parent 4)

Parents also explained taking a step-by-step approach to increasing responsibility of youth with CF. Parents described preparing and completing treatments for their child as being unhelpful and detrimental to their ability to self-manage their CF in the future. As parents observe that youth are capable of completing a task independently, they encourage them to complete it on their own. Parents believed that by gradually increasing responsibility, youth will be less overwhelmed when they are managing their CF independently as adults. Further, encouraging responsibility in youth was described as contributing to their self-confidence.

The moment that I recognize that she can be responsible for something, I let her. Or actually, I make her. I think it is a sense of her feeling empowered. But I also don’t want to be creating a “You are a child, and so you cannot do this and so now you are a grown up and you are responsible for this”. I want it to be, “She is a person and what she can do, she takes on”... She needs to be in a place where she is fully responsible for herself at university or college and... “Meh, I don’t feel like doing this. And Mom and Dad, they are not around to check on me”, that is not good for her. And what happens will happen. I know that. But I think if it is not a huge change with the responsibility of it all, it won’t feel like such a burden and overwhelm her. (Parent 5)

It is just been like “Okay the next thing we want him to master is putting the medication in the neb by himself”, you know? And it has been like years of step
and step and step so that it is not overwhelming for him to do everything all at once. And so, we really started at like when he was a toddler, and could help us shake his inhaler, right, little things like that we started when he was a toddler, because he wanted to do it by himself, right? And so, we started at that age and so it’s just been kind of drops in a glass and eventually it is all full. So, honestly it doesn’t ever feel like we’ve had to teach him anything, but it is all over time.

(Parent 7)

Finally, parents expressed fearing that as youth get older, they will become less compliant with their treatments. As a result, health care professionals and parents attempt to be proactive and encourage knowledge and responsibility from a young age in preparation for the future. Parent 7 shared:

She [CF Nurse Coordinator] is challenging him to learn more about it because they’re I guess when they get to be teen years, compliance is really like drops off quite a bit. And so for a lot of years now, we have been really trying to work to make sure that you know, these things are engrained in him before compliance becomes a push back.

5.8.3 Struggles with independence. In the final subtheme within the topic of encouraging independence in youth with CF, participants highlighted several struggles associated with building independence and managing CF. One barrier that parents described as preventing youth from managing their CF independently was attention difficulties. Parent 2 explained their child struggles with remembering to take medications, as well as the scheduling and organizing of treatments due to experiencing attention difficulties. Further, parents described another barrier for youth managing their
CF independently was their age. Being at a young age, parents explained youth would rather be spending their time doing other things outside of managing their CF. Parents described youth being bored while spending hours completing their treatments. They also explained that as youth get older, they may develop attitude that contributes to non-compliance with their treatments.

*Barriers that get in the way... wanting to be a kid. Not wanting to sit for physio, not wanting to go to the doctor. (Parent 4)*

Parents identified themselves as being a barrier that prevents their youth from managing their CF on their own. Participants expressed difficulty in letting go of having control over their youth completing treatments and allowing their youth to be more independent. Parents explained that sometimes it is easier to complete a task for their child rather than watching them fail. Parent 2 shared their experience acting as a potential barrier to their youth becoming more independent:

*We know how important it is for her to be doing consistently. So rather than giving her the chance to do it and fail, we want to be on her a little bit more, I guess. And that kind of prevents sometimes the independence from kicking in. Right, because we don’t want her to fail. You know, failure in that it is pretty serious.*

Similarly, Parent 6 elaborated on the difficulty of letting go of control for parents:

*Balancing dependence with independence, so the risk at letting your child live with CF, to take a more like to ease back and allow them to sort of learn for themselves and take care of their own health and fail, the risk is their health. You know, I can let my daughter climb a tree and fall and hurt her arm, or scrape her*
knee when she is learning how to ride a two-wheeler. But when it comes to their care, it can become detrimental, and it is really difficult to balance the dependence with the independence.

Parent 7 shared the same perspective on struggling with letting go of control for parents; however, also explained the importance of letting youth fail. Parent 7 reported their experience with letting go of control and the helpful contribution it made to building independence in their youth.

*Letting go some responsibilities from the parents to kind of put it on the kids seems to be really hard because sometimes the kids push back, sometimes the kids aren’t interested, or sometimes they just don’t do it... Well, *child’s name* failed lots. We let him fail, right? You know, let him forget his pills and then you know, he would come out and he would go, “Oh, I forgot my pills yesterday”, yup but you know what? He doesn’t forget them anymore, because he has had that consequence, right? So some things, you can let your kids fail at, right? (Parent 7)*

Finally, parents highlighted the role of mental health in youth having the ability to manage their CF independently. Participants explained that completing treatments is more difficult and requires more help and encouragement from others when you are experiencing low mood. Poor mental health may act as a barrier to developing independence. Parents emphasized the importance of youth having good mental health and well-being in order to feel confident self-managing CF. Parent 1 shared:

*I think it is just state of mind. I really do think that the mental health is the biggest piece about this all. Because if she can have a positive mindset about it, it all just*
seems easier. And if she is down in the dumps on a day, everything feels harder, like anybody right?

5.9 Improving Services

The sixth theme that was uncovered from parent participant responses focused on parents’ opinions and suggestions for improving services that help with managing CF and coping with CF. Four subthemes were generated. Parents identified services they currently lack that were perceived as being necessary in terms of their youth managing and coping with CF. Parents elaborated on the need for more opportunities to gain social support for youth and families with CF. Barriers to accessing mental health care services were also discussed. Finally, parents provided opinions on an Internet-delivered mental health program designed for youth with CF.

5.9.1 Services needed. In the first subtheme, parents identified several services they believed would be beneficial to have available to help youth manage their CF and cope with having CF. Parents discussed the lack of specialized services available within Saskatchewan and suggested having access to more specialized health care professionals would be helpful. Specifically, parents emphasized the need for a greater focus on mental health care for youth with CF. Parents described the current services available at the CF clinic such as the option to speak with a social worker or psychiatrist as being helpful, however emphasized the need for more consistent availability of mental health professionals for their youth. Participants believed it would be helpful to have more opportunities for youth to meet with a mental health professional to learn how to talk about, express, and cope with their emotions. Further, parents suggested it would be helpful for mental health care to be integrated into the CF clinic rather than having to
access services outside of the clinic. Parents also expressed the need for mental health services during the transition from pediatric to adult care. Parent 6 highlighted the need for more access to mental health services and described the importance of learning positive coping skills:

*I think just a continued dialogue to be able to have and ways of dealing with her emotions and assuring her that there is no shame in what she is feeling, that it is common to almost everybody, and that it is okay to feel that and that there are ways to um, yeah to get through that, and to deal with it, and to not have that continually overwhelming you. It is possible... I think moreso than anything else I think just accessibility to mental health. Our system here is really full it seems, and we don’t even have enough doctors to be able to help everyone that needs it.*

Similarly, Parent 3 expressed the need for more mental health services for youth with CF and emphasized the importance of learning appropriate coping skills early to prevent potential issues in the future:

*I think that the mental health aspect of the clinic is missing... Because it is not an easy illness to deal with, and I can’t even imagine being her and being in her shoes and what that feels like. And once they get older and realize the exact route that most patients go down. I think it is hard, like I’ve heard a lot about depression and anxiety and severe issues, and that is so important to be addressed. Like early. I think the earlier the better, because I think the earlier that they can get those coping skills and know that this is normal, that it is okay to feel this way, this is what I can do to make it feel better, and then she is not, doing what everybody else is doing and trying to cope with things and start getting involved with the bad stuff, you know with*
addictions, you know other things. I think it would prevent a lot. But I think that needs to be more of a factor in her care. And especially getting older.

In addition to requiring better access to mental health services for youth with CF, parents suggested the need for mental health services for the entire family. Parents described challenges associated with having a family member with CF for parents and siblings and that mental health services should be available to address the needs of the family as a whole. Moreover, participants believed that services should be tailored to the specific family’s needs. For example, whereas some families may benefit from meeting with a social worker, others may benefit from meeting with a psychologist. Parents expressed that taking care of their own mental health and coping effectively is critical to creating a healthy environment for their family and to the well-being of youth with CF.

Parent 1 shared:

*I mean, I really do think that it would be a huge benefit for there to be a mental health something for all family members... We as parents needing to figure out how to cope with this all on a marriage stand-point, on a family stand-point, on a worrying about our child stand-point, and just making sure that we [parents] are both healthy enough to create the environment that is best for her as she deals with this all.*

Similarly, Parent 7 expressed the need for more focus on the entire family:

*I feel like there is a gap between, you know, patient care versus family care. And that is why, one thing that kind of bothers me a little bit, is that I feel like the social worker and the psychiatrist and even the doctor, could be asking you know, “How is your family doing?”, right? And checking-in on those things, because a*
lot of the times in clinic we are so focused on our CF kid, we don’t even think to bring up anything else. You know we get kind of tunnel-vision as parents, right?

Finally, Parent 2 suggested that in addition to mental health services for the family, it would be beneficial to have an assistance program for parents. Parents of youth with CF spend much of their time providing care to their child with CF and may not have the appropriate time to take care of their own mental health. Parent 2 suggested providing assistance to parents and opportunities to connect with other parents of youth with CF would be beneficial:

I think, you know, a lot of the questions are about the kids and how they are doing. I think there is another side of it too, with the parents and how they are doing, and having the ability to detach a little bit and have respites and I feel like there is kind of a lack of assistance there…. The amount of things that we have to remember, and you know, you’re constantly second guessing yourself, just everything in order to make sure that she is staying healthy. I think there’s opportunity to really help the parents out, give them time to connect I think more. Because a lot of your time can be spent, go to work, do treatments, get kids in bed, and then you don’t really have any time to yourselves... I could see a scenario so I could see where there is some sort of assistance program to help out with that for parents that need a little break.

5.9.2 Needing social support. In the second subtheme, parents elaborated on the social isolation associated with having CF. Parents reported their youth lacking connections with other youth with CF. Parents shared the frustration and difficulty they experience not having a community of social support. Participants suggested it would be
helpful for youth to have a way to connect with other youth with CF and that managing emotions associated with CF would be helpful if they understood they were not the only people experiencing them. One parent expressed the need for social support as the most salient need for their child:

*The one that honestly, I think would be, I would love is just for her to be able to talk to other kids her age, younger than her, older than her, about what is going on with them. It is so frustrating to not be able to have her in the same room as another girl the same age as her to talk about what is going on and just to be real, because nobody will understand it the way that they will. And that sense of comradery, you know? And just the conversations and the depth of what is going on, without having to explain to anybody their routine and everything...I think that that would be an incredible way of giving them the support that they need. And I know how excited she gets when she sees an older person that has CF. And they, on the outside, they definitely look healthy, if they are in the same place, they have to be to be anywhere near. But just the hope, and the brightness in her eyes of seeing that, I think that it just challenges any of the dark fears that she might be having and entertaining. And not that those aren’t without merit, but it just brings hope and that kind of thing. (Parent 5)*

Although many participants described lacking connections with other families with CF, one parent shared a helpful experience their child had connecting with an adolescent with CF. The ability to relate to each other and help one another was perceived as a positive experience that would be beneficial for all youth with CF to engage in. Parent 3 shared:
There’s an older girl [older youth with CF], when she [Parent 3’s youth with CF] was a little bit younger and wasn’t wanting to do her sinus rinses, the girl’s mom, she sent a video of her doing a sinus rinse, and talked her through it kind of thing. And what she was doing, and why she was doing it. And at the time, she [older youth with CF] was kind of like, “What? Why would you want to watch that? Why would you tape that?”. But then she realized that it helped somebody. And I think that is cool because, they’ve experienced it, yeah. I just think that that would be a cool idea!

5.9.3 Barriers to access. In the third subtheme, participants identified several barriers to accessing mental health services for their youth with CF. Parents suggested one barrier to accessing services was the limited specialized health and mental health professionals available in the province. Parents expressed the need for more specialized mental health professionals that specifically deal with chronic illnesses. Other barriers associated with accessing mental health services included the cost of paying for mental health services, as well as travelling to access mental health services for families that live in rural areas. Further, parents reported wait times to access mental health services as a barrier. Finally, participants expressed the difficulty with having to access mental health services outside of the clinic. As families are busy with completing other treatments and attending other health care appointments, parents also described time as a barrier to accessing mental health services.

Because she doesn’t want to go sit for an hour. And sometimes, right now in the CF clinic, if we want her to be one-on-one with it, we have to book an appointment, outside of that. Which with all of the appointments we go to, it is just
challenging to sort of add more appointments to the thing and I feel like mental health is really, really important… But it is not a one-stop-shop. She can’t go to clinic and speak with a psychologist, do you know what I mean? Or… I know they are just starting screening, and they are looking at more of it, but we need more, with mental health. (Parent 1)

5.9.4 Informing novel approach. In the final subtheme, parents provided their opinions on youth with CF participating in a mental health program delivered via the Internet. Parents felt their youth would be open to trying an Internet-delivered mental health program and believed that because CF is an isolating condition, using an Internet program could be a beneficial way to connect with other youth with CF. Parents also shared their opinions on the potential drawbacks of offering a program delivered using the Internet. Parents stressed the importance of monitoring of the program to ensure the safety of youth using the program. Parents expressed further concerns about the use of the Internet and potential for bullying on the Internet. One parent shared that youth are learning the Internet is not safe and that offering an Internet-based program could be perceived as dangerous. Moreover, parents motivated to limit their child’s screen-time may prevent use of the program. Parents also suggested making connections with others on the Internet may be difficult as it may be difficult to develop trust. Some participants expressed concern about the lack of control of the information youth would receive on the program and the potential for misinformation. As CF presents in a variety of ways, parents were concerned youth would be receiving information about CF unrelated to how they experience CF themselves. Parent 2 shared:
I don’t know if she would at this point [connect with others with CF]. We probably wouldn’t put her, not at her age right now, put her in a space like that. I feel like there might be a lack of control from our perspective of what she might be consuming. And what could be said on there that could be not factual. You know, it is very easy for this disease to show up in very different ways. So, all of a sudden if she is receiving information that really is not related to her, or her condition at this point, I don’t know how beneficial that would be. It might be a negative experience for her.

Participants also made suggestions on important components to include in the program. Participants recommended taking a holistic approach and including education about all components of CF (i.e., physical health and mental health components). Parents suggested having categories to select from based on age and gender of the youth. As CF manifests differently based on gender and is a progressive disease, individuals of different gender and ages may require different information and support. Including developmentally appropriate information was highlighted as being important. Parents also suggested including information about the variety of ways CF can manifest. Additionally, incorporating a physical literacy component was suggested. Parent 6 described learning medical language in a developmentally appropriate way as a potential component of the program:

*I think it also needs to, some of the things that I find educational also have a little too much jargon in it. It can be tough to comprehend and understand. So I think you want to dumb it down, but there is only so much you can do, right?... I think that is an important component would be learning the medical language...it*
would be nice to almost have like a cystic fibrosis specific medical dictionary that talked about, here are the things. I think that a jargon dictionary would be incredibly important.

Participants provided ideas on important aspects of mental health to focus on in the program and how to present this information to youth. Parents believed it would be important to acknowledge potential emotions experienced by youth with CF, how to communicate and express emotions, and provide information on and ways to practice positive coping strategies. Parent 2 suggested:

*I think building habits would be great for her to practice. You know, acknowledgement of feelings and possible ways of either talking about them or expressing them, or I don’t know, tactics for dealing with them. Maybe an acknowledgement of all the different feelings that can I guess be perceived.*

Parent 3 added it may be beneficial to include an interactive component to learn how to deal with difficult situations and emotions. Parent 3 shared their experience using an app to learn to cope with emotions and believed including interactive vignettes of dealing with emotions would be helpful for youth with CF.

*I think, like myself, I got an app on my phone, it’s like a CBT app called iCope. And it is awesome! I think to walk through certain situations or something like that to be, if she is upset about something, she could pretty much walk herself through those feelings and deal with it... Like really think about what she is going through at the time, processing things. I think that would be interesting to have something like that. (Parent 3)*
Another component perceived as being helpful to include in an Internet-delivered mental health program was stories from other individuals with CF. Parents described sharing strategies to make treatments less boring among youth with CF or reading about treatment strategies used by others would be beneficial. For example, one parent shared their child practices piano while completing their nebulizer treatment. Sharing treatment strategies with other youth with CF and hearing from others about their personal treatment strategies was perceived as a valuable inclusion. Relating to others’ experiences was described as a way of providing social support to youth with CF. Parents 6 and 7 shared similar opinions on including stories from others with CF:

*Story-telling. I think a blog-like effect would be important, and I think that that is probably maybe where that could be the strongest in the internet world, is people who are willing to share their stories on multiple occasions through whether it be an experience or day-to-day life where they could go on and read and maybe a little bit of interaction back and forth, because I think it... I can never experience CF for her, so I can never give her that insight, so I think stories from others who have experienced things would also be an important component. (Parent 6)*

*Well I hope that there would be like adults writing stories about when they were kids, providing their experiences so that... And maybe not like 37-year-olds, but maybe young adults. So that you know, the kids can relate to their feelings and have those adults write when they were 10 and when they were 15 or whatever. So, you know, they can see someone who has been through it. (Parent 7)*
Parents emphasized the program should be interactive, fun, and easy to use. Including games to learn and connect with other youth with CF was suggested. To accommodate the potential attention difficulties experienced by youth with CF, it was recommended the program be delivered in short modules, as well as incorporating a way to set reminders for scheduling, organizing, and completing treatments. Parents expressed if youth were required to sit and focus for long periods of time this would discourage use of the program. Parents suggested using a character to deliver the information would be perceived positively. Additionally, setting easily achievable goals and use of a rewards system was described as motivating use of the program.

*I think just having it interactive and fun. Like a lot of words would not be the right solution. A lot of reading and a lot of words like just like describing it where it feels like you’re just reading it in school. I think things that are interactive and ways like, ways that made it feel like they would be doing the same thing they would be doing on other apps... I think that if it just turned into an app that was like feeling like they were doing school would be a downer. (Parent 1)*

5.10 Discussion

Part Two provides descriptions of the challenges of youth with CF and the information and services they require from the perspective of parent caregivers. I will discuss the results of Part Two within the context of the research questions. I will also situate the results of Part Two within the relevant literature and demonstrate how the current study builds on existing research. Finally, implications of parent responses and opinions in informing the development of an Internet-delivered mental health program for youth with CF will be expanded upon.
5.10.1 Challenges. The first research objective was to understand what types of challenges youth with CF and their parent caregivers face. Participants of Part Two described several challenges experienced by youth with CF, as well as challenges faced by their families. Three main challenges emerged from parent responses including emotions related to living with CF, psychosocial challenges, as well as treatment challenges. Parents identified emotional challenges experienced by youth with CF related to their condition. Emotions such as envy and worry were highlighted by parents. Youth with CF were described as feeling envious of their healthy peers as they may have less responsibility and more opportunities. Parents described the lifestyle of managing CF becoming normal for youth, despite being able to observe the difference between them and their peers. Jamieson et al. (2014) discussed emotions associated with comparisons made between youth with CF and their healthy peers and found that over time, youth with CF create a sense of normalcy in their life and become less concerned with comparing their capabilities with the capabilities of healthy peers.

