Career Development Projects and Actions of Emerging Adults with Cystic Fibrosis and their Parents: A Qualitative Exploration

by

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ABSTRACT

This study explored the ways in which emerging adults with cystic fibrosis (CF) engage in joint goal-directed processes related to career development with their parents. Using the conceptual framework of contextual action theory, and procedures from Stake’s (2005) multicase study approach and Young, Valach and Domene’s (2005) action project method, this study addressed the question: How do emerging adults with CF describe their career development as joint goal-directed action in the context of their relationships with their parents? Several unique processes and experiences emerged from the analysis, as well as two common themes: parental support and health. Overall, the findings revealed that the career development of emerging adults with CF is constructed though numerous joint goal directed actions, which were embedded in a relational context with their parents. There are also several implications of these findings for counselling practice.
DEDICATION

This thesis is dedicated to my sister.
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Chapter 1: Literature Review

Introduction

According to Cystic Fibrosis Canada (2015), “cystic fibrosis is the most common fatal genetic disease affecting Canadian children and young adults” (p. 1). Over 4,100 individuals have been diagnosed with cystic fibrosis (CF) in Canada, with 122 new diagnoses occurring in 2016 (Cystic Fibrosis Canada, 2017). Individuals with CF in Canada are living longer, with the median age increasing from 20 years in 2011 to 22.7 years in 2016 (Cystic Fibrosis Canada, 2011; 2017). Also, 60% of all individuals with CF in Canada are over the age of 18 (Cystic Fibrosis Canada, 2015). As medical advances improve survival and quality of life, more individuals with CF are entering the workforce (Cohen-Cymberknoh, Shoseyov, & Kerem, 2011; Targett et al., 2014).

Current research on the career development of individuals with CF has largely focused on factors such as employment experiences (Demars, Uluer, & Sawicki, 2011; Edwards & Boxall, 2010; Higham, Ahmed, & Ahmed, 2013), health-related quality of life (Havermans, Colpaert, Vanharen, & Dupont, 2009; Hogg, Braithwaite, Bailey, Kotsimbos, & Wilson, 2007; Targett et al., 2014), and disease severity (Burker, Sedway, & Carone, 2004; Frangolias, Holloway, Vedal, & Wilcox, 2003; Gillen, Lallas, Brown, Yelin, & Blanc, 1995; Goldberg, Isralsky, & Shwachman, 1985; Havermans et al., 2009; Hogg et al., 2007; Laborde-Casterot et al., 2012; Targett et al., 2014; Taylor-Robinson, Smyth, Diggle, & Whitehead, 2013). In contrast, there is an absence of literature on relational influences in the career development of emerging adults with CF. This is problematic because research has revealed that family relationship variables, such as
attachment, support, and warmth, have a significant influence on career development across all developmental levels (Whiston & Keller, 2004). Furthermore, Iles and Lowton (2009) found parents of adolescents and emerging adults with CF continued to be involved in many aspects of their life, both during and after transition to adult health services. Therefore, attending to the relational system will provide new insights into the career development of emerging adults with CF, adding to the existing literature.

The remainder of this chapter will address: (a) the scope and bounds of the thesis, (b) definitions of key terms, and (c) a description of literature that is relevant to the topic of this thesis. Using the University of New Brunswick’s manuscript style thesis format, Chapter 2 presents a description of the qualitative study that was conducted for this thesis. Finally, Chapter 3 consists of a discussion of the implications of this study for counselling practice and future research.

**Scope and Bounds**

Although this study will broadly explore career development in emerging adults with CF, the focus will be on the joint goal-directed processes associated with career development, not on their health. Therefore, this research was not designed to directly explore physical health or the medical treatment and management of emerging adults’ CF. In addition, this study only explored the emerging adult perspective on career development as situated in the parent-emerging adult relationship. Parental views on career development in emerging adults with CF and direct observation of parents’ joint actions with their emerging adult children were not included in this research because of anticipated difficulties recruiting participants.
Definitions

Emerging adulthood. Emerging adulthood is defined as the developmental period, occurring in Western societies such as Canada, spanning from the late teens through the twenties, specifically those aged 18 to 29 years (Arnett, Zukauskiene, & Sugimura, 2014). This period is characterized by exploration in love, work, and worldviews (Arnett, 2000). Arnett (2000) claims that emerging adulthood is different from adolescence and adulthood demographically, subjectively, and with regard to identity exploration.

Career development. According to Arnett (2000), emerging adulthood is a distinct period of the life course characterized by change. As a result, career development in emerging adulthood is an important time for educational and occupational exploration and engagement, as well as formation of vocational identity (Domene, Landine, & Stewart, 2015). Research has also revealed that these explorations occur within a relational context; emerging adults work together with other people to pursue their career development, including romantic partners (Domene et al., 2012) and parents (Young et al., 2011; Young et al., 2008). Therefore, this study broadly defined career development as actions that emerging adults engage in with their parents to achieve goals related to education, work and/or identity.