Additionally, feelings of worry related to disease outcomes and health procedures were emphasized by parents. Youth with CF were described as potentially lacking disease knowledge contributing to feelings of anxiety. Prior research has suggested that youth may lack knowledge about their condition and this uncertainty may contribute to psychological distress (Anton-Paduraru et al., 2015; Bregnballe et al., 2007). Further, dealing with the uncertainty of their prognosis was discussed. Dealing with the unpredictability of a progressive disease and worrying about health outcomes and procedures has been identified in previous studies (Cayse, 1994; Hayes & Savage, 2008; McNeill, 2004; Ward, Brinkham, Slifer, & Paranjape, 2010). These findings suggest
addressing feelings of worry and uncertainty, as well as providing education about CF may be an important focus in addressing the anxiety potentially associated with living with CF.

An emotional challenge faced by parents of youth with CF was identifying and differentiating between emotions associated with living with a chronic illness and emotions associated with growing up. Parents discussed being aware of the potential psychological challenges associated with living with a chronic illness and expressed worry about their child’s coping. Previous research highlighted parental interest in services that helped children cope with feelings of isolation or feeling different overall stress, and managing their mood or anxiety related to CF (Everhart et al., 2019). Providing parents with appropriate information to be aware of and recognize emotions related to living with CF, as well as effective coping strategies to help manage these emotions in their youth may be an important focus when considering prevention and intervention programs for this population.

In addition to the emotional challenges faced by youth with CF and their parents, psychosocial challenges related to living with CF were also identified. Consistent with previous findings that suggested youth with CF struggle socially as they often miss out on opportunities and feel isolated, parents described youth with CF feeling different from their peers based on their lifestyle restrictions and isolation often required due to their condition. As a result, youth may have difficulty creating relationships with peers. These findings suggest the need for social support for youth with CF. Social support, social connectedness, and validation of experience is known to be beneficial across many illness populations; however, is severely reduced in individuals with CF (Kirk & Milnes, 2016).
Emotional support from friends and family, as well as opportunities to interact with other youth with CF have been recommended to promote feelings of connectedness and positive coping (Jamieson et al., 2014). Social support experienced from friends, or others with an ability to understand one’s experience, is known to improve adherence to medical treatments and quality of life (Helms, Dellon, & Prinstein, 2015). Research across various chronic illness populations has demonstrated that greater levels of social support are associated with fewer depressive symptoms, higher levels of self-efficacy, greater adherence to treatments, and better quality of life (Frisina, Borod, & Lepore, 2004). Parents in the current study reported while some youth feel self-conscious about their condition and limit communication about CF to avoid feeling different from their peers, others educate their peers about their condition contributing to feelings of being understood and included. As feeling different and communicating about CF to peers is challenging for some youth with CF, providing information and support related to communicating with peers about CF may be helpful.

Parents also discussed other challenges with communication about CF faced by youth. In terms of communication with health care professionals, parents reported the consistency of their health care team and building rapport is associated with youth feeling comfortable communicating about CF with their health care team. Parents suggested youth feel uncomfortable communicating with health care professionals when they are nervous or confused about a health procedure. Previous qualitative findings demonstrated that youth may feel ignored and devalued when health care professionals direct conversations solely towards parents and use medical terminology that is difficult to understand (Al-Yateem, 2012). Previous research has recommended the development of
strategies to improve communication between families with CF and health care professionals (Everhart et al., 2019). The use of developmentally appropriate language and education about health procedures provided by health care professionals to youth with CF may promote better communication.

Other challenges with communication involved struggles encountered by parents communicating about harsh aspects of CF with their youth. Parents expressed feeling uncertain about the timing of conversations of disease prognosis and life expectancy. While many participants reported not communicating with their youth about life expectancy, they also expressed feeling worried about other ways their youth would find out about these aspects of their condition. Families of youth with CF may benefit from psychosocial support focused on effective communication with others and within families about CF (Quittner, Flores, & Barton, 2016). Moreover, parental discussions with youth about life expectancy may require additional support from health care professionals (Everhart et al., 2019).

Finally, parents identified the demanding nature of treatments as a challenge faced by youth with CF. Participants described treatments as time-consuming and interfering with many aspects of daily life. Parents also emphasized that completing treatments is essential and not optional. Previous studies reported youth described treatments as invasive, intensive and physically strenuous; however, youth believed persevering with treatments was necessary to avoid potential health deterioration and complications (Barker & Quittner, 2016; Jamieson et al., 2014). As maintaining a rigorous treatment routine is a salient challenge associated with living with CF, providing effective ways to cope with this challenge may be beneficial.
5.10.2 **Type of information needed.** The second research objective was to understand what type of information youth with CF and their parents need. Parents believed youth with CF need developmentally appropriate information about their condition and how it affects their body. Youth with CF also need to understand their treatments, as well as understand the rationale for completing their treatments. Disease knowledge and treatment knowledge in youth with CF has been linked to treatment adherence (Faint et al., 2016). Parents described that as there is no tangible and instant reward when completing treatments, it is important for youth to have an awareness of the long-term benefits of maintaining their treatment routine. Additionally, parents believed information should be delivered to youth using a gradual approach where they learn more and accept more responsibility as they grow older. Similar to previous research that demonstrated incorporating youth in their health care is important in promoting independence in managing CF (Lipstein, Muething, Dodds, & Britto, 2013; Miller, 2009), parents in the current study emphasized the importance of youth being involved in their own health care and participating in decision-making processes. In preparing for the future, parents explained that if youth learn and take on responsibility gradually, they will be less overwhelmed and more capable of being independent as adults.

Based on the challenges previously discussed that youth with CF face, it is also important for youth to have information about emotions and struggles they may experience associated with living with CF, as well as effective coping strategies to help deal with those challenges. Parents described mental health as a contributing factor to youth’s ability to learn about and manage their CF. Psychological symptoms in individuals with CF and their parents has been associated with decrease in a variety of
health outcomes such as decreased lung function and worse treatment compliance (Ploessl et al., 2014; Hilliard et al., 2015). Findings from the current study combined with existing literature emphasize the need for more information and services to address and prevent mental health issues. Moreover, as parents are often the individuals teaching youth about CF, treatments, as well as coping, it may be important for parents to have appropriate disease knowledge and coping skills to teach to their children. Discussions of coping and strategies to promote resilience in individuals and families with CF have been highlighted as a need to provide comprehensive CF care (Muther et al., 2018).

5.10.3 Type of services needed. The third research objective involved understanding the service needs of youth with CF and their parents. Parents identified two main services needed for youth with CF. First, parents reported needing better access and a greater focus on mental health care for youth with CF. Parents explained youth with CF require consistent opportunities to learn how to express and cope with emotions related to their condition. Preventative mental health services were identified as being important. Integrating effective preventative approaches to buffer against potential risk factors in youth with CF has been suggested (Muther et al., 2018). Parents highlighted the potential for youth to develop more intense mental health issues as their disease progresses and that developing effective coping strategies early would be valuable. Moreover, parents desired access to mental health care for the entire family, including parents and siblings. Incorporating family-centered care may improve concerns about family functioning within the context of coping with having a family member with a chronic illness (Muther et al., 2018). Second, parents reported a need for social support. Parents discussed the isolating aspects of living with CF for their youth and the lack of
social support for their families. Parents expressed needing opportunities to connect with other families with CF.

When considering the service needs of youth with CF, it is also important to recognize the current barriers to accessing services. Participants reported several barriers mainly related to accessing mental health services, such as the limited mental health professionals available to provide services, financial barriers, travel, as well as having to access services outside of the CF clinic. In developing methods to provide services needed by youth with CF, understanding the barriers to access they currently face is essential to reduce barriers and effectively address their needs.

5.10.4 Benefits and drawbacks of service via Internet. The fourth research objective of the current study was to determine the perceived benefits and drawbacks of youth participating in an Internet-delivered mental health program. Parents believed providing a mental health program delivered using the internet would be perceived positively by youth and highlighted the opportunity for connecting with other youth with CF as a benefit. Drawbacks of offering a program using the Internet included safety concerns, as well as the potential for misinformation about CF. Ensuring families with CF are accessing credible information has been noted (Havermans et al., 2015; Jamieson et al., 2014; Jordan & Chambers, 2016). These concerns demonstrate the need for the inclusion of safety features and monitoring of the program. Additionally, parents attempting to limit their child’s screen usage may prevent use of the program. Although some parents believed it may be difficult to create connections with others using the Internet, many perceived this as a positive opportunity that is currently lacking for youth with CF.
5.10.5 Components of program. Finally, the fifth research objective involved gaining insight on what components should be included in an Internet-based mental health program for youth with CF. In accordance with the information needs identified by parents of youth with CF, participants suggested the program include an educational overview of all aspects of CF including physical health and mental health. It was recommended categories based on gender and age be included to tailor to the individual needs of each youth. Incorporating education about medical language in a developmentally appropriate way was also suggested. Parents explained it would be important to acknowledge emotions potentially experienced related to having CF, ways to communicate about emotions, as well as coping strategies. Using interactive vignettes and hearing stories from other youth with CF were identified as potential components. Parents emphasized the importance of the program being fun and easy to use. Using a character to deliver information and using games to learn about CF was suggested as a way to grasp the attention of youth. Additionally, accommodations for youth with attentional difficulties should be considered. For example, ensuring modules are short and incorporating scheduling and organizational techniques may be a valuable inclusion.
6.0 Chapter 6: Part Three (Health Care Professionals)

6.1 Introduction

With the goal of further understanding the challenges faced by youth with CF and their families, it is necessary to learn from individuals who have worked with these families in a health care setting. Gathering information from health care professionals is a valuable addition to youth and parent perspectives and provides a different perspective of families’ challenges and needs within the realm of CF treatment and care. Health care professionals have in-depth knowledge of CF and the current services offered, as well as the gaps in services for youth with CF. They also understand information and service needs from a health care system standpoint and possess valuable information on the logistics of health care delivery. Including health care professionals is an essential component to understand the information and service needs of youth with CF, as well as the feasibility of an Internet-delivered mental health program.

This chapter will explore health care professionals’ perspectives of what challenges youth with CF face and what information and services they need based on their experience working with this population. In particular, health care professionals’ knowledge and experiences will be illustrated with the goal of achieving the research objectives. Despite some differences in perspectives and experiences, many commonalities and conclusions were found in their responses.

6.2 Summary of Participants

In order to maintain participants’ anonymity, I have decided to provide collective descriptive information on the demographics of participating health care professionals. I have also decided to assign each participant a number and will refer to them using the
assigned number. Demographic characteristics for health care professional participants are summarized in Table 4. The sample included four health care professionals, three females and one male. Participants ranged in age from 34 to 61 years old ($M_{\text{age}} = 44.00$, $SD = 10.46$). All participants reported living in an urban environment. In terms of ethnicity, all participants self-identified as Caucasian. All health care professional participants reported working full-time in their position. The mean amount of time health care professionals reported working with individuals with CF was 15.17 years.

6.3 Summary of Themes

Thematic content analysis uncovered six major themes from the in-depth interviews: (1) emotional challenges; (2) social challenges; (3) lifestyle restrictions; (4) developing independence; (5) barriers to care and managing CF; and (6) focusing on future mental health care. Subthemes were found under each major theme and will be elaborated on. Direct quotes are included to provide support for themes and subthemes, as well as to provide a detailed illustration of participant experiences and opinions as they relate to the themes and subthemes. The themes and subthemes are listed in Table 5. The complete thematic scheme for health care professional perceptions is illustrated in Figure 4. The thematic scheme for health care professional perceptions is represented by a funnel in which information concerning youth challenges, experiences, and opinions on services all inform the development and improvement of services for youth with CF.

6.4 Emotional Challenges

Health care professional participants described several emotional challenges faced by youth living with CF. Participants described the challenges they perceived as most salient based on the patients with CF they have worked with. Participants relayed
Table 4.

Demographic characteristics of the health care professional sample.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Health care professional (n = 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of healthcare professional</strong></td>
<td></td>
</tr>
<tr>
<td>Registered nurse</td>
<td>1 (25%)</td>
</tr>
<tr>
<td>Dietitian</td>
<td>1 (25%)</td>
</tr>
<tr>
<td>Social worker</td>
<td>1 (25%)</td>
</tr>
<tr>
<td>Physician</td>
<td>1 (25%)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>3 (75%)</td>
</tr>
<tr>
<td>Male</td>
<td>1 (25%)</td>
</tr>
</tbody>
</table>

Note: Data represented as n (%) unless otherwise indicated.
Summary of Themes from Part Three.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
</table>
| **Emotional Challenges**            | 1. Emotions related to CF  
2. Dealing with uncertainty  
3. Accepting the condition       |
| **Social Challenges**               | 1. Feeling different  
2. Communicating about CF  
3. Balancing family relationships  
4. Elevated self-consciousness  
5. Feeling disconnected from CF community |
| **Lifestyle Restrictions**          | 1. Managing rigorous treatments  
2. Missing out                   |
| **Developing Independence**         | 1. Understanding CF  
2. Modelling  
3. Increasing responsibility    |
| **Barriers to Care and Managing CF**| 1. Accessibility  
2. Parent caregiver beliefs and attitudes  
3. Patient beliefs and attitudes |
| **Focusing on Future Mental Health Care** | 1. Improving care  
2. Directing a novel form of service delivery |
Figure 4. Representation of themes from health care professionals.

Health Care Professional Perceptions

Focusing on future mental health care
that youth with CF and their families have varying emotional experiences that are often linked to the developmental stage of the child or adolescent, the timing of the diagnosis, attitudes the child or adolescent hold toward their prognosis and the future, as well as how well the family accepts the diagnosis of CF. Three main subthemes emerged in this topic area including the differing feelings youth experience related to having CF, dealing with the uncertainty of the disease and their prognosis, and challenges associated with accepting the condition.

6.4.1 Emotions related to CF. In the first subtheme, participants described various emotions youth experience related to living with CF. Emotions identified include anger, confusion, feeling scared, guilt, shame, embarrassment, and frustration. For example, Health Care Professional 2 expressed:

*I think that it’s probably pretty scary, I think it can be confusing at times, and I think that it makes life just a little bit difficult... I think that... there’s probably some anger and I think there is some questioning as to why them. I think there’s probably some exhaustion and some frustration.*

More severe emotional presentations such as depression and anxiety were also identified as being experienced by youth with CF. Health Care Professional 1 specifically described experiences of depression and anxiety and how they may influence treatment non-compliance when emotional needs are left unmet. Health Care Professional 1 shared:

*I think that if you are living with anxiety or depression, and not dealing with those feelings and thoughts, it is hard to comply and do things [treatments].*

Further, the timing of the diagnosis of CF was described as affecting the types of emotions experienced. People who are diagnosed at birth were perceived as having a
different emotional experience, as they do not know a life without CF. In contrast, people
who are not diagnosed at birth, live part of their lives without knowing they have CF.
Once the diagnosis of CF is made and their lives change, participants described
individuals with CF may experience feelings of resentment and anger associated with this
change in health status and lifestyle.

*I guess I have two views because for the children that we now identify as
newborns, the life with CF, they don’t know any different. That’s just, since
they’ve been born, this has been the procedure, and probably, just don’t know the
difference. But the children that were diagnosed later, who do kind of know life
before CF, I feel like they probably have a little bit of resentment, or different
feelings, because they do know life before all of the medicine and all of the
treatments and that kind of thing. (Health Care Professional 1)*

Participants also differentiated between emotions experienced by children and
emotions experienced by adolescents. Several participants explained that the
developmental stage of the individual and their understanding of CF has an impact on
their experience and their emotions. Children were described as not understanding the
severity of their condition and not thinking about the impact CF may have on their life,
and as a result may not experience intense emotions related to CF. Children were also
thought to comply to treatment routines as they simply follow their parents’ instructions.
In contrast, adolescents were described as reflecting more on the impact CF has on their
lives and futures, and may experience more intense emotions associated with their
condition based on their understanding of CF. Additionally, adolescents were viewed as
more independent and described as experiencing some frustration with reminders from
parents to complete their treatments. Participants explained that with more independence, there is also an option for adolescents to make choices to not complete treatments despite encouragement or persistence from parents.

*I think that the young child maybe doesn’t comprehend the entirety of the condition, they know, they are told they have it, they know that they have to do certain things. But I think as they get into the age group where they’re thinking about things more, yeah I think it changes. I don’t see young children so much being angry and sad and having... they are more just kind of like you know, “Well this is something we do”, just their kind of developmental stage, they don’t really...yeah.* (Health Care Professional 1)

### 6.4.2 Dealing with uncertainty.

In the second subtheme, participants described the uncertainty experienced by youth with CF related to their future. Participants explained various emotions associated with the uncertainty of disease outcomes and their life potential. Health Care Professional 4 highlighted the burden of the illness and the difference between youth with CF and their peers when thinking about the future. Emotions associated with uncertainty that were identified by participants included *sadness, anxiety, and frustration.*

*And the sadness of course. Thinking about their own experiences and their own future and knowing that it is not going to be as bright as other people because of what they have to deal with.* (Health Care Participant 4)

Additionally, emotions associated with uncertainty were related to treatment engagement and compliance. Health Care Professional 3 explained that youth with CF who feel frustrated about their possible prognosis and their futures sometimes lose
purpose in completing their treatments and lack the ability to recognize the importance of treatments to maintain their health status. Participants explained that in general, youth lack a future-oriented awareness and may not see the long-term benefits in maintaining their rigorous treatment routines. Participants suggested that there is not always a tangible reward associated with completing a treatment, such as immediately feeling healthy. Lack of a tangible reward can make it difficult to see the benefit in complying with treatments, despite it being beneficial in the long-term. Health Care Professional 3 shared:

A lot of them, I mean, they know they have CF, they’ve either read about it or just simply know that their life is possibly shorter, they have to take care of themselves. I think in some cases we’ve had kids over the years that just “I’m not going to go to university anyway. I’m not going to get married”. So I think that impacts their mental, the way they feel, right? “Why am I doing this now if I’m not gonna…survive?” So that I think, also impacts them.

6.4.3 Accepting the condition. The final subtheme within the emotional challenges theme includes difficulties related to accepting a diagnosis of CF. Participants explained the importance of accepting the diagnosis of CF for the physical and mental well-being of the child or adolescent. Families that accept the diagnosis of CF were described as thriving in terms of their treatment compliance. Additionally, participants emphasized the importance of parent emotional acceptance of CF and willingness to fully engage in all of the factors necessary to manage CF. Participants stated that parents who accept the diagnosis and cope well themselves model that behaviour for their children, and as a result tend to have children that also accept the diagnosis and cope well. Health
Care Professional 1 described that many families she encountered accepted of the diagnosis and remained positive:

*I think even if they [children with CF] are born, and have newborn screening now and they have it [CF], I’m sure they still know that they are different, and that they have different needs than other children. But I think from what I have seen in families and children, for the most part, they are very positive about the diagnosis and very just kind of “This is how we deal with it”.*

Health Care Professional 4 described their experience working with families and how often it is possible to predict a child’s outcome based on the family’s acceptance of the condition and the associated expectations of the condition:

*If they [parents] can accept it it’s a lot easier for the kids to accept it, and that is their routine. I know in my own experience just looking after kids over the years, the children who tend not to do as well are the ones that are in families that their parents don’t do well, they just don’t accept that this is what needs to be done and carried through … A lot of times here, my experience dealing with families, and I used to tell people, you can almost tell from the start how well someone is going to do with their CF, because you get impression about how the family is likely to deal with it. So, you get parents that get the diagnosis, and “Okay, well I’m not happy about the diagnosis, but what do I need to do?”. And they are ready to just launch in and do whatever it takes, and you know that those children are going to do well. Other ones that don’t quite accept it as well, and maybe don’t have the coping skills themselves, and then they don’t pass those on to the kids as well, and*
then the kids end up being sicker because they’re not getting their treatments for instance.

In alignment with the topic of acceptance, Health Care Professional 4 elaborated on the impact the timing of diagnosis may have on the family’s acceptance and level of engagement in treatments. Health Care Professional 4 differentiated between the experience of a family where the child is diagnosed with newborn screening (i.e., within the first month of being born) and the experience of a family where the child is diagnosed later in life. Children who are diagnosed later in life are often diagnosed as they are displaying symptoms of CF and appear as they are sick. Health Care Professional 4 explained that parents who see that their child is sick often accept the diagnosis and are prepared to commit to the treatment expectations of CF in order for their child to feel better. In contrast, children who are diagnosed at birth often appear healthy and display no symptoms of being sick or having CF, therefore parents do not see that their child is necessarily sick. Timing of the symptom presentation may affect their acceptance of the condition and how well they commit to adhering to the treatment expectations. Health Care Professional 4 emphasized the importance of parental acceptance of the condition for children to manage their CF, as well as the possible implications not accepting the diagnosis and adhering to treatments may have on their mental health.

In the last ten years, we are diagnosing newborns. There is a newborn screening program. So almost all of them are picked up in the first month or so, and during that first month, most of these children are doing fine. Often people with CF don’t demonstrate problems until later on. They’re not thriving at six months of age or they’ve got this bad cough at a year of age or something. Whereas at the
beginning, they are healthy kids. And so we are calling out of the blue and saying
to families, “Yeah there is an indication your child might have cystic fibrosis, we
want to bring them in and do a sweat test to find out for sure”. You do the test, it
is positive, “Okay, now your child has CF”. And it is different in terms of their
emotional acceptance of the condition, because they’ve never seen their child
sick. So trying to convince them that “Yes, you’ve got to give them their enzymes.
Yes, you have to do physiotherapy...You have to be vigilant for their
infections...”, they are not as motivated to do those things. When they’re not as
motivated, the kids aren’t going to be as motivated. It may come when the
children maybe start having symptoms, and maybe they don’t thrive as well, and
maybe they start having a chest infection and now the parents realize, “I guess
I’d better get on this”. But that kind of, distorts the whole reason why we are
doing the newborn screening in the first place, is you want to start treatment early
so they do that much better, you don’t want to wait until they are showing the
symptoms like in the past. So that’s an issue.... And that is going to have an
impact on the mental health of the children as well, if the same thing, “Yeah we
do our treatments and everything but it is not a big deal”, “How am I going to
start accepting that I have to do them? And do them regularly? When I don’t see
my parents doing that?” (Health Care Professional 4)

Additionally, participants shared worries that if those who are diagnosed at birth
do not adhere to their treatments appropriately, the longevity of people with CF may
begin to decrease. Newborn screening was described as a preventative approach to ensure
that people with CF received treatments immediately to increase their longevity, however
it is thought that based on the level of parental acceptance during this time of diagnosis, it may be having the opposite effect.

6.5 Social Challenges

The second main theme that emerged from responses provided by health care professional participants included social challenges experienced by youth with CF. Participants elaborated on aspects of CF that influence the social lives of youth and how they experience relationships. Four subthemes were identified in this topic area including the experience of feeling different from peers, differing experiences and feelings toward communicating about CF, challenges experienced in balancing family relationships, feeling self-consciousness about certain aspects of CF, and feelings of being disconnected from the CF community.

6.5.1 Feeling different. In the first subtheme, participants shared that one notable social challenge experienced by youth with CF is the experience of feeling different from their peers. Participants identified differing expectations and responsibilities across those with and without CF. For example, having to comply with a rigorous daily treatment routine or being isolated from friends to prevent infections are necessary measures for youth with CF. Participants suggested that it may be difficult for them to relate to their peers as their daily lives are vastly different. Participants explained this can make it increasingly difficult to create relationships. The social challenge of feeling different was also described as potentially having an effect on their mood.

*I think that relationships are probably pretty hard for them in terms of peer groups because of some of the challenges that come with CF, and the meds, and the routine...I think it affects their relationship with their peers. I hope that it is*
always positive, but not always is it, and kids can be cruel and that can affect their mood. And I think that like with any sort of chronic illness there is some isolation, and that is difficult too in terms of when it’s a flu season, being kept home and just kind of the different rules that there are for people who live with illness. (Health Care Professional 2)

Health care professionals also emphasized feelings of “sticking out” and being identified as different. Participants highlighted experiences by younger children at school standing out from their peers as they need assistance taking their required medications. Participants also pointed out that they may become increasingly aware of the differences between themselves and their peers as they become older.

I think being different and being identified as different, you know, for some of them... I always think about school-aged kids moreso, because you can be identified easily in school if you’re going to the principal, sometimes they have to go to the principal to get their enzymes, so again you’re being singled out. Some of them just can’t take their enzymes and pretend everything is normal like the rest of the kids. (Health Care Professional 3)

Health Care Professional 3 elaborated on the feelings of being different based on the age of the child and explained that because adolescents have more independence, in efforts to reduce feelings of being different they may avoid doing things that make them stand out in front of their peers. For example, adolescents may decide not to take their enzymes at school or comply to other necessary treatment-related tasks that make them different, resulting in other health issues. Hiding the condition was also described as something that adolescents do in attempts to be more like their peers. This suggests that
feelings of being different may be associated with treatment non-compliance for some youth with CF.

*I think with the school-aged kids, the parents have a little more control. And the older kids, they want to exercise their independence and to be the same as everyone else. So I think that might be where we find, like with the kids I worked with, they might not want to take their enzymes, they might not want to go to their locker to take their enzymes, and then they end up with bowel problems, sore tummies, and then, that can also end poorly when they have to go to the bathroom quickly and... you’re just not the same as your peers.* (Health Care Professional 3)

6.5.2 Communicating about CF. In the second subtheme within the social challenges theme, health care professionals shared varying perspectives of youth experiences communicating about CF to others in their lives. Participants described the experience of youth with CF communicating to different groups of people including their doctors and nurses, family, friends, and teachers. Health care professionals provided two different perspectives of how youth feel about talking to their doctors and nurses about CF. Some participants described that they think it is easy for them to communicate to health care professionals about CF based on the knowledge that the health care professional already has about the condition. From this perspective, youth with CF would not need to go into detail or give any background information about their condition, making it easier to talk about, and perhaps less invasive. Moreover, many youths meet with the same team of health care professionals at the CF clinic every few months and are therefore develop rapport with the team. They also may understand that it is an
expectation for them to talk about their CF to their doctors and nurses. Despite the fact that it may be comfortable for some, participants also highlighted that personality may be a factor that contributes to how comfortable a person will be in disclosing information about their condition to their physicians and nurses. For example, Health Care Professional 2 and Health Care Professional 4 shared:

*I think it is probably easier [communicating with health care professionals]... probably easier because we expect to do it. We meet with them every few months and we ask all sorts of questions, and more embarrassing questions about poop and things. And so, I think it’s probably easiest for them to talk in clinic, easier there perhaps than it is with other people. Still a lot of it is based on personality too. Some children have no issues and will be open about almost anything, and others are pretty quiet. So you have to tease things out of them sometimes. Another perspective that emerged focused on the notion that some youth experience communicating to their doctors and nurses about CF as stressful and overwhelming. Participants relayed that depending on the treatment compliance of the child or adolescent, they may be nervous to tell their doctors and nurses about how they have been managing their CF. Further, health care professionals explained that reports from youth with CF about their condition and management of their treatments are not always necessarily accurate. Health care professionals also emphasized the importance of building rapport with their patients in order to gather accurate information, as well as for patients to feel comfortable disclosing information and asking questions about CF.

*I think sometimes, it’s overwhelming for them because they don’t really know what to tell us and what to explain, or how to explain things. But I think we try
really hard to be, to build a really good rapport with our patients. So, I hope that they feel comfortable, that they could approach us if they had questions, or if they needed more information or if they wanted to talk about new stuff coming... I think probably it’s that as it gets older it just becomes part of what we do hopefully, and they learn more about it themselves so I hope they are more comfortable. (Health Care Professional 1)

So we have a small clinic, and some of us have been here a really long time. So we have some kids that are fairly open and they are really great at talking about things that we talk about like “What are your bowel habits?”, “Do you take your meds?”. But I do think that it is a bit of a challenge overall, because I think in some cases, they know what the right answer is but they haven’t been doing it. So sometimes we don’t hear the truth, or depending on the team member, we might hear different stories. So, I think sometimes they know what they are supposed to be doing and then sometimes, maybe we don’t hear the whole truth? So it’s probably stressful for them to sit in front of us... Yeah and maybe if they didn’t do it, having that little bit of guilt or having that sly look in their eye like “Uh, yeah I did it once and a while” or “Sometimes I forget my enzymes”. (Health Care Professional 3)

Communicating with the family about CF was described as being fairly comfortable because it is a part of the routine. Communicating with friends about CF was described as sometimes being awkward and embarrassing. Personality was indicated as a factor that also influences communication with friends about CF. While some youth
are very open and outgoing, others may be shy and introverted influencing how they feel about communicating about their CF. Health care professionals explained that they encourage youth to disclose their condition to their friends at a young age and that this helps normalize it. For example, Health Care Professional 4 expressed:

Friends...a little bit tougher. Again, it depends on the personality, probably as much as anything, and what kind of friends they have and how much you’re willing to share. We try to indicate to younger kids that if they talk about it with their friends, their friends will find it interesting for the first little while, and after they will just ignore it because it’s just, that is who you are, right? So, if one of your friends has red hair, it’s just “That’s the girl with red hair”. Well, “That’s the girl over there who has cystic fibrosis”. They tend to accept it when they are young. But it is difficult for some kids, the ones that are particularly shy they may not want to do that, and they might want to try to hide things and keep it under-wraps. And just not want to be different from other people, and they have trouble with that... Especially too probably for adolescents. But if they’ve already shared that information at a younger age, then they find it easier. They don’t have some secret they are hiding.

In terms of communicating with teachers about CF, most participants believed there is likely little communication with the teacher about their condition, aside from perhaps being aware of the child’s needs at school. In efforts to not stand out from others, youth with CF were thought to limit communication with their teachers about their condition. Participants also explained that teachers may also try to limit communication with the child about CF in attempts to not treat them differently or have them singled out.
Chances are the school already knows. So, chances are the teacher knows as well. I’m not sure how much direct interaction takes place regarding that. Probably [teachers] try not to bring it out in the open and be succinct… You know, if they have to remind the child that they need to go for their physio or something, they might do that, but probably not something that they would share with the classroom. Kind of think most of them probably don’t interact with the teacher with regard to their disease much. (Health Care Professional 4)

Health Care Professional 3 spoke specifically about CF as an invisible illness. They explained that because people cannot see that someone with CF has an illness, it can be confusing for people to understand, and as a result may make it increasingly difficult for youth with CF to talk to others about their condition.

I think it can be awkward to talk to their family, friends, and teachers because CF, its better now, but it wasn’t a well-known illness and it seemed to get confused with other illnesses. And our CF kids don’t necessarily look ill, so it’s hard to explain an illness to a person who doesn’t see it. It’s not really how our minds work, hey? So, I think it can be awkward and I think it can be difficult and I feel like it could potentially have repercussions in being treated differently, which kids are trying to avoid. (Health Care Professional 3)

6.5.3 Balancing family relationships. The third subtheme focused on participants’ perceptions of youth experiences within their families. Participants described the challenge of being the member of the family with a chronic illness and how that affects their family relationships. For example, participants described the amount of attention given to and time spent with the child or adolescent with CF in the family and
how that impacts the family dynamics, especially when there are other siblings in the family who do not have CF.

*I think that it would affect family relationships in that the parents will have to spend a lot of time with the child with CF. So, it would affect, you know, maybe that would make you closer with your parents then. And then also sibling relationships in that, if they see that more time is spent with that one sibling. I think that would be another part. (Health Care Professional 1)*

Participants also explained that youth with CF may experience an emotional burden related to worrying about how their CF is impacting their families. They mentioned that some youth may attempt to work hard and provide reassurance to their parents that they are doing well in attempts to reduce the stress they see in their parents.

Moreover, they elaborated on feelings such as *guilt* and *shame* related to feeling like they are a burden on their family. They are not responsible for the cause of the illness, nevertheless they may feel responsible for the impact their illness has on their family’s lifestyle.

*I think the other thing that probably comes into play, I think maybe more so for adolescents...would be the thought that “I’m a child that has this illness and I’m putting a strain on the parents”. Maybe hearing things like “Oh we can’t do this because you have to do this” or “We can’t go see your sibling’s game because I have to do your physiotherapy or I have to take you somewhere”, that kind of thing. So, I think there’s probably a bit of guilt in that as well, that they are the cause of some extra stress in the family, not just for themselves... Even shame comes into it at some point. Thinking “Well, I’ve got this thing that is impacting*
my life, and impacting the people around me”. And of course, younger kids don’t necessarily think that older people do, so it is not their fault or anything, but often children feel that way because if they are the cause no matter how, through any kind of strife, then they think they are responsible and they feel that. (Health Care Professional 4)

6.5.4 Elevated self-consciousness. In the fourth subtheme, participants described the elevated levels of self-consciousness that adolescents with CF experience related to their condition. Participants discussed the relationships between being self-conscious and creating relationships with other people. Health Care Professional 4 spoke about the process of an adolescent “coming out” about CF to their peers and how it can be difficult if they have been attempting to hide their condition. Further, embarrassment was described as an emotion experienced for some adolescents related to their condition and communicating about it. Personality differences were suggested as a factor that influences whether an adolescent will be open to communicating about their CF or if they will hide their CF from others.

I think a lot of adolescents in particular, if they haven’t already kind of ‘come out’ to their friends about their condition then that is a difficult thing for them as well because they need to do things at school, they might need to do chest physiotherapy, might need to take their enzymes, and they often don’t like doing that in front of other people. And of course, if they are sick, then they have to be able to explain to other people why they are sick and why they can’t do things that other kids do, so that is not easy… I think embarrassment for some. I know that certainly we’ve had a number of children that really try to hide their experience
from others, they don’t show it openly. Others are the reverse, they seem to take it upon themselves to educate everybody around them, and so they seem to accept it a little bit better. (Health Care Professional 4)

Additionally, body image was described in detail as a major concern for adolescents when socializing and forming relationships with others. Attempting to inhibit visible symptoms of CF such as coughing to avoid being different from others was discussed. Finally, participants also discussed adolescents feeling self-conscious about the impact that CF may have when forming relationships and being intimate with another person. Participants highlighted the awareness of mortality as something adolescents may be self-conscious about. For example, Health Care Professional 4 shared:

*I think body image is a huge thing for adolescents and not just being maybe thinner because they have some issues with their diet and with their energy levels and things...Body image is a real concern. Especially if somebody has been sick a lot, and they are thin, and coughing all the time, and then people ask why they are coughing, then they have to have an explanation for that. I see a lot of adolescents that do their best to inhibit their coughs and not stand out... Just the thought that, you know, if they want to be forming relationships that they will be carrying into this relationship a condition that is going to have an effect on that. Quite often by the time people get to be adolescents they are kind of aware of their mortality with this condition, and so that may be an issue they bring forward to any kind of relationship. And just intimacy and knowing that you’ve got lung disease and coughing all of the time and producing sputum and I’m sure that has an effect on*
their own body image, and how it might affect how they feel about how other people relate to them. So, I think that is probably a big issue for adolescents.

6.5.5 Feeling disconnected from CF community. The final social challenge described by health care professionals was the disconnectedness of the CF community. In general, participants believed youth with CF had little connection with each other, partly due to infection prevention and control guidelines that prevent peer-to-peer exposure in people with CF. Participants discussed some families being a part of CF chapters or groups, however that most of these connections were limited to parent caregivers of youth with CF. Participants also mentioned that parent caregivers that are not a part of these groups likely do not make any connections with other families that have children or adolescents with CF. Health Care Professional 1 shared an experience of observing a father of a child with CF navigating her first experience connecting with other families at a conference:

_I think there’s certain kinds of groups that maybe if they were involved in a chapter or that kind of thing then I think they have some connections. But I think a lot of them, I think there is a fair amount of our families that don’t have that connection with other families. And going to these information things is kind of their way to kind of try and connect. It was interesting to watch that thing [conference] I went to maybe a month ago...one of our families who their child is only two, and the dad came alone because they just had another baby, and how he kind of was feeling the waters with the other families and they were kind of like “You should come to this”, you know? It was interesting to see how they were
trying to support and bring him in and I think that if they don’t go to those things though, they don’t get that exposure. (Health Care Professional 1)

Health Care Professionals 2 and 3 shared similar beliefs that outside of CF chapters, families likely do not create connections with other families. Moreover, youth with CF were believed not to have connections with each other, aside from knowing of each other based on connections through their parents.

*I don’t know that it [connection among families with CF] is popular, I don’t know that it is an issue. There is a provincial chapter with a local chapter and families involved in the chapter support each other and connect with each other. But beyond the chapter, no. And I don’t know that the kids do either.* (Health Care Professional 2)

*I would say, I don’t think [connection among families with CF]. There are some parents that might be connected through the chapter, the CF chapter. But I do not think that the kids are connected… Some of them might know each other, the parents that are more involved with the chapters, but no.* (Health Care Professional 3)

Additionally, Health Care Professional 4 provided information about online connections among youth with CF. The uniqueness of CF in comparison with other health conditions was also highlighted. In other health conditions, people are able to connect with each other and there are more social support opportunities, whereas people with CF experience social isolation and restrictions based on infection prevention guidelines in order to stay healthy. These restrictions make it more difficult for
individuals with CF to connect with one another, and in general, the CF community was described as being disconnected compared to other communities of individuals living with other chronic illnesses.

*I don’t think there’s too many outside sources [sources to connect with others with CF]. I pretty much doubt that most young youth are going to be going on the CF websites and things and looking up information there. Some do share in groups, especially adolescents I think, maybe more than younger children. So, there are like Facebook groups and things like that with other kids that have CF, so some of them will have other friends. We discourage them from meeting face-to-face. So, unlike a lot of other conditions, where you can go to a camp or you can meet other people who have the same condition, they have a tougher time doing that. (Health Care Professional 4)*

6.6 Lifestyle Restrictions

The third major theme that emerged from the data included descriptions of the lifestyle restrictions experienced by youth with CF and their families. Health care professionals described the responsibilities associated with living with CF and managing care for a person with CF, and how that impacts other aspects of life. Specifically, two subthemes were identified that included the challenge families face managing the required rigorous treatment routines for CF, as well as the experience of missing out due to various aspects and expectations of the condition.

6.6.1 Managing rigorous treatments. In the second subtheme, participants described the challenge of maintaining a rigorous and time-consuming treatment routine. Participants described these time-consuming treatments as an extra responsibility that
may limit the flexibility of a family’s ability to do certain activities. Managing treatments was also described as an emotional burden for the family. The time it requires to complete treatments may interfere with other activities that the child and family could be doing. Further, attending doctor’s appointments and the CF clinic was described as another time-consuming requirement that takes away from other aspects of life. As a result, youth and their families may miss out on various activities and opportunities. In the following excerpts of participant responses, participants describe the challenge of managing treatment routines and provide examples on how it may impact family life:

*I think the main one is kind of the added responsibilities and time restraints. Because they have to do, you know, medications and treatments. So, I think that would be the major challenge that they have. Those [treatments and medications], added on to an already busy life, like kids and families busy, and then you have those extra “Well we want you to do this for thirty minutes in the morning and thirty minutes in the afternoon. You have to take this medication every meal and every time you eat…”* (Health Care Professional 1)

*I think it is a bit of a challenge emotionally and physically for them. It takes a lot of time to manage CF, to do it properly, with medications, always having to eat right, make sure you take your medications. Yeah, so I think it’s a little bit emotionally challenging and physically challenging because of the physiotherapy they require also, which would be a few times a day. They have a lot of needs.* (Health Care Professional 3)
6.6.2 Missing out. In the second subtheme, participants highlighted that youth with CF often miss out on activities or opportunities as a result of the requirements of managing their condition. They explained that the extra responsibilities such as completing treatments and attending doctor’s appointments may encroach on youth’ time with friends. Additionally, participants described the academic and social challenges that may be experienced due to missing school for treatments, doctor’s appointments, or feeling sick. Participants expressed that there is extra stress associated with missing out and that as youth get increasingly sick, they may be unable to fully participate in school and other activities with their peers.

I mean I think if they are ill, being out of school affects their academics and then that is a stressor that gets added on. They might get behind; they might miss out on things at school that other people are doing... I one hundred percent encourage them to do activities, but I think that changes, that gets affected as well because if they’re ill, or they’re not feeling well, that will affect their activity or their performance level, so in competitive stuff... I think that its physically, probably pretty hard on their body because they don’t feel good some of the time or part of the time or the ones [youth with CF] that are more complex have bigger challenges physically. (Health Care Professional 2)

Health Care Professional 3 and Health Care Professional 4 mentioned that although some have difficulties participating in activities, most youth with CF strive to remain active, stay involved, and maintain relationships with friends.

I think most of them have pretty good friend relationships from what we hear at clinic cause we only see them every few months. Yeah, they dance, we have some
that they’re athletes, they’re dancers, they just are all active. Most of them are active in some way, and they seem to have friend groups. Whether it’s on the football team, dance class, they talk about kids in school. Some in band! (Health Care Professional 3)

6.7 Developing Independence

The fourth theme identified from responses of health care professional participants was focused on how youth with CF develop independence in managing their CF on their own. Health care professionals provided information about what is important that youth know and do so that they can feel comfortable managing their CF independently. They also elaborated on how youth learn about CF, how to manage their CF, and how to deal with the emotions they experience related to having CF. Three subthemes emerged within this topic including understanding CF, modelling, and increasing responsibility.

6.7.1 Understanding CF. In the first subtheme, health care professionals discussed the importance of youth with CF having a developmentally appropriate understanding of the disease and the treatments that are required to manage the disease. Participants explained that because there are many different variations in the ways that CF presents across individuals, it is important that youth understand the specific aspects of CF that affect them (e.g., lung issues, digestive issues). Participants also believed that youth with CF should have an understanding of their individualised treatment plan and the components that make up their treatment plan. Gaining disease knowledge and treatment knowledge was thought to contribute to the development of independence.
I think that they need to be aware of what medicines they are taking, what medicines there are, and what is the best treatment plan for them. And a treatment plan should encompass a holistic view in terms of the mental and physical. (Health Care Professional 2)

In addition to understanding CF in general and the treatments that they are engaged in, participants also highlighted the importance of understanding the rationale for completing each specific treatment. Health care professionals expressed that without understanding “why” they are required to complete their treatments, there will be a lack of treatment compliance. Participants described that youth should be aware of what their treatments help with and what the consequences are if they do not comply with their treatment routine. Health Care Professional 3 emphasized that when youth comply to their treatments and take care of themselves, they are able to live to their full potential.

I think they need to know why they are taking what they take. For example, “I take my enzymes so my stomach doesn’t hurt, my vitamins so my bones stay good...”. So I think just keeping them as knowledgeable... Why do you do physio? So you can feel better. I think just also giving them the reasons why and giving them the independence to explain to us what they are taking... I think our kids, who do well...they know that they have CF and I think once they’ve learned that, “If I don’t do these certain things, I’m getting sicker, I’m not feeling well.”. For them socially, “I’m having more bowel movements, passing gas in class.”. Teaching them what it means to manage it in a way where they feel good and can feel good around their peers. So again, going back to why do you take those medications? Why do you need to do physio? So you can feel good, you can
participate. In some cases, we’ve had some kids that get so sick that maybe they can’t take part in certain activities with their friends like running, biking, or playing... You can live a healthy life, or as healthy as possible, when you are doing your treatments to your potential. (Health Care Professional 3)

Finally, Health Care Professional 2 added that it is important for youth to know when, where, and how to access health care services when managing CF becomes especially challenging. Health Care Professional 2 added that if youth need more information they should know where to call or access information that they require. Although youth with CF typically only attend the CF clinic every few months, health care professionals mentioned that the CF clinic team is accessible in terms of answering questions and providing information between clinic visits. Understanding the access to services associated with CF was also interpreted as contributing to youth becoming more independent in managing their own care.

6.7.2 Modelling. Participants focused on how youth learn to manage their CF and learn to deal with the emotions they experience related to CF in the second subtheme. They explained that the management of CF is primarily learned through the parents and CF health care professionals. Participants described how health care professionals deliver information and guidance about CF and the required treatments to the family at clinic and then it is the parent’s responsibility to model and reinforce the treatment routine at home. Health care professionals also highlighted the importance of youth attendance and participation at clinic to learn more about CF and how to manage it independently. Both the parents and health care professionals model important health behaviours and encourage the maintenance of youth’ treatment routines. Participants emphasized that if
the parents demonstrate commitment to consistency in treatments, their children will model that behaviour. Health care professionals highlighted the importance of parents in teaching their youth the appropriate skills and create a consistent routine to manage CF. The family environment was believed to be very important in developing independence in managing CF for youth.

*I think a lot of it would come from the family. We just had a family recently who, I think their little girl is six, and they were like, “When do we tell her about it? And when do we explain more about it?”. So, I think a lot of it will come from the family, and then as they get older, I assume Internet, and the physicians and health care people as well. But I think the majority of it would come from the family. And even how to manage it, a lot of it is going to be how they were shown, how like parents would be teaching them as they grow and that’s how they learn it.* (Health Care Professional 1)

Similarly, participants believed that youth learn to manage emotions associated with their CF through their parents and the CF clinic team. Participants shared that if parents are modelling positive coping skills and are supportive of their children, this behaviour will be modelled by their children as well. Health care professionals emphasized the pivotal role that parents play in teaching their children about emotions and how to effectively cope with difficult emotions. Learning how to cope with emotions through the parents is another factor that contributes to developing independence in managing CF.

*In terms of coping tools, as we grow, we learn to cope differently and we learn to cope in different ways. And I think it is also affected by the parents, and if the*
parents are coping in a positive way then we know that our kids will copy that same technique, right? (Health Care Professional 2)

Participants also mentioned that if parents are stressed, children can sense their stress and that emotion may be transferred to the child. If parents are modelling negative coping skills, youth will model this behaviour. Health Care Professional 3 provided a perspective of negative modelling by parents:

I’d say probably from their parents. Depending on how their families manage. We have some that yeah, are real worriers and they’re always putting that on. We’ve had some that you can kind of sense that when their kids are really sick you can see the worry…and the kids feel that, right? They can sense that their parents are really scared. (Health Care Professional 3)

6.7.3 Increasing responsibility. The third subtheme that was generated within the topic of developing independence was the experience of increasing the level of responsibility for youth with CF as they get older. Health care professionals described the importance of gradually learning about CF and treatments over time for a seamless transfer of responsibility as they grow older. Youth with CF and their families carry a huge responsibility in managing CF. Health care professionals expressed that they hold expectations that families will manage and comply to rigorous treatment routines. Participants explained that for younger children, the burden of responsibility in managing CF is held by the parent and that over time as children become adolescents, the burden of responsibility is transferred from parent to child. Health care professionals described the importance increasing their responsibilities over time, as at some point youth will need to be independent. Health care professionals expressed that to avoid children being
overwhelmed by the burden of responsibility, gradual learning that is developmentally appropriate using a “step-by-step” approach is critical. Health care professionals described several techniques they use to increase the responsibility level of youth. For example, as children get older, health care professionals direct the conversation at CF clinic appointments to the child instead of to their parents. This practice allows children to advocate for themselves instead of looking to their parents for guidance and reassurance. Using this technique encourages children to become more comfortable reporting their health status independently, and also allows them to clarify their beliefs and feelings that may not be represented in their parents’ reports to health care professionals. The following excerpts from participant responses describe the process of increasing responsibility in youth with CF:

One of the things we are trying to do here is that as the kids get a little bit older, is ask the kids the questions so that they can learn to know what medications they are taking, because some of them will say “Oh, I take a blue pill” or “I take this...”. So it’s at least giving them some independence or some responsibility to pay attention... I guess that would go back to us, getting them to be responsible as to why, for example, “Why do you need your medications? Which ones are you on? And what do they do for you?”. And that’s something we’ve gotten better at in the last few years is giving them that responsibility. And explaining “Why do you use that pill? Is it so your stomach isn’t full of acid? Is it so you don’t have to go to the bathroom?”. So giving them the rationale as to why they are doing it, so they can own it. (Health Care Professional 3)

6.8 Barriers to Care and Managing CF
The fifth major theme uncovered in data from health care professionals included participants’ perceptions of the barriers to receiving care for CF and managing CF. Participants elaborated on several barriers they believed that youth and their families face when trying to access services to help them manage their CF. They also described more personal barriers that families experience related to managing CF. The three subthemes that emerged were accessibility, family beliefs, and patient beliefs and compliance.

6.8.1 Accessibility. In the first subtheme, participants discussed accessibility to CF-related health care services and the barriers that may limit accessibility of these services. In terms of health care, participants believed that youth with CF were receiving appropriate health care and were not having difficulty accessing services to help them manage their CF. Health care professional participants described that they felt the CF clinic effectively manages the care of youth with CF; however, they identified barriers in accessing and managing mental health care for youth with CF. For example, when asked if they thought that youth with CF had any difficulties accessing services to help manage their CF, Health Care Professional 1 responded:

_I don’t think so. I think maybe they do and they don’t tell us. But we do our best if they have any questions or if they need anything, we do our best to kind of direct them wherever we think would help with them, or give them the best information._

_For us as a clinic, I think we’ve been able to manage the majority of their services, probably just not their mental health services the same...as much as we would like to._

Barriers to accessing mental health services described by participants included having to come to the hospital for clinic appointments. One participant described
attending the hospital as a stressful event for families, and that it would be beneficial to have clinic take place outside of the hospital setting. Another participant explained that communication between health care professionals to make a referral for psychological services can be difficult. For example, communication difficulties between the patient’s psychologist or psychiatrist and the health care professional at the CF clinic were noted (e.g., relaying information about symptoms observed, interventions that may be beneficial). Financial barriers to accessing mental health services were also discussed, such as the cost of attending appointments with a psychologist. Participants also mentioned the cost and time barrier associated with travelling to access psychological services for families that live in rural centres. Another barrier identified by participants was the limited number of specialized mental health professionals available in some regions of the province. Finally, mental health wait-lists were identified as another perceived barrier for youth with CF. In the following excerpts, participants identified some of the barriers associated with managing CF and accessing health and mental health services. One participant suggested using technology as a method to eliminate some of these barriers.

*But, our low-income families, we have this clinic in the southern part of the province, and for travel, like that can be a huge burden for families when you don’t have the money too. So, I think for our low-income families, finances coming to clinic and I think...like coming to the hospital is hard.... I’d like to be able to see our rural kids have the same access though, right? Like think about one person being able to be that mental health support, but then again that’s a barrier for our families that have to drive. So, if there was an alternative way for*
that one person to be available like online or Facetime, or something, you know?

Like in a technological way, then that would be even better. (Health Care Professional 2)

6.8.2 Parent caregiver beliefs and attitudes. The second subtheme that was uncovered focused on the beliefs of the parent caregivers as a potential barrier to youth managing their CF effectively and independently, as well as accessing services to help manage their CF. Health care professionals described that parent beliefs may prevent youth from learning about CF and learning to be independent in managing their own care. Participants explained that some parents are hesitant to allow their children to manage their own care in fear that they may fail. Participants discussed the struggle some parents have letting go of control of managing treatments for their children and the barrier this creates for children to learn how to manage their treatments independently.

I went to a conference this year and they had parents of young children and then parents of university age and they talked about how hard it was for them to let go of managing it all. Because they wanted to know everything...So I think that is a barrier because the parents don’t want to let go of that control either. (Health Care Professional 1)

Moreover, a challenge that was identified associated with increasing responsibility in youth with CF was the difficulty parents have deciding when to let their child take on certain tasks on their own. Health Care Professional 4 described that whereas some parents experience difficulty in letting go of responsibility, others give their children too much responsibility. Participants described the need for a balance between giving the child responsibility that is developmentally appropriate and providing
enough support that the child can succeed with their treatments. Health Care Professional 4 added that it is helpful for youth to have other responsibilities in their life aside from managing their treatments. If youth can learn to be responsible in other areas of their life, they will be able to transfer these skills to managing their CF as well.

*I think probably the biggest challenge people face is just having an idea of when the children are at the point where they can. So that, you know, “Here are your enzymes for the day, you need to take them. Go.”. Maybe the enzymes at the younger ages are a little easier because they get included in the lunch they take to school, and they just take them at the time. But doing other kinds of activities like your physiotherapies is tough if you’re on your own because you can’t just do the chest percussions and things, you have to use the pep devices or some other way... As I say, the information about why is probably the most important. I think the families have to probably decide at some point when their children are ready for that next step. And it’s probably different in every family. I’ve seen some families where little children 8 years of age are expected to manage everything, and obviously they’re not ready for it, but the parents think they are and that creates a conflict. And then other families where as adolescents, they’re still not doing very much of their own stuff and kind of need to be coached into it. (Health Care Professional 4)*

Parents’ knowledge of treatments and openness to commit and engage in treatments was also recognized as a potential barrier to youth learning to manage their CF independently. Health care professionals emphasized the importance of parents understanding the importance of treatments and encouraging the treatment routine.
Health Care Professional 3 described the important role parents play in setting an example for their children and how lack of openness and knowledge can act as a barrier to managing CF:

Maybe the parents’ openness. Because really when the kids are little, you’re relying on the parents to do physio... some of the barriers are the parents. And then again that leads to the example you give your kids, right? If physio is only 3 to 4 times a week, the other days aren’t a worry, you learn that maybe?... Even knowledge, I guess. We have families that I just don’t think they understand how important it is to do their treatments, to take their medications regularly, or stay on top of it. Or in some cases we also have families where they’ll say, “Well, she knows what she has to do”, but they’re still children, right? So, you have to guide them. And I think teaching that guidance is lifelong. And in some cases, they expect really young kids to take responsibility on their own... when they actually need more guidance. They need help. Like they’re still a kid. (HCP 3)

Further, participants explained that some parents censor how much information they reveal to their youth about CF. Health care professionals described that some parents limit the amount of information about the harsh aspects of the condition, such as information about life expectancy, to protect their children. Although this was interpreted as parents attempting to be helpful, health care professionals believed censoring information the child receives as unhelpful in the long-term and that all information about CF should be delivered in a developmentally appropriate way. For example, Health Care Professional 4 shared:
We have had some parents that don’t want us to be open with the children, that
don’t want us to say everything, and one some years back that didn’t want their
child to know that this is a condition that is going to shorten their life... I don’t
think that is helpful. I mean, yeah, it may be a hard conversation to have with
your kids, but it’s better that they have an idea about that because they are going
to hear it at some point. And especially when you’re watching television and a
commercial comes on about “here is somebody with cystic fibrosis” and they’re
in bad shape and they’re going to die young and you are thinking “Oh wait a
minute! That’s what I got”.

Finally, Health Care Professional 3 and Health Care Professional 4 added that
parental beliefs about stigma associated with receiving mental health services may
prevent youth with CF from accessing the services they need. Removing the stigma and
normalizing the experience of receiving mental health interventions was believed to be
necessary to eliminate stigma as a barrier for accessing services.

And then getting them to maybe even see it as normal going to talk to somebody,
because there is a stigma sometimes attached to that too... We’ve had parents that
the stigma has prevented them from, “Yeah we don’t need to talk to them we’re
fine”, but you know they’re not. So just that. The stigma is there and we’d like to
remove that I think. (Health Care Professional 3)

And sometimes the barrier has been the parent as well. That we feel the child
would be helped by talking to a counsellor or seeing a psychologist and the
parent doesn’t want that. Not always sure why, whether they think there is a
stigma to it or something, or just feel that we are trying to label the children or wanting to put them on medications or that kind of thing. So, it happens sometimes, yeah. It’s difficult to make that referral and make it easy. (Health Care Professional 4)

6.8.3 Patient beliefs and attitudes. Another group of barriers that prevent youth from managing their CF and accessing services to help with their CF included various attitudes and beliefs about their treatments and services. Individual attitudes and personalities of youth were described as potentially preventing them from complying to their treatments and managing their CF on their own. Participants described that attitudes toward engaging in treatments and other helpful health behaviours may also change as children get older. For example, Health Care Professional 3 explained:

*I think it [treatment compliance] depends on the age, right? We’ve had some kids we’ve been able to show they didn’t gain weight. And I think for some of them a switch just has to go off when they’re ready to take responsibility. Some of them, it doesn’t phase them.*

Similarly, Health Care Professional 2 described the difficulty with compliance in adolescent patients based on their desire for independence:

*Compliancy in teenager-hood is difficult. The teenager years are so hard, and they are so focused on their self and their selfish needs and promoting their independence that they don’t see the importance in that self-care bit, nor do they want to be told what to do or how to do it, right? So, it’s a challenge.*

In addition to individual attitudes of youth acting as a barrier to managing CF, health care professionals described the present-focused nature of youth as acting as a
barrier. Participants explained that often, youth have difficulty thinking about the future and the long-term results of complying to treatments. Further, their engagement in treatments may differ based on whether they receive instant and tangible reward for completing a treatment, rather than simply a long-term outcome. For example, youth may be more engaged in medication treatments as they provide an instant physical relief of a symptom and there is a physical consequence of feeling sick when they do not comply with their medication treatments. In contrast, youth may be less engaged in psychological therapies as often it requires working over a period of time to achieve a long-term result.

In the following excerpts, participants discuss the present-oriented mindset of youth as a barrier to engaging in certain treatments:

*But in terms of for the psychological bit too, counselling is so hard for teenagers because it can be awkward, it can be time-consuming, and it’s a lot of deep-down personal work. And our teenagers, I just think our teenagers struggle with that, because they don’t have that insight yet to realize what they are doing is helping them in the long-run. So, they don’t see the importance of showing up for appointments, or following through with the recommendations, or doing the hard work and digging deep, because they are just focused on the moment, right? And that instant gratification piece. (Health Care Professional 2)*

*Medications they tend to, if they don’t take them, they have a negative impact like they might have to go to the bathroom right away, they might have tummy aches, so those I think they are more engaged in. They’re more likely to take their medications, because you can physically feel it right away. Physical activity, I*
think a lot of the kids are... I’d say most of the kids are pretty active... Things that you see that are tangible right now, right? And psychology probably isn’t as tangible to them, or someone to talk to. Because you don’t feel that immediate relief like from taking your treatment or clearing your lungs from physio. (Health Care Professional 3)

Finally, health care professionals highlighted that sometimes the barrier to complying to treatment routines is the desire to avoid feeling different from others. Participants described that sometimes youth with CF will decide not to do their treatments in a social setting in attempts to “fit in”. The social challenge associated with feeling different from others may act as a barrier to managing CF. For example, Health Care Professional 3 shared:

I think fitting in [as a barrier], right? Fitting in with others and not being singled out, by maybe having to run to your locker to get your enzymes or having to stop and take them... Time factor, if they are out with their friends, you know, you’re out for pizza, you forgot, you just enjoy, you don’t wanna be different. And I think that is a big thing we see.

6.9 Focusing on Future Mental Health Care

The final major theme that emerged from health care professional responses was on the topic of future mental health care for youth with CF. Two subthemes emerged within this topic including improving care and directing a novel form of service delivery. Participants shared a variety of opinions on components of the services youth with CF currently receive that they perceived as beneficial, as well as opinions on where the gaps in mental health care occur and what could be improved. Finally, participants shared
valuable input about the benefits and drawbacks of youth with CF participating in a mental health program on the Internet. Health care professionals elaborated on their beliefs about whether youth would be open to using an Internet-delivered mental health program, what components they believed should be included in an Internet-delivered mental health program, and what they believed would motivate or prevent youth from using this type of program.

6.9.1 Improving care. In the first subtheme, participants discussed current mental health services within CF care. They also elaborated on the gaps in mental health care for youth with CF and what they perceived as being important to improve mental health care in the future. Health care professionals described the major focus on the physical aspects of CF at the clinic. They explained that mental health care is not prioritized the way that physical care is for youth with CF. Some participants discussed mental health care for youth with CF as being “reactive” instead of preventative. One participant specified that mental health services are often not accessed or provided until there is a crisis.

*I think we come into the picture a bit too late, when there’s an issue with it [mental health], right? And then me as a social worker or the clinic nurse having that first point of contact, then I think it comes up. We tend to teach in a reactive manner, right? ... I think that we as healthcare professionals always focus on the physical aspects that we can treat, right? So, we’re always looking at the bloods, and the lungs, the headscan or the mental scan often gets left to the backburner and like I said, gets left to when it is too late and when a family or a person is in a crisis and a crisis is harder to dig out of, right?...I think we tend to focus pretty heavy on the physical and the medication and the importance of that and we tend*
to forget to encourage those other therapies or activities that do give a sense of normalcy, that do give a positive sense of coping. We forget to put as much importance on those as well. (Health Care Professional 3)

Participants explained that one addition to the CF clinic that has helped improve the focus on the mental health of youth with CF is their annual mental health screening. Health care professionals perceived the annual screening for mental health issues in youth with CF completed by a psychologist as highly valuable.

*I think we are doing a better job now that we are doing screening, because we are making it a part of the conversation at least annually. I think that will get better as screening goes on and it becomes a normal part of clinic... (Health Care Professional 2)*

Participants believed that having annual screening is an important component to their CF clinic and also expressed that it would be helpful to have more than just a screening. Participants suggested adding a psychologist to the CF team would be helpful for several reasons. For example, health care professionals described that because CF is a difficult condition to live with and that there are a variety of emotions and challenges related to having CF, youth with CF need a safe and private space to talk with a professional. They also expressed the importance of having a consistent professional available to speak with youth to provide consistent support. Further, the CF team is multidisciplinary and adding a psychologist would be a valuable addition to the other disciplines represented on the team. The addition of a psychologist was also perceived as important in eliminating the need to go outside of the clinic to access mental health services. Finally, participants also emphasized the importance of providing more support
for the entire family (i.e., parents and siblings) and that having a psychologist on-site would help with this.

*Not too many clinics have psychologists attached to the clinics. And that is something which I think people are trying to improve, it’s not kind of standard of care at our clinics at the moment but maybe someday it will be. And that is the hope, that we will at least have those available as well. Because it’s important, it is a multidisciplinary clinic, and we should have as much input from everybody as possible.* (Health Care Professional 4)

### 6.9.2 Directing a novel form of service delivery

In the second subtheme, participants discussed their perceptions of improving mental health care through an Internet-based mental health program. Health care professionals believed that youth would be open to using an Internet-delivered mental health program. Participants described that based on youth’ reliance on technology devices, they would likely engage in a mental health program that was technology-based. Participants also added that accessing a mental health program online would be something they could do privately and independently reducing the risk of being singled out. The following are excerpts of participants’ descriptions of the perceived benefits of an Internet-delivered mental health program:

*Just like technology is changing and our apps are changing, and like if there was a different way to do it rather than a traditional form of therapy or counselling or whatever you want to say. Because that’s where kids are at, they’re doing the cool thing, they’re doing the trendy thing, and we kind of have to keep up with that to keep their attention, right?... I think that they would find it convenient. I think that*
it’s where we are in this day in age, and I think that it would just be equivalent to anything else that they are getting from online, from their homework, to their interests, to now their CF care, right? (Health Care Professional 2)

Based on their reliance on devices, I would probably say they would probably be more open to that [Internet-delivered mental health program]. It’s at their fingertips maybe a little bit more. And not having to go somewhere… They can access it even in private. Something they could do on their own and, yeah, not have maybe everybody knowing what they’re doing, right? (Health Care Professional 3)

Participants also described some drawbacks to receiving a mental health program via the Internet. The main perceived drawback described was the potential for receiving misinformation on the Internet. Health Care Professional 4 expressed the worry of youth with CF receiving misinformation about CF on the Internet and that this would be a drawback to the program. The importance of ensuring appropriate and accurate information was emphasized for the engagement in and success of an Internet-delivered mental health program.

I think obviously if it’s from a reputable website, then I think the parents would be happy with that as well. Always have to be a bit careful when we are talking about the Internet, and some families, they know that there is all sorts of misinformation out there, and so they don’t want to be asking their children to go on and look up stuff on their own. (Health Care Professional 4)
Participants also reported believing that youth with CF would be interested in engaging in an online community where they could connect with other youth with CF. Based on infection prevention and control guidelines that limit peer-to-peer exposure for people with CF, communicating via the Internet was perceived as a viable option to create connections in the CF community.

*I think they would [engage in online community]. I do. And again, I think again from like the conferences and things that I’ve gone to and hearing speakers and different things, that something that they really, really miss because now because of infection and control they can’t really be together, they used to go to camps together, you know, like other conditions, they can’t have those kinds of things. So I think they would like that.* (Health Care Professional 1)

When asked if youth would engage in an Internet-delivered program if it were monitored by a health care professional, participants had mixed responses. While some participants thought that this would make them more likely to engage in the program, others thought that this would prevent their use of the program. Some participants believed that having someone monitor the program would be helpful and would motivate them to use the program, while others thought that this would create a “school-like” environment that would discourage them from using it.

*I’m thinking maybe a little less likely [to engage in an Internet-delivered program if monitored by a health care professional]. Like most kids online, if they are doing that type of thing, they want it to be more of a personal kind of a connection. Where going online with a health care professional feels like you’re going back to school.* (Health Care Professional 4)
Participants also described factors that would motivate and prevent youth from using an Internet-delivered mental health program. One factor contributing to motivating use of the program was creating a reinforcement system so youth could receive rewards or incentives for participating. Additionally, receiving encouragement from the clinic team and making it an expectation from the clinic that they need to participate was highlighted as a potential motivator. Participants believed that if using an Internet-delivered mental health program was an expectation similar to their other treatments, youth with CF would be motivated to use the program.

In addition to factors that would motivate use of the program, participants identified factors that would prevent use of the program. For example, access to a device to use the program on was one factor that would prevent use of the program. Participants also described that not all youth are engaged in technology and that an Internet-delivered program may be outside the scope of their interests. Further, participants discussed that some youth with CF may be avoiding thinking about their condition and challenges associated with it and that this may prevent them from using a program that specifically asks them to think about it. Finally, family beliefs were mentioned as a factor preventing program use. For example, some families may not see the benefit in using an online program and would rather seek help with mental health face-to-face.

_As far as prevention, it’s possible that some just don’t like that kind of thing, just don’t like looking stuff up on the Internet and, especially if they are the kind of adolescent that tries to minimize their condition or hide it, they may not even want to think about it. Just denial is something that sometimes they try to cope with. So, they may not be interested. Again, some families might think, “Well this Internet_
thing...it’s better if you talk to somebody face-to-face. Why would you want to do that?”. (Health Care Professional 4)

Finally, health care professionals provided input on what they perceived as being valuable components to include in an Internet-delivered mental health program for youth with CF. Participants suggested information about CF and treatments should be included in the program. Additionally, participants suggested information on emotions related to CF and validating and normalizing emotional experiences would be an important component. Including information about emotions associated with a chronic disease was emphasized. Participants also recommended including a feature to remind youth to check-in with their mental health. Further, resources on how to access further services or a feature to allow them to request further services for mental health care were proposed.

Just making sure to cover the gamut, “Yeah, you’re probably going to feel depressed at times, we all do for a variety of reasons, but you’ve got a good reason to feel depressed. How can we help you deal with this?” ... So, talking about anxieties, talking about depression. (Health Care Professional 4)

An education piece, how they might be feeling, what that looks like, what that feels like, and that there is a certain element of normalcy to it. That we all feel it. But that because you have a life-threatening illness, there are some complications and then this is who you can call if it gets out of control or you can’t cope or you need more help. (Health Care Professional 2)

Health care professionals emphasized the importance of including relevant information and allowing input and feedback from youth that use the program.
Participants explained that including stories from other people with CF would be a helpful component to make the content relatable.

*It is probably helpful to them to at least hear about other people’s experiences... I think having other people with cystic fibrosis present their stories as well, because I think they’re probably going to connect better with their peers than somebody who happens to be an expert in the area. So having somebody say, “Well this is what I was going through, and this is how I dealt with it”. And I think they would be more likely able to relate to that... Probably allowing in some ways for feedback too so that if I’m an adolescent online and I’m listening to people, a way that I can maybe give my feedback or something, or contribute to the discussion.* (Health Care Professional 4)

Finally, health care professionals suggested keeping information short in order to keep youth’s attention. They also emphasized the importance of making the program interactive and fun by potentially incorporating games. For example, Health Care Professional 2 suggested:

*If there was a game that could be associated with it [the education piece of the program]. A jeopardy type game on the Internet or you know, if you popped a bubble and then the bubble had a question and you answered it! I think that would be motivating!*  

**6.10 Discussion**

Part Three expands our understanding of the challenges faced by and information and service needs of youth with CF from the perspective of health care professionals. Part Three adds to the existing literature by contributing rich and valuable accounts of lived
experiences and personal opinions of health care professionals. In the following discussion, I will explore the results within the context of the overall research objectives and situate the results in the existing literature. Further, implications of the results in informing an Internet-delivered mental health program will be expanded upon.

6.10.1 Challenges. The first research objective was to understand what types of challenges youth with CF and their parent caregivers face. Health care professionals discussed several challenges that youth with CF experience related to their condition and the impact CF has on their lives. Specifically, emotional challenges were identified, such as various feelings associated with having CF. As previously discussed, chronic illness is a risk factor for psychological problems (Bennett, 1994). Further, an abundance of research provides evidence of elevated psychological symptoms such as depression and anxiety in youth with CF and their parent caregivers (Bregnballe et al., 2007; Kostakou et al., Quittner et al., 2014; Smith et al., 2010; Stodolak et al., 2018; Yohannes et al., 2012). The descriptions of anxiety and depression in the current study align with previous literature suggesting this is a salient challenge for youth with CF. The results of the current study are consistent with previous findings that suggest youth with CF and their parents may experience a variety of emotions associated with their condition (Jamieson et al., 2014). The findings also contribute to the existing literature by providing detailed descriptions of other emotions typically experienced by youth with CF that may not be represented in studies that focus solely on clinical levels of psychopathology.

Uncertainty associated with having CF was identified as a challenge faced by youth with CF and their families. Previous literature has highlighted the constant worry of living with the unpredictability of CF, including concerns about the physical effects of
the illness, symptom exacerbations, and the implications the illness has on children’s’ futures (Cayse, 1994; Hayes & Savage, 2008; McNeill, 2004). Living with fears and worries about future lives and health is common in families with CF (Hayes & Savage, 2008). In the current study, uncertainty about the future was described as a challenge faced by youth with CF and was described as being associated with experiencing emotions such as anxiety and sadness. The disease progression of CF is highly variable and somewhat dependent on processes out of the individual’s control, such as the type of mutation an individual has (Mitmansgruber, Smrekar, Rabanser, Beck, Eder, & Ellemunter, 2016). Tolerance of feelings of uncertainty has been suggested to be critical in effectively coping with the progression of CF (Mitmansgruber et al., 2016). Limited research has focused on intolerance of uncertainty (i.e., a dispositional characteristic that results from negative beliefs about uncertainty and its implications; Buhr & Dugas, 2009) related to having CF, however uncertainty about illness progression and treatment might be an important factor for this population (Mitmansgruber et al., 2016). In one study, participants with CF reported they needed more information on ways to deal with the unpredictability of their future (Sawicki, Sellers, McGuffie, & Robinson, 2007). Dealing with uncertainty is clearly a major challenge for individuals with CF, and may be an important focus when considering the development of a mental health program for this group. Further, challenges with uncertainty were discussed in the context of treatment compliance and disease outcomes. Participants described that uncertainty about future health and life expectancy of youth may contribute to a loss of purpose in maintaining treatment compliance. This finding may suggest the need for encouragement and
education surrounding long-term benefits of treatments in order to motivate treatment compliance.

Health care professionals described the timing of diagnosis of CF as a factor that influences the emotions experienced related to having CF. Previous literature has demonstrated the content and timing of diagnosis can affect parental and child emotional reactions and attitudes toward the new diagnosis (Havermans, Tack, Vertommen, Proesmans, & de Boek, 2015). Shock, anger, acceptance, and denial have been identified as common emotions when receiving the diagnosis (Havermans et al., 2015). Further, the results of the current study are consistent with research that demonstrates the importance of accepting the diagnosis from the start for treatment compliance and positive disease outcomes in the future (Havermans et al., 2015). In the present study, health care professionals suggested that accepting the diagnosis of CF is related to positive coping and resilience for families, and is critical for managing and complying to treatments. Families that have trouble with acceptance were also described as having trouble coping with CF and managing CF. Similarly, findings from Havermans et al. (2015) indicated that the content and timing of diagnosis affect the use of coping strategies that may prevent long-term problems coping with CF.

Another group of challenges described by health care professionals were psychosocial challenges. Health care professionals in the current study reported youth feel different from their peers as a result of their differing responsibilities and expectations. Youth with CF may find it difficult to relate to their healthy peers and may experience feelings of isolation. These findings are consistent with previous literature that described youth with CF feeling socially isolated and out of place due to missing school
and activities (Jamieson et al., 2014). Further, youth with CF reported having difficulty relating to their healthy peers and felt they were more compassionate and mature based on their lived experience with CF (Jamieson et al., 2014). Previous studies have suggested the benefits of connecting with others with CF and that this experience may be helpful in accepting their own abilities rather than comparing themselves to their healthy peers (Jamieson et al., 2014).

Another social challenge faced by families of youth with CF included the difficulties of balancing family relationships. Families often experience a burden of responsibility caring for a child with a chronic illness (Acka, Uzun, Pekcan, Akkus, & Gulec, 2016). Having a child with a life-threatening illness adds new responsibilities and changes role expectations (Young, Dixon-Woods, Findlay, & Henry, 2002). In addition to the burden the family experiences, participants in the current study described that youth with CF also experience feelings of responsibility and guilt for the burden their illness has placed on their families. These findings align with previous research that found children that are highly dependent on family members to help with treatments felt guilty taking time away from their parents, as well as parents time spent with siblings (Jamieson et al., 2014). The impact of CF on the family lifestyle, such as depriving families of vacation time or other activities have also been described (Jamieson et al., 2014).

Health care professionals also identified the feeling of self-consciousness that youth with CF experience related to their condition. Participants described feelings of embarrassment about communicating about CF, and feelings of self-consciousness about their body image and forming relationships as significant challenges for youth with CF.
Previous qualitative studies have also described that feelings of embarrassment about physical stature, coughing in public, or taking medications in social settings are challenges (Christian & D’Auria, 1997). As described in the current study as well as in the literature, treatment non-adherence may be influenced by feelings of self-consciousness and the desire to appear normal (Jamieson et al., 2014). In efforts to be the same as peers, youth may refrain from telling friends and teachers about CF, and may not want to do treatments in front of others, resulting in poor adherence. Education and discussions about how to disclose their condition to others may be important to improve psychosocial outcomes (Borshuk et al., 2016). Employing the use of evidence-based techniques such as problem-solving and role-playing have been suggested to help youth practice disclosing to others and handle potential unsupportive reactions (Baile & Blatner, 2014; Borshuk et al., 2016).

Health care professionals explained the uniqueness of CF in comparison with other chronic illnesses, as people with CF are isolated from face-to-face communication with each other (Saiman et al., 2013; Schaffer, 2015). In the cases of other chronic conditions such as asthma (Leotourneau et al., 2012), cancer (D’Agostino, Penney, & Zebrack, 2011), diabetes (Dale, Williams, & Bowyer, 2012), and general developmental disabilities (Stewart, Barnfather, Magill-Evans, Ray, & Letourneau, 2011) there are support groups available and a strong community to be associated with for social support (Lewis, Klineberg, Towns, Moore, & Steinbeck, 2016). Participants described the disconnectedness within the CF community, and that many families lack connections with other families with CF. In previous studies, having a shared experience and interacting with other people with CF promoted social support and sharing of information
and coping strategies (Jamieson et al., 2014). The challenge of being socially isolated and lacking social support highlights the need for innovative methods to create connections among the CF community.

Finally, health care professionals elaborated on the lifestyle restrictions experienced by youth with CF and their families. Families with CF are required to manage rigorous, time-consuming treatments, as well as spend significant amounts of time at clinic visits, doctors’ appointments and in the hospital. Treatments have been described as invasive, intensive, and physically strenuous (Barker & Quittner, 2016; Jamieson et al., 2014). Families with CF often miss out on activities and opportunities due to their demanding lifestyle. Youth with CF are highly susceptible to infections requiring them to avoid high risk environments (i.e., places where there are other people with CF or individuals that are sick; Russo, Donnelly, & Reid, 2006). Susceptibility to infection limits their lifestyle, reduces their ability to participate in activities, and increases feelings of anxiety, uncertainty and isolation (Jamieson et al., 2014). Despite these challenges, health care professionals in the current study highlighted that many youths with CF are resilient and maintain involvement in activities.

6.10.2 Type of information needed. The second research objective was to understand what type of information youth and their parents need about CF. Health care professionals discussed that youth should have an appropriate amount of disease knowledge to understand CF and their treatments. Research has suggested that children with CF may not be informed about their disease and the uncertainty, lack of knowledge, and lack of coping skills may be related to the psychological challenges they face (Anton-Paduraru et al., 2015; Bregnballe et al., 2007). Health care professionals in the current
study also emphasized the importance of understanding the rationale for completing their CF treatments. This is consistent with previous research that suggests adherence to CF treatments is associated with disease and treatment knowledge (Faint et al., 2016). Providing information about CF and CF treatments may be important in improving treatment adherence and various distressing emotions associated with having CF.

Health care professionals emphasized the importance of “gradual learning” for youth with CF. Information about CF and responsibilities for self-management were suggested to be delivered using a step-by-step approach. Child and adolescent participants in previous studies felt they should be given more responsibility with age (Hafetz & Miller, 2010), and should be given a period where they could prove their ability to manage CF independently (Bregnballe, Shiotz, & Lomborg, 2011). Moreover, the ability to self-manage treatments was related to feelings of control of one’s own health, and contributed to a sense of mastery and normalcy (Jamieson et al., 2014). Additionally, incorporating youth in the decision-making processes was considered important in promoting independence and confidence in self-management of CF (Lipstein, Muething, Dodds, & Britto, 2013; Miller, 2009).

Health care professionals also highlighted the important role parents play in modelling and encouraging appropriate treatment adherence and coping skills for their children. As treatment adherence occurs in youth’s daily lives, family processes may either facilitate or impede adherence (Barker & Quittner, 2016). Providing the appropriate information to their child about CF and demonstrating positive coping skills is essential to developing independence in managing CF. The important role of parents suggests that it is also necessary for parents to understand CF, CF treatments, as well as
the rationale for completing treatments. Further, parents that demonstrate positive coping were described as having children that also cope better. The latter finding is consistent with related research that demonstrates high parental distress is a barrier to effective participation in child care (Power & Franck, 2008). Elevated rates of depression in parents adversely affect child adherence to treatments (Barker & Quittner, 2016). The family environment was highlighted as being an important factor in encouraging youth to manage their CF effectively. Psychosocial stress in early life has been linked to poor physical and psychosocial outcomes in children with respiratory disease (Goldbeck et al., 2014). This relationship is moderated by the way children and parents respond to stressors (Goldbeck et al., 2014). Further, Ernst et al. (2010) reported that health care professionals working with CF found significant improvements in health outcomes of children with CF as a result of positive changes in the family environment. Educating parents on coping skills and how to model appropriate coping skills for their children may be beneficial in encouraging positive coping in youth with CF.

When considering information that youth with CF need, it is also necessary to gain an awareness of potential barriers that may prevent them from learning about their CF, how to manage CF independently, and how to cope with having CF. Parent beliefs were identified as a barrier to youth managing their CF. Participants described parents having difficulty finding a balance between assisting their child with treatments and letting go of control to allow their child to manage their treatments independently. Previous literature demonstrated that children that are dependent on their parents to encourage and manage adherence to treatments believed that the loss of assistance from their parents when they moved away from home contributed to feelings of depression
(Jamieson et al., 2014). Parents may need guidance and information on how to gradually increase responsibilities of their children to ensure their children are prepared for the future.

Participants also elaborated on parent attitudes towards disclosing information about the life-expectancy of CF and prognosis to their children. Health care professionals believed censoring information about the harsh aspects of CF is unhelpful and should be delivered in a developmentally appropriate way. Havermans et al. (2015) reported that censoring disease-related information was related to treatment non-adherence. Limited research addresses how and when patients with CF should receive information about their prognosis (Saunders et al., 2017). In one study, more than half of patients with CF learned about their prognosis independently. Patients described the discussion of prognosis as a “milestone” in disease self-management and suggested this information be delivered in-person by a health care professional. Despite health care professionals’ concerns about patient mood and treatment adherence after learning about disease prognosis, patients reported learning about prognosis did not negatively affect their perspective and resulted in positive effects on adherence. This study emphasized that overall, patients desire early, individualized communication about prognosis and that age-appropriate educational materials may be useful in initiating conversations between families and health care professionals (Saunders et al., 2017).

Finally, youth’ beliefs were also considered a barrier to managing their CF independently in the current study. Patient beliefs about the importance of treatment, as well as the lack of instant-gratification gained from completing treatments was suggested as a barrier to encouraging adherence. The present-focused nature of youth was focused
on as a factor that relates to potential non-adherence, as they may fail to see the long-term benefits in adhering to their rigorous treatment regimens.

Children’s health beliefs have been related to their treatment adherence (Dempster, Wildman, Materson, & Olmor, 2018). The health belief model (Janz & Becker, 1984; Rosenstock, Stretcher, & Becker, 1988) states that people will act if they feel personally susceptible to their disease progressing and if they believe the severity of their disease will compromise their functioning negatively. Additionally, people consider whether engaging in the health behaviour would be beneficial and that the barriers to treatment are worth defeating. Studies have shown that children who perceive themselves as less vulnerable to their disease worsening demonstrate lower treatment adherence and overall well-being (Partridge et al., 2002; Skinner, John & Hampson, 2000). Additionally, children who perceive increased barriers to treatment are more likely to have low adherence (Dziuban, Saab-Abazeed, Chaudhry, Streetman, & Nasr, 2010; Logan, Zelikovsky, Labay, & Spergel, 2003; Modi & Quittner, 2006). Adolescents have attributed reasons for not adhering to treatments not having an immediate benefit (Dziuban et al, 2010). In contrast, children who believe their treatments are necessary, beneficial, and controllable by adhering are more likely to adhere (Griva, Myers, & Newman 2000). As some parents do not explain the dangers of CF and nonadherence to protect their children, children may not fully understand their prognosis and risks for not adhering (Beales, Lennox-Holt, Keen, & Mellor, 1883; Dempster et al., 2016; Lastor, Holsey, Shendell, McCarty, & Celano, 2009). Studies have also found that some children lack knowledge that CF is a lifelong condition and have difficulty recognizing how time-consuming treatments are beneficial (Beales et al., 1983). Considering the health beliefs
of children and their parents is important when understanding the type of information that would be beneficial to facilitate appropriate management and coping with CF. By addressing parent and child beliefs that may act as barriers to managing CF, appropriate education can be provided about the potential misguided notions and promote the overall adherence and well-being of youth with CF (Dempster et al., 2016).

6.10.3 Type of services needed. The third research objective focused on identifying services youth and their parents need to help manage their CF and to deal with the challenges associated with having CF. Health care professionals believed that youth with CF were accessing appropriate health care services. Despite the access to health care services, they described barriers to accessing and receiving mental health services. Mental health care for youth with CF was described as being an important focus that is currently lacking in their treatment plans. Health care professionals described that current care for youth with CF focuses on their physical health, and that mental health care tends to be “reactive”. Mental health care services were described as needing to be improved for this group. Annual screening for mental health concerns was mentioned as a recent addition to CF clinics that has been beneficial. Participants suggested adding a psychologist to the clinic team would be helpful and providing a more preventative approach to mental health care would also be beneficial. Additionally, it was suggested that ensuring a holistic treatment plan that included mental health care is needed, as well as focusing on the mental health needs of the entire family.

These findings are in alignment with suggestions made by the U.S. Cystic Fibrosis Foundation and European Cystic Fibrosis Society that recommend during all routine care, all individuals with CF and their parents should be offered education and
preventative, supportive interventions to develop effective coping skills and disease management skills (Quittner et al., 2016). For individuals with symptoms of depression and anxiety, there should be a flexible model of clinical intervention (Quittner et al., 2016). From the findings of the current study, and the recommendations included in the literature, developing a mental health service to suit the needs of youth with CF that also considers the potential barriers to mental health services is important. Moreover, ensuring that the approach to mental health service is flexible and addresses the specific needs of the individual may be important. For example, some individuals may benefit from a preventative program, whereas others with more acute needs may benefit from a more specific intervention. Providing the appropriate level of mental health care will be an important focus in the development of a mental health program for this group.

**6.10.4 Benefits and drawbacks of service via Internet.** The fourth research objective was to gain insight on the perceived benefits and drawbacks of receiving a mental health program via the Internet. Based on youth’s current interest in technology, participants believed that youth would be open to using a program delivered using the Internet. They also highlighted that an Internet-delivered program would be something that could be done privately and independently, a feature which youth would appreciate.

The main drawback of receiving service via the Internet was the potential for receiving misinformation. This relates to the findings previously discussed on censoring health information to children. There is a concern that harsh aspects about CF or inaccurate information about CF could be revealed through connecting with others online. It is important to take this concern into consideration when developing an Internet-delivered program. Some suggestions to navigate this concern include
incorporating a health care professional to periodically monitor the content being shared through the program and ensuring accurate information is portrayed on the program. Previous studies have emphasized the importance of guiding parents to credible information about CF on the Internet (Havermans et al., 2015; Jamieson et al., 2014; Jordan & Chambers, 2016). Moderating of social media groups by health care professionals has previously been used to provide a credible source of information, as well as to monitor and correct any misinformation shared within the group (Edwards, Wicking, Smyth, Shields, & Douglas, 2018). Although some participants believed that monitoring would reduce the likelihood of youth’ participation in the program, it is likely necessary to include monitoring as a safety feature to reduce the sharing of misinformation. Despite these concerns, previous use of peer-to-peer health care where patients and their families used the Internet to share information and gain social support were successful (Jamieson et al., 2014). Health care professionals added that some families may fail to see the benefit in receiving a service via the Internet. Incorporating education about the program for families prior to implementing the program may be beneficial to ensure families are aware of what to expect from an Internet-delivered program.

6.10.5 Components of program. The final research objective was to determine what components should be included in an Internet-delivered mental health program for youth with CF. Health care professionals provided specific information on what they considered to be important inclusions should an Internet-delivered mental health program be developed. First, participants suggested that information about CF and treatments should be included. They also suggested incorporating information on potential emotions
youth with CF may experience. Further, they believed that validating and normalizing these emotions would be beneficial. Including individual stories and allowing the option to give feedback were also highlighted as potential components. Finally, health care professionals emphasized that the program be short, fun, and interactive. Based on participant responses, motivation to use the program may be achieved through a reinforcement system, as well as encouragement from the CF clinic. The suggestions and feedback provided will be used to inform the development of components within an Internet-delivered program.
7.0 Chapter 7: Conclusion

The results of the present study offer detailed insight into the challenges and experiences of youth with CF, their needs, and the feasibility of an Internet-delivered mental health program for youth with CF. Gaining knowledge from the perspectives of three different groups contributes to formulating a clear understanding of their experiences and informing the development of appropriate services to suit their specific needs. Each individual in the study shared important information and insights about their experiences. The information that finds consensus across all participant groups is highly valuable. In this section, I will highlight the main findings and summarize the key messages across participant responses. Strengths, limitations and directions for future research will also be discussed.

7.1 Integrated Discussion

Understanding the challenges youth with CF face is critical to addressing their needs and informing services. Each participant group provided insight into the challenges faced by youth with CF. Across all participant groups, challenges that were emphasized included emotional challenges, social challenges, and treatment challenges. The results indicated that youth with CF experience a variety of emotions associated with their condition. Experiencing worries about health, disease outcomes, and hospital procedures was highlighted. Dealing with uncertainty about disease prognosis also appears to be a challenge for youth with CF. Further, more intense emotions such as depression and anxiety were mentioned. In terms of social challenges, social isolation, feeling different from peers, communicating about CF, and feelings of self-consciousness were reported.
Finally, participants emphasized the demanding nature of treatments and the lifestyle restrictions placed on youth with CF and their families as a major challenge.

Perceptions of the information and service needs of youth with CF were also described in the current study. All participant groups suggested the importance of youth with CF needing information about CF and how it affects their body. It was recommended this information be delivered to youth gradually and in a developmentally appropriate way. Opinions concerning disclosing information about life expectancy and disease prognosis to youth differed between parent and health care provider participants. While parents felt uncertain about the timing of conversations of disease prognosis and often reported not communicating about this information with their child, health care professionals believed censoring information about the harsh aspects of CF is unhelpful. Limited research has focused on how and when individuals with CF should receive information about their prognosis (Saunders et al., 2017). One study demonstrated that patients desire early, individualized communication about prognosis and that age-appropriate educational materials could aid in initiating these conversations among families and health care professionals (Saunders et al., 2017). Deciding what information about disease prognosis related to CF should be presented and how to present that information will be important considerations when developing our Internet-delivered program for youth with CF. Moreover, future research should delve into this area in more detail to determine best practices for delivering this information to youth.

Participants also emphasized the importance of youth understanding their treatments and rationale for completing their treatments. Based on the aforementioned treatment challenges, youth may also need information on coping with the demanding
nature of their treatments and the restrictions posed on their lives due to the necessity of completing treatments. Participant groups also believed it would be important to include youth in their own care and decision-making about their health to promote independence. Gradually learning about CF and becoming more involved in their care was suggested by participants to avoid feelings of being overwhelmed as an adult. Previous research has demonstrated adherence to treatments worsens as youth get older (Bishay & Sawicki, 2016). Ensuring youth gain appropriate disease and treatment-related information gradually may improve adherence in adolescence. As parents were identified as the primary individuals who teach youth about CF, it is also important for parents to have appropriate disease and treatment knowledge.

Participants across groups reported a lack of focus on mental health care within their overall CF care. Barriers to accessing mental health services included time conflicts, travel, financial barriers, and limited mental health professionals available to provide care. Reported barriers in the current study were in alignment with previous research (Fidkia et al., 2015; March et al., 2009; Ritterband & Palmero, 2009; Weisz et al., 2004). A greater focus on mental health care for youth with CF was perceived as being required. Preventative mental health care was recommended to prepare youth to cope effectively with potential challenges they may face in the future. Suggestions made in the current study are consistent with recommendations made by the ICMH that all individuals with CF should be offered education and preventative, supportive interventions to develop effective coping and disease management skills (Quittner et al., 2016). Developing and implementing a flexible, stepped-care approach to care where youth with CF would receive a mental health prevention program followed by further intervention for youth
with more acute needs may be beneficial. Offering a program using the Internet may be a favourable approach that allows for wide dissemination of a consistent program and may reduce the current barriers to access mental health care. Based on the emotional and social challenges of youth with CF, mental health programs to address these needs may include providing appropriate education about emotions and coping strategies, potential ways for youth with CF to connect to gain social support, encourage feelings of normalcy, and validate their shared experiences, as well as increased support in communicating about their condition and dealing with feelings of self-consciousness related to living with CF.

Participants across groups also offered specific feedback about the development of an Internet-delivered mental health program for youth with CF. This idea was endorsed by participants. Youth were thought to be open to engaging in a mental health program delivered using the Internet. One main benefit of the program identified was that it would give youth a way to incorporate mental health into their treatment routine in a way that could be completed privately and independently. Potential drawbacks of the program included safety concerns using the Internet and the potential for receiving misinformation about CF. Considering the concerns of youth, parents, and health care providers will be important progressing forward with program development. Ensuring information about CF is represented accurately and safety features such as including monitoring of the program by a health care provider will be a critical focus. Additionally, participants were concerned the program may be too time-consuming. The need to accommodate the potential attentional difficulties in youth with CF by keeping the program short was mentioned.
In terms of components to include in the program, covering all aspects of CF (i.e., physical and mental health) was perceived as necessary, such as including information about CF and ways to cope with emotions related to living with CF. Delivering information in a developmentally appropriate way was emphasized. Additionally, including a social support component where youth could read stories from other individuals with CF or connect with other youth with CF was highlighted as an option. Relating to other individuals with CF was seen as a way youth could be validated and would help normalize their experience. All groups suggested including a rewards system, using games to learn, and having a character deliver information as methods to make the program fun and engaging.

7.2 Strengths and Limitations

The current study offers valuable insights into the challenges of youth with CF and their families, as well as the information and services they need and their views on receiving an Internet-delivered mental health program. A primary strength of the current study is the inclusion of three different perspectives (i.e., youth with CF, parents, and health care professionals). Previous qualitative studies have only included perspectives of either group rather than combining perspectives (Ellerton et al., 1996; Moola & Norman, 2011; Moola et al., 2012; Bregnballe et al., 2011). By including individuals from three different groups, a more complete understanding of experiences of youth with CF was achieved. Each participant group was able to elaborate on different aspects of the challenges and needs of youth with CF. Further several of these studies have excluded inclusion of younger children under the age of 12 years. By including younger ages of youth in the study sample, the experiences of these youth are represented. Additionally,
conducting a qualitative study to inform the development of future mental health care is beneficial in ensuring appropriate information and components are included as well as avoiding any potential issues for participant engagement. Overall, the present study provided an updated account of the challenges and needs of youth with CF from a variety of perspectives that is essential to inform future care of this population.

Despite the study’s strengths, there are several limitations to consider that direct future research. First, the current study lacked participation of adolescents with CF (i.e., ages 13 to 18 years). Adolescent recruitment was a major challenge during completion of the study. The Canadian Cystic Fibrosis Registry (CCFR) reported 124 individuals living with CF in Saskatchewan in 2017, 61 of those being children and adolescents. As such, there are a limited number of adolescents available for participation in the province. Further, participation in the study was voluntary and adolescents eligible for participation were not required to participate. As adolescents with CF likely have different challenges, experiences, and needs than young children with CF based on their developmental stage, this is an important perspective missing from the current study. Although parents and health care professionals could provide some insight into adolescents’ experiences, including adolescents in the sample is essential to fully understand their experience and perspective. Developing methods to engage adolescents in research participation and in the development of and participation in mental health prevention and intervention programs should be considered in the future.

Second, as the study included participation of young children, building rapport was essential prior to interviews to ensure youth felt comfortable sharing information about their experiences living with CF. As the time to build rapport was often short,
youth may not have shared their in-depth details of their experiences. Additionally, based on their age and developmental understanding of their condition, youth may not have possessed further information or insights to share. Third, all of the participants were residents of Saskatchewan, and their experiences, particularly related to the health care system and availability of services within CF clinics, may not generalize to others in different provinces within Canada. Further, there may be variability among experiences between clinics in Saskatchewan. The experience of families and health care professionals that attend the CF clinic in Regina may differ from families and health care professionals that attend the CF clinic in Saskatoon. Finally, the subjective nature of qualitative research, and the potential for research bias is a potential limitation. A different researcher, in a different place or time, may have generated different themes. However, appropriate measures were employed to ensure the rigour and trustworthiness of the chosen qualitative method.

7.3 Future Directions and Implications

Several possibilities for future research and clinical innovations can be generated using knowledge and experiences provided by youth with CF, parents, and health care providers in the present study. Based on the findings of the current study, I believe that future research should focus on a) incorporating the perspectives of adolescents with CF, b) developing, implementing, and evaluating an Internet-delivered mental health program for youth with CF based on their expressed needs, and c) developing, implementing and evaluating support programs for parents and siblings of individuals living with CF.

First, including the perspective of adolescents with CF is a next step in this program of research. During adolescence, lung function decline is often accelerated and
the frequency of hospitalizations and CF-related complications and exacerbations often increases (Vandenbranden et al., 2012). Treatment burden and complexity may increase as a result (Sawicki, Ren, Konstan, Millar, Pasta, & Quittner, 2013). Additionally, adolescence is a time of heightened developmental challenges such as forming their identity, self-image, and self-esteem (Chao et al., 2016; Ersig, Tsalikian, Coffey, & Williams, 2016). Adolescents are also gaining more independence and responsibility, and have less support from their parents. For some, they may not be prepared for this independence leading to feelings of anger toward their condition and parents (Muther et al., 2018). The challenges, information and service needs, and opinions on receiving an Internet-delivered mental health program and components that should be included in this type of program likely differ greatly from that of younger children. Capturing the direct perspective of adolescents is critical when considering the development of a mental health program to address their needs.

Second, the results of the current study, combined with results from perspectives of adolescents with CF may direct the development of an Internet-delivered mental health program for youth with CF. Following the design and approach to the development, implementation, and evaluation of an Internet-based program for children with chronic pain, a next step in this program of research will be to develop an Internet-delivered mental health program for youth with CF and to trial the program with youth with CF, their parents, and health care professionals to determine the acceptability and utility of the program (Stinson et al., 2013; Stinson et al., 2014; Stinson et al., 2016). Receiving initial feedback from families and health care professionals can inform potential changes to the program before fully evaluating the effectiveness of the program.
A final opportunity for future research emerging from the results of the present study concerns the needs of family members of individuals with CF. Although the current study focused on the needs of youth with CF and informing the development of services to address their needs, the needs of family members of individuals with CF were also highlighted. Taking a similar approach to the current research and exploring the challenges and needs of parents and siblings may be beneficial. Families play an important role in the treatment management of youth with CF and ensuring the entire family is also receiving appropriate mental health services is critical to the health and well-being of the family as a whole (Fiese & Everhart, 2006). Developing, implementing and evaluating services to address the needs of other family members could be an interesting opportunity for future research.
8.0 References


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doi:10.1016/j.chc.2004.05.006


9.0 Appendices

Appendix A

Child Demographic Information

1. Which gender does your child identify with?
   - Female
   - Male
   - Transgender Female
   - Transgender Male
   - Trans/Non-Binary
   - Not listed __________
   - Prefer not to Answer

2. How old is your child?
   
   Age: ______

3. What is your child’s ethnicity?
   - White/Caucasian
   - Black/African
   - Hispanic
   - Asian
   - Aboriginal/First Nations
   - Middle Eastern
   - Mixed Ethnicity
   - Other (please specify)

4. What grade is your child in?
   - Grade 2
   - Grade 3
   - Grade 4
   - Grade 5
   - Grade 6
   - Grade 7
   - Grade 8
   - Grade 9
   - Grade 10
   - Grade 11
   - Grade 12

Responses from the following two questions allow us to calculate your child’s body mass index (BMI)

5. What is your child’s height?
   - feet ______ inches
   - Do not know
6. What is your child’s weight?
   _____ lbs
   _____ Do not know

7. What is your child’s FEV$_1$ percent predicted (forced expiratory volume in 1s as a percentage of predicted)?
   _____
   _____ Do not know

8. Has your child had haemoptysis or pneumothorax in last 6 months?
   YES    NO

9. Is your child currently on intravenous antibiotics?
   YES    NO
   If YES, for how long
   _____ months _____ weeks _____ days

10. Is your child on the national waiting list for lung transplantation?
    YES    NO

11. Does your child have an existing mental health condition (e.g., attention deficit/hyperactivity disorder, depression, panic disorder, schizophrenia)?
    YES    NO

12. If YES, please list:

13. Is your child currently on psychiatric medication for a mental health condition?
    YES    NO
    If YES, please list mental health condition and associated prescribed medication

<table>
<thead>
<tr>
<th>Mental Health Condition</th>
<th>Medication</th>
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14. Is your child currently receiving psychotherapy for a mental health condition?

YES     NO
Appendix B

Youth Semi-structured Interview Guide

1. Can you tell me what is cystic fibrosis (CF)? Describe it in your own words.
2. Can you tell me what it has been like for you to have CF?
3. What are the hard parts about having CF?
4. Can you tell me about how CF affects your life?
5. What kinds of emotions/feelings have you ever experienced related to your CF? For example, have you ever felt mad or sad or worried about having CF? Can you tell me about those times?
6. What do you think is important to know and do so that you can take care of your CF on your own?
7. What is it like to talk about your CF to your doctors and nurses? Family? Friends? Teachers?
8. What information do you need to have about medicines and other treatments such as seeing a physical therapist or a psychologist to feel comfortable taking care of your CF or on your own?
9. How have you learned about your CF and how to deal with it? Did you learn about CF from a specific person? Tell me about that.
10. What services or help would you like to have to help you manage CF?
11. How have you learned about emotions/feelings related to CF (i.e., sadness, anger, worry) and how to deal with those emotions/feelings?
12. What services or help would you like to have available to help you with emotions/feelings related to CF (i.e., sadness, anger, worry)?
13. Can you tell me about any difficulties you have had learning more about your CF and how to deal with it?
14. What do you need to know about your CF in general to feel ok taking care of your CF on your own?
15. If you had to tell someone else about how to deal or cope with their CF what would you tell them?
16. Of the kinds of treatments that you might have been given or offered—including medication, physical therapy, or psychological therapies—are there some kinds of treatments that you are more likely to try than others?
17. Have you had any trouble getting treatments such as physical and psychological therapies?
18. Can you tell me about any problems you have had getting help to deal with how CF might impact on your everyday life?
19. How would you feel about getting information on ways to cope with emotions/feelings related to CF (i.e., anger, sadness, worries) from a program on the Internet?
20. Would you be interested in being able to connect or talk with other young people with CF on an Internet program?
21. Would you want to connect or talk with other young people with CF if was monitored or run by a health care professional (e.g., nurse, social worker)? The health care professional might check in time to time to make sure everyone is safe in the discussion for example.
22. What could help or stop you from using this kind of Internet program on a regular basis?
23. If an Internet program was created to help young people like you cope with CF and the emotions/feelings, what do you think would be important to include in the program?
24. Is there anything else you would like to tell us about what you think is important to know?

Questions modified from previous studies (Stinson et al., 2013; Stinson et al., 2014).
Appendix C

Informational Poster

CYSTIC FIBROSIS
Research

YOUR CHILD’S MENTAL HEALTH IS IMPORTANT

STUDY 1
Seeking Children and Adolescents (AGES 8 – 18) with DIAGNOSED CYSTIC FIBROSIS (CF) and parent/guardian to complete an Internet-based survey. The study aims to further our understanding of mental health needs of children and adolescents with CF and their parents. Participants will be entered into a draw to win 1 of 3 $50 Best Buy gift cards.

STUDY 2
Seeking Children and Adolescents (AGES 8 – 18) with DIAGNOSED CYSTIC FIBROSIS (CF), parent/guardian, and siblings of those with CF to participate in a 30-60 minute interview about the mental health needs of children and adolescents with CF and their siblings. Participants are provided $25 for participation in interview.

TO PARTICIPATE IN SURVEY:
www.surveymonkey.com/r/CysticFibrosis1

TO PARTICIPATE IN INTERVIEW:
hilaryp045@gmail.com

These projects have been approved by the Research Ethics Board at the University of Regina. If you have questions regarding your rights as a participant you may contact the committee at (306) 585-4795 or research@ur_regina.ca.
Appendix D

Parent Demographic Information

1. Which gender do you identify with?
   Female
   Male
   Transgender Female
   Transgender Male
   Trans/Non-Binary
   Not listed __________
   Prefer not to Answer

2. How old are you?
   Age: _______

3. What is your ethnicity?
   _____White/Caucasian       _____Black/African       _____Hispanic
   _____Asian                 _____Aboriginal/First Nations    _____Middle Eastern
   _____Mixed Ethnicity       _____Other (please specify)

4. What is your HIGHEST level of education?
   _____Some elementary school       _____Some University
   _____Grade 8                     _____University Diploma
   _____Grade 9                     _____University Degree
   _____Grade 10                    _____Trade School
   _____Grade 11                    _____M.A.
   _____Grade 12                    _____Ph.D.

5. What is your current relationship status?
   _____Single                    _____Divorced            _____Common law/cohabiting
   _____Married                   _____Separated            _____Dating
6. What is your current employment status? (Select all those that currently apply)

______Employed-full time  _____Employed part-time
______Student  _____On disability  _____Other (please specify)

8. What is your current family size?

______ number

9. What is your current household income?

______Less than $30,000  _____$30,000-$49,999  _____$50,000-$99,999
_____ $100,000-$499,000  _____greater than $500,000

9. Where do you live?

_____urban setting  _____rural setting

10. What province do you live in? ______________________

11. Do you have an existing health condition?

YES  NO

12. If YES, please list:

13. Do you have an existing mental health condition (e.g., attention deficit/hyperactivity disorder, depression, panic disorder, schizophrenia)?

YES  NO

14. If YES, please list:

15. Are you receiving any intervention for an existing mental health condition?

YES  NO

If YES, please check as appropriate

_____psychiatric medication  _____psychotherapy  _____other
## Parent Caregivers Semi-structured Interview Guide

1. Can you tell me what you think it is like for your child/adolescent to have CF?
2. What do you think are the challenges or hard parts about having CF for your child/adolescent?
3. Can you tell me how you think CF affects other parts of your child’s/adolescent’s your life?
4. What kinds of emotions do you think your child/adolescent experience related to their CF?
5. What do you think is important to know and do so your child/adolescent can learn to manage or take care of their CF independently (or on their own)?
6. What do you think it is like for your child/adolescent to talk about their CF to their doctors and nurses? Family? Friends? Teachers?
7. What information does your child/adolescent need to have about medicines and other treatments such as physical and psychological therapies to feel comfortable managing their CF independently (or on their own)?
8. How do you think your child/adolescent learns about their CF and how to manage it?
9. What services would you like your child/adolescent to have available to help them manage CF?
10. How do you think your child/adolescent learns about emotions related to CF (i.e., worries, anger, sadness) and how to manage them?
11. What services would you like your child/adolescent to have available to help them with emotions related to CF (i.e., worries, anger, sadness)?
12. Have you had any difficulties accessing services for your child/adolescent to help them learn more about their CF and how to manage it? Please explain.
13. What does your child/adolescent need to know about their CF in general to feel comfortable managing it independently (or on their own)?
14. What do you think are the barriers that get in the way of helping your children/adolescents to learn how to manage their CF?
15. Of the treatments potentially offered—including medication, physical, or psychological therapies—are there some treatments that children/adolescents are more engage in than others?
16. Have you had any trouble accessing psychological services for your child/adolescent? Please explain.
17. How would you think your child/adolescent would feel about getting information on ways to cope with or treat emotions related to CF (i.e., worries, anger, sadness) from an Internet-based program?
18. Do you think your child/adolescent would you be interested in using an online community where they could communicate to other young people with CF? Why or why not?
19. Would your child/adolescent be more or less likely to participate in an online community if it was moderated by a health care professional? Why or why not?
20. What do you think could motivate or prevent your child/adolescent from using the program on a regular basis?
21. If an Internet-based program was created to help young people cope with CF and
the associated emotions/feelings, what do you think would be important to include in the program?

22. Is there anything else you would like to tell us about what you think is important to know?

Questions modified from previous studies (Stinson et al., 2013; Stinson et al., 2014).
Appendix F

Health Care Professional Demographic Information

Please complete the questionnaire below.

1. Which gender do you identify with?
   Female
   Male
   Transgender Female
   Transgender Male
   Trans/Non-Binary
   Not listed __________
   Prefer not to Answer

2. How old are you?
   Age: _______

3. What type of health care professional are you?
   _____ Social Worker   _____ Physician
   _____ Nurse   _____ Psychologist
   _____ Dietitian   _____ Other (please specify)

4. How many years have you been working with individuals with CF?

5. What is your ethnicity?
   _____ White/Caucasian   _____ Black/African   _____ Hispanic
   _____ Asian   _____ Aboriginal/First Nations   _____ Middle Eastern
   _____ Mixed Ethnicity   _____ Other (please specify)

6. What is your HIGHEST level of education?
   _____ Some elementary school   _____ Some University
   _____ Grade 8   _____ University Diploma
   _____ Grade 9   _____ University Degree
7. What is your current relationship status?
   _____ Single                         _____ Divorced             _____ Common law/cohabiting
   _____ Married                     _____ Separated            _____ Dating
   _____ Widowed                   _____ Other (please specify)

8. What is your current employment status? (Select all those that currently apply)
   _____ Employed-full time   _____ Employed part-time
   _____ Student                        _____ On disability       _____ Other (please specify)

9. What is your current household income?
   _____ Less than $30,000   _____ $30,000-$49,999   _____ $50,000-$99,999
   _____ $100,000-$499,000   _____ greater than $500,000

10. Where do you live?
    _____ urban setting       _____ rural setting
Appendix G

Health Care Professionals Semi-structured Interview Guide

1. Can you tell me what you think it is like for a child/adolescent to have CF?
2. What do you think are the challenges or hard parts about having CF for a child/adolescent?
3. Can you tell me how you think CF affects other parts of a child’s/adolescent’s life?
4. What kinds of emotions do you think a child/adolescent experience related to their CF?
5. What do you think is important to know and do so a child/adolescent can learn to manage or take care of their CF independently (or on their own)?
6. What do you think it is like for a child/adolescent to talk about their CF to their doctors and nurses? Family? Friends? Teachers?
7. What information does a child/adolescent need to have about medicines and other treatments such as physical and psychological therapies to feel comfortable managing their CF independently (or on their own)?
8. How do you think a child/adolescent learns about their CF and how to manage it?
9. What services would you like a child/adolescent to have available to help them manage CF?
10. How do you think a child/adolescent learns about emotions related to CF (i.e., worries, anger, sadness) and how to manage them?
11. What services would you like a child/adolescent to have available to help them with emotions related to CF (i.e., worries, anger, sadness)?
12. Have you had any difficulties accessing services for your child/adolescent patients to help them learn more about their CF and how to manage it?
13. What does a child/adolescent need to know about their CF in general to feel comfortable managing it independently (or on their own)?
14. What do you think are the barriers that get in the way of helping children/adolescents to learn how to manage their CF?
15. Of the treatments potentially offered—including medication, physical, or psychological therapies—are there some treatments that children/adolescents are more engage in than others?
16. Have you had any trouble accessing psychological services for a child/adolescent?
17. How would you think a child/adolescent would feel about getting information on ways to cope with or treat emotions related to CF (i.e., worries, anger, sadness) from an Internet-based program?
18. Do you think a child/adolescent would you be interested in using an online community where they could communicate to other young people with CF?
19. Would a child/adolescent be more or less likely to participate in an online community if it was moderated by a health care professional?
20. What do you think could motivate or prevent a child/adolescent from using the program on a regular basis?
21. If an Internet-based program was created to help young people cope with CF and the associated emotions/feelings, what do you think would be important to include in the program?
22. Is there anything else you would like to tell us about what you think is important to
Questions modified from previous studies (Stinson et al., 2013; Stinson et al., 2014).
Appendix H

Introductory Email to Healthcare Professionals

Hi,

Myself (Dr. Kristi D. Wright, Registered Doctoral Psychologist, Associate Professor of Clinical Psychology, University of Regina, Regina, SK) and Dr. Heather Switzer (Registered Doctoral Psychologist, Senior Psychologist, Children’s Program, Wascana Rehabilitation Centre, Saskatchewan Health Authority Regina, SK) are beginning a very important study examining the information and service needs of children and adolescents with CF.

Recently a large, multi-country study was completed looking at the psychological functioning of children and adolescents with CF but it did not include Canada. It is very important for us to understand the functioning and needs of Canadian children and adolescents with CF and their parents as there may be differences in the information that has been gathered from other countries. In addition, the need to address issues in psychological functioning by creating methods of mental health service delivery is evident. The primary purpose of the current study is to explore the information and service needs of children and adolescents with CF, their parent caregivers, and healthcare professionals. This study will also investigate the information and service needs of healthy siblings of children and adolescents with CF. The information obtained will inform the development of an evidence-based, interactive, Internet-delivered, mental health program for children and adolescents with CF and their siblings.

This project has been approved by the Research Ethics Board (REB) at the University of Regina and has received operational approval from the Saskatchewan Health Authority (August 28, 2018). In order for this project to be successful we ask for your participation. Your participation would first involve completing a short demographics form. The next part of the study involves participating in a focus group interview with the research coordinator and other health care professionals. Focus group questions will include general introductory questions about informational and service needs of children and adolescents with CF, as well as more specific questions that will allow you to elaborate on your own personal experiences should you desire to share. Questions concerning the benefits and/or drawbacks of receiving a mental health service via the Internet will also be included. Focus group interviews will range from 30 minutes to 90 minutes in length and will be conducted at a convenient time and location for you. All interviews will be audiotaped and field notes will be made during the interviews. At the end of the study you will be offered a $25 honorarium.

Upon completion of this study (approximately August 2019) a study summary will be circulated to all CF clinics in Canada. Findings will also be disseminated through publication in peer-reviewed journals, scientific conferences, and talks in the general community.

Thank you very much for considering participating in this very important study!
Appendix I

Parent Consent Form

Project Title: A Qualitative Exploration of the Information and Service Needs of Children and Adolescents with Cystic Fibrosis and their Siblings

Primary Investigator: Kristi D. Wright, Ph.D., R. D. Psych.
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Regina SK S4S 0A2
Phone: (306) 585-4180
Email: kristi.wright@uregina.ca

Co-Principal Investigator: Heather Switzer Ph.D., R. D. Psych.
Senior Psychologist, Children’s Program
Wascana Rehabilitation Centre
Saskatchewan Health Authority
2180 23rd Avenue
Regina SK S4S 0A5
Phone: (306) 766-5446
Email: heather.switzer@saskhealthauthority.ca

Research Coordinator: Hilary Power, BSc (Hons)
M. A. Clinical Psychology Student
University of Regina
3737 Wascana Parkway
Regina SK S4S0A2
Email: hap157@uregina.ca
**Purpose:** You and your child (or multiple children if applicable) are being invited to take part in a study to examine the information and service needs of children and adolescents who have cystic fibrosis (CF) and their healthy siblings. Recently a large, multi-country study was completed looking at the psychological functioning of children and adolescents with CF but did not include Canada. It is very important for us to understand the functioning and needs of Canadian children and adolescents with CF and their families as there may be differences in the information that has been gathered from other countries. In addition, the need to address issues in psychological functioning by creating methods of mental health service delivery is evident. The primary purpose of the current study is to explore the information and service needs of children and adolescents with CF, from the perspective of children and adolescents with CF, their parent caregivers, and healthcare professionals. The study will also investigate the information and service needs of siblings of children and adolescents with CF. The information obtained will inform the development of an evidence-based, interactive, Internet-delivered, mental health program for children and adolescents with CF. This study has been approved by the Research Ethics Board (REB) at the University of Regina and has received operational approval from the Saskatchewan Health Authority (August 28, 2018).

**Voluntary Participation:** Participation in this study is completely voluntary, so it is your decision whether or not you want to take part. To help you decide whether you do or do not want to participate, it is important to understand what this research involves. This consent form will describe the study, the purpose of the research, what will happen during the study, and the possible risks and benefits. If you do decide to take part in this study, you will be asked to endorse this consent form to indicate your informed consent to participate. Although, even after you indicate you want to participate you can choose to drop-out at any time, refuse to answer any questions, as well as request that the information collected not be used. Lack of participation will not result in any negative consequences. It is important to note that if your child does not want to participate, this does not negate your participation.

**Who is conducting the study:** The Primary Investigator is Dr. Kristi D. Wright, a Registered Doctoral Psychologist. The Co-Primary Investigator is Dr. Heather Switzer, a Registered Doctoral Psychologist. The Research Coordinator is Hilary Power, a Master’s student in Clinical Psychology at the University of Regina. These findings will contribute to her Master’s thesis, a requirement to earn this degree. Study findings will also contribute to another Masters student’s thesis, Shelby Shivak.

**Procedures:** Before you decide if you wish to participate, we would like to provide you with information about the procedures involved in the study so that you can make an informed decision. Firstly, you will be asked to read and complete an informed consent form. Then your child will be asked to read and complete an assent form. We encourage you to read the assent form along with your child. Following consent and child assent, you will be asked to complete a short demographics form about you and your child. The next part of the study involves participating in an interview with the research coordinator. Your child will be asked to participate in an individual interview with the research
coordinator. You will be allowed to be present during your child/adolescent’s interview. Interview questions will include general introductory questions about informational and service needs of children and adolescents with CF, as well as more specific questions that will allow you to elaborate on your own personal experiences should you desire to share. Questions concerning the benefits and/or drawbacks of receiving a mental health service via the Internet will also be included. Interviews will range from 30 minutes to 90 minutes in length. All interviews will be audiotaped and field notes will be made during the interviews.

**Potential Risks:** There are no known or anticipated risks to you or your child by participating in this research.

**Potential Benefits:** No direct benefit can be guaranteed. However, it is anticipated that the findings from this investigation will facilitate further knowledge of the information and service needs of children and adolescents with CF, as well as the potential usefulness of service provision via the Internet. Although participants may not benefit directly from this study, it has the potential to greatly improve our understanding of the information and service needs of children and adolescents with CF and may serve to inform the development of tailored intervention and support programs.

**Compensation:** Upon the completion of the study, you will be offered an honorarium of $25 as a token of thanks for participating in the study. Compensation for travel for those living outside of Regina will be provided. Compensation for parking will be provided.

**Confidentiality:** Any information gathered during the data collection process is confidential and will be used for research purposes only by the University of Regina. All information collected will be given a unique number. The file will not contain any identifying information. The consent forms, assent forms, and demographics forms, do not contain any identifying information. The email address provided for the provision of the $25 honorarium is not linked to any data collected. The individual interviews will also be audiotaped. The audiotaped will later be created into an interview script. Only the study personnel (Research Coordinator, Research Assistants, and Drs. Wright and Switzer) will have access to the audiotapes and scripts. Should you reveal any identifying information during the interview, it will be removed from the script.

**Data Security and Storage:** All of the information that we collect will be stored on a lap top/lab computer (requiring an access code) at the University of Regina in the primary investigator’s research lab for 5 years after the end of the project.

**Right to Withdraw:** As a reminder participation in this study is voluntary, and you can decide not to participate at any time or choose not to answer any questions you don’t feel comfortable with. However, once the focus interview is completed we will not be able to remove your responses as it may be difficult to entirely remove your contribution without impacting the responses of other participants. The responses to your questions during the focus groups and interviews will be confidential and your personal information will not be linked to your responses. By participating and completing the study your free and informed consent is implied and indicates that you understand the above conditions of participation in this study. Please consider printing a copy of this information form for your records.
Follow up: A summary of study results will be available once all data have been collected and analyzed. This will likely take over a year. For this information, or any further questions regarding research findings, you may contact the researchers using the information at the top of page 1.

Questions or Concerns: If you have any questions, concerns, or feedback about the research study or the results of the research study, please feel free to contact the researchers using the information at the top of page 1.

If you have any questions or concerns about your rights as a research participant, you may contact the Chair of the Research Ethics Board at the University of Regina at (306) 585-4775 (email: research.ethics@uregina.ca) or the Saskatchewan Health Authority at research&performance@saskhealthauthority.ca.

Participant Consent to Participate:

Are you 18 years of age or older?

Yes  
No

Have you read and understood the information page?

Yes  
No

Do you freely and voluntarily consent to take part in the research?

Yes  
No

Signature: _______________________________

Completion of this questionnaire implies consent to participate in this project. If you have questions you may e-mail the Primary Investigator, Dr. Kristi Wright, at
kristi.wright@uregina.ca or Co-Principal Investigator, Dr. Heather Switzer, at heather.switzer@saskhealthauthority.ca. You may also contact the Chair of the Research Ethics Board at the University of Regina at (306) 585-4775 or by e-mail: research.ethics@uregina.ca or the SHA at research&performance@saskhealthauthority.ca.
Appendix J

Health Care Professional Consent Form

Project Title: A Qualitative Exploration of the Information and Service Needs of Children and Adolescents with Cystic Fibrosis and their Siblings

Primary Investigator: Kristi D. Wright, Ph.D., R. D. Psych.
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Co-Principal Investigator: Heather Switzer Ph.D., R. D. Psych.
Senior Psychologist, Children’s Program
Wascana Rehabilitation Centre
Saskatchewan Health Authority
2180 23rd Avenue,
Regina SK S4S 0A5
Phone: (306) 766-5446
Email: heather.switzer@saskhealthauthority.ca

Research Coordinator: Hilary Power, BSc (Hons)
M. A. Clinical Psychology Student
University of Regina
3737 Wascana Parkway
Regina SK S4S0A2
Email: hap157@uregina.ca
Purpose: You are being invited to take part in a study to examine the information and service needs of children and adolescents who have cystic fibrosis (CF). Recently a large, multi-country study was completed looking at this very topic but did not include Canada. It is very important for us to understand the functioning and needs of Canadian children and adolescents with CF and their families as there may be differences in the information that has been gathered from other countries. The primary purpose of the current study is to explore the information and service needs of children and adolescents with CF, from the perspective of children and adolescents with CF, their parent caregivers, and healthcare professionals. This study will also investigate the information and service needs of the healthy siblings of children and adolescents with CF. This study has been approved by the Research Ethics Board (REB) at the University of Regina and has received operational approval from the Saskatchewan Health Authority (August 28, 2018).

Voluntary Participation: Participation in this study is completely voluntary, so it is your decision whether or not you want to take part. To help you decide whether you do or do not want to participate, it is important to understand what this research involves. This consent form will describe the study, the purpose of the research, what will happen during the study, and the possible risks and benefits. If you do decide to take part in this study, you will be asked to endorse this consent form to indicate your informed consent to participate. Although, even after you indicate you want to participate you can choose to drop-out at any time, refuse to answer any questions, as well as request that the information collected not be used. Lack of participation will not result in any negative consequences.

Who is conducting the study: The Primary Investigator is Dr. Kristi D. Wright, a Registered Doctoral Psychologist. The Co-Primary Investigator is Dr. Heather Switzer, a Registered Doctoral Psychologist. The Research Coordinator is Hilary Power, a Masters student in Clinical Psychology at the University of Regina. These findings will contribute to her Master’s thesis, a requirement to earn this degree. Study findings will also contribute to another Masters student’s thesis, Shelby Shivak.

Procedures: Before you decide if you wish to participate, we would like to provide you with information about the procedures involved in the study so that you can make an informed decision. Firstly, you will be asked to read and complete an informed consent form. Following consent, you will be asked to complete a short demographics form. The next part of the study involves participating in an interview with the research coordinator. Interview questions will include general introductory questions about informational and service needs of children and adolescents with CF, as well as more specific questions that will allow you to elaborate on your own personal experiences should you desire to share. Questions concerning the benefits and/or drawbacks of receiving a mental health service via the Internet will also be included. Focus group interviews will range from 30 minutes to 90 minutes in length. All interviews will be audiotaped and field notes will be made during the interviews.
Potential Risks: There are no known or anticipated risks by participating in this research.

Potential Benefits: No direct benefit can be guaranteed. However, it is anticipated that the findings from this investigation will facilitate further knowledge of the information and service needs of children and adolescents with CF, as well as the potential usefulness of service provision via the Internet. Although participants may not benefit directly from this study, it has the potential to greatly improve our understanding of the information and service needs of children and adolescents with CF and may serve to inform the development of tailored intervention and support programs.

Compensation: Upon the completion of the study, you will be offered an honorarium of $25 as a token of thanks for participating in the study. Compensation for travel for those living outside of Regina will be provided. Compensation for parking will be provided.

Confidentiality: Any information gathered during the data collection process is confidential and will be used for research purposes only by the University of Regina. All information collected will be given a unique number. The file will not contain any identifying information. The consent forms, and demographics forms, do not contain any identifying information. The email address provided for the provision of the $25 honorarium is not linked to any data collected. The individual interviews and focus group interviews will be audiotaped. The audiotape will later be created into an interview script. Only the study personnel (Research Coordinator, Research Assistants, and Drs. Wright and Switzer). Should you reveal any identifying information during the interview, it will be removed from the script.

Data Security and Storage: All of the information that we collect will be stored on a lap top/lab computer (requiring an access code) at the University of Regina in the primary investigator’s research lab for 5 years after the end of the project.

Right to Withdraw: As a reminder participation in this survey is voluntary, and you can decide not to participate at any time or choose not to answer any questions you don’t feel comfortable with. However, once the focus interview is completed we will not be able to remove your responses as it may be difficult to entirely remove your contribution without impacting the responses of other participants. The responses to your questions during the focus groups will be confidential and your personal information will not be linked to your responses. By participating and completing the study your free and informed consent is implied and indicates that you understand the above conditions of participation in this study. Please consider printing a copy of this information form for your records.

Follow up: A summary of study results will be available once all data have been collected and analyzed. This will likely take over a year. For this information, or any further questions regarding research findings, you may contact the researchers using the information at the top of page 1.
**Questions or Concerns:** If you have any questions, concerns, or feedback about the research study or the results of the research study, please feel free to contact the researchers using the information at the top of page 1. If you have any questions or concerns about your rights as a research participant, you may contact the Chair of the Research Ethics Board at the University of Regina at (306) 585-4775 (email: research.ethics@uregina.ca) or the Saskatchewan Health Authority (SHA) at research&performance@saskhealthauthority.ca.

**Participant Consent to Participate:**

Are you 18 years of age or older?

Yes

No

Have you read and understood the information page?

Yes

No

Do you freely and voluntarily consent to take part in the research?

Yes

No

Signature: _______________________________

Completion of this questionnaire implies consent to participate in this project. If you have questions you may e-mail the Primary Investigator, Dr. Kristi Wright, at kristi.wright@uregina.ca or Co-Principal Investigator, Dr. Heather Switzer, at heather.switzer@saskhealthauthority.ca. You may also contact the Chair of the Research Ethics Board at the University of Regina at (306) 585-4775 or by e-mail: research.ethics@uregina.ca or the SHA at research&performance@saskhealthauthority.ca.
Appendix K

Child Assent Form

Project Title: A Qualitative Exploration of the Information and Service Needs of Children and Adolescents with Cystic Fibrosis and their Siblings

Primary Investigator: Kristi D. Wright, Ph.D., R. D. Psych.
Associate Professor
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Co-Principal Investigator: Heather Switzer Ph.D., R. D. Psych.
Senior Psychologist, Children’s Program
Wascana Rehabilitation Centre
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2180 23rd Avenue,
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Phone: (306) 766-5446
Email: heather.switzer@saskhealthauthority.ca

Research Coordinator: Hilary Power, BSc (Hons)
M. A. Clinical Psychology Student
University of Regina
3737 Wascana Parkway
Regina SK S4S0A2
Email: hap157@uregina.ca

PARENT: PLEASE READ ALOUD TO OR ALONG WITH YOUR CHILD.

You are being invited to join a study about what information and services children and adolescents with cystic fibrosis and their siblings need. This study has been approved by the Research Ethics Board of the University of Regina and Saskatchewan Health Authority.

What will I be asked to do?
(1) You will be asked to answer some questions about what information and services you think children and adolescents with CF or siblings of children and adolescents with CF need, as well as some questions about what it is like to have CF (or what you think it is like to have CF). This will take about 1 hour to do. (2) You will be asked to read and select YES on this Assent form.

Are there any risks if I do the study?
No, we do not think that there are any risks if you do this study.

Are there any benefits if I do the study?
Your participation will help us learn important information, and help us understand what information and services children and adolescents with cystic fibrosis need. You will be given $25 for participating in the study.

Will anybody know how I answered the questions?
Your answers to the questions we ask are personal. It is our job to keep your answers confidential, which means that we do not talk to anyone else about what you tell us. When you answer the questions your name is not linked to your answers, so we do not know that those are your answers. All of the information we collect will be kept on a computer that needs a password, in a locked cabinet at the University of Regina.

Sometimes children like you tell us about a serious problem that their mom or dad or guardian might not know about. If the problem is so serious that someone might get hurt, it is our job to tell your parent or guardian or someone who can help, because we want to make sure you are safe. But, if we need to talk to someone else we will discuss it with you first to explain why it is important to share this information.

Do I have to participate?
No, you only have to join the study if you want to. Your participation is voluntary.

Can I stop participating?
Yes, you can stop participating at any time or choose not to answer any questions you don’t feel comfortable with. Nobody will be mad if you decide not to participate, or if you decide to stop doing the study before you are finished. It is your choice. If you do decide that you don’t want your answers in the study you will have approximately 1 week to let your parent know and your parent can inform us. If you decide to stop doing the
study at any point, you will still be offered a gift of $25 as a token of thanks for participating in the study if your parent provides their email address.

**Who can I talk to if I have any questions?**
If you have any questions or have something to say about the study you can email the researchers, Dr. Kristi D. Wright (kristi.wright@uregina.ca) or Dr. Heather Switzer (heather.switzer@saskhealthauthority.ca).

If you have questions about your rights as a participant, you may contact the Chair of the Research Ethics Board at (306) 585-4775 (email: research.ethics@uregina.ca) or the SHA at research&performance@saskhealthauthority.ca.

**Participant Assent to Participate:**

- Have your parent/guardian provided consent for you to take part in the research?
  - Yes
  - No

- Signature of Parent: _________________________

- Have you read and understood the information about the study?
  - Yes
  - No

- Do you freely and voluntarily agree to take part in the research?
  - Yes
  - No

Completion of this questionnaire implies consent to participate in this project. If you have questions you may e-mail the Primary Investigator, Dr. Kristi Wright, at kristi.wright@uregina.ca or Co-Principal Investigator, Dr. Heather Switzer, at heather.switzer@saskhealthauthority.ca. You may also contact the Chair of the Research
Ethics Board at the University of Regina at (306) 585-4775 or by e-mail: research.ethics@uregina.ca or the SHA at research\performance@saskhealthauthority.ca.
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Appendix L

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University of Regina

Research Ethics Board
Certificate of Approval

PRINCIPAL INVESTIGATOR
Dr. Kristi Wright

DEPARTMENT
Department of Psychology

REB#
2018-114

TITLE
A Qualitative Exploration of the Information and Service Needs of Children and Adolescents with Cystic Fibrosis and their Siblings

APPROVED ON
August 28, 2018

RENEWAL DATE
August 28, 2019

APPROVAL OF
Application for Behavioural Research Ethics Review
Poster

Introductory Email
Consent Form

Questions
Demographic Questionnaire

Full Board Meeting 
Delegated Review 

The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, or related documents.

Any significant changes to your proposed method, procedures or related documents should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for the renewal and closure forms:
https://www.uregina.ca/research/for-faculty-staff/ethics-compliance/human/ethicsforms.html