Contextual action theory. Contextual action theory (CAT) is based on the idea that goal-directed action is central to understanding human experience (Young, Valach, & Domene, 2005). Within this theory, the construct of action is described in a
multidimensional framework, including multiple perspectives on action, three levels of action, and four action systems (Young et al., 2005). According to CAT, action is understood from three perspectives: manifest action (e.g., observable verbal and nonverbal behaviour), internal processes (e.g., an individual's thoughts and emotions that accompany the action), and social meaning (e.g., individual and social understandings that are constructed about the action; Young et al., 2005). In addition, action is organized into three levels: elements, functional steps and goals. Elements are at the lowest level of action and are composed of verbal and nonverbal behaviour(s). According to Young and colleagues’ (2005), elements are both observable and measurable. Functional steps are the next level of action. A functional step is a combination of elements, which are seen as moving towards a goal. Goals make meaning of the action process and are the final level of the action organization. They are “dependent on insight, actor-observer agreement, and social convention” (Young et al., 2005, p. 217). In CAT there are also four action systems: individual action, joint action, project, and career (Young et al., 2005). Individual and joint actions occur daily (e.g., cognitively, socially, environmentally) over a short period of time. Projects are defined as a series of actions that combine over a common goal, over a mid-length period of time. Career does not specifically relate to employment, but is the extension of an individual's goal-oriented behaviour over a long period of time, and can include a number of projects related to the same overarching goal.

**Existing Research**

The following literature review provides a description of the existing research concerning the career development of individuals with CF, starting by providing a brief
overview of CF, focusing specifically on diagnosis, life expectancy, and medical
treatment and adherence. Next, the psychological, psychosocial, and cognitive and
academic functioning of individuals with CF will be addressed. An examination of
previous literature on family functioning in children with CF will then follow. Lastly, this
review will provide a discussion surrounding the career development of individuals with
CF, as well as relationship attachments and processes in career development.

**Overview of cystic fibrosis.** CF is the most prevalent autosomal recessive disease
in children and young adults in Canada, with CF affecting more than 4,200 Canadians
(Cystic Fibrosis Canada, 2017). CF affects all racial and ethnic groups; however, CF is
most common in Caucasian populations. For example, among individuals with CF in
Canada, in 2016, 92.8% were Caucasian, 0.8% were Black, 0.7% were Asian, 0.9% were
First Nations People, 0.2% were South Asian, 0.05% were Hispanic, 0.8% were two or
more races, and 4.3% were unstated (Cystic Fibrosis Canada, 2017). CF is a progressive,
degenerative disease that mainly affects the lungs and digestive system (Cystic Fibrosis
Canada, 2017). An abnormal build-up of mucous in the lungs causes respiratory
problems, as well as prevents the pancreas from digesting and absorbing nutrients (Cystic
Fibrosis Canada, 2017). Symptoms experienced by individuals with CF include persistent
coughing with increased mucous, wheezing, shortness of breath, chest infections, bowel
disturbances, failure to gain weight, and salty tasting sweat (Cunningham & Taussig,
2013). In addition to these symptoms of CF, individuals with CF may experience a wide
range of complications, such as delayed puberty (Cystic Fibrosis Canada, 2014c), fertility
problems (Cystic Fibrosis Canada, 2014b), and chronic pain (Hayes et al., 2011; Ravilly,
Robinson, Suresh, Wohl, & Berde, 1996). In addition, 22.8% of Canadians with CF have
CF-related diabetes, while 37% and 53.4% have Pseudomonas aeruginosa and Staphylococcus aureus respectively, which are strains of bacteria that cause lung infections (Cystic Fibrosis Canada, 2017).

**Diagnosis.** Over the past decade, medical advances (e.g., antibiotics, drug delivery systems, pulmonary rehabilitation, transplantation) have increased medical knowledge and understanding of CF. One major change has been the way in which individuals with CF are diagnosed (Farrell et al., 2008). In the past, individuals who had family members with CF or features consistent with CF received diagnostic testing (Farrell et al., 2008). Today, most Canadian provinces provide newborn screening for a range of specific disorders, including CF, which has led to improved early identification and diagnosis. For example, in 2016, 54.1% of all new diagnoses in Canada were made through the newborn screening program (Cystic Fibrosis Canada, 2017). After the newborn screening, a diagnostic test (e.g., sweat chloride test, DNA analysis) must be performed to confirm a diagnosis of CF (Farrell et al., 2008). Research suggests that early diagnosis and treatment improves nutrition and cognitive functioning (Farrell et al., 2005; Koscik et al., 2004), as well as helps maintain healthy respiratory function (Dankert-Roelse & Merelle, 2005; Mak, Sykes, Stephenson, & Lands, 2016), and reduces hospitalizations (Dankert-Roelse & Merelle, 2005).

**Life expectancy.** Due to these advances in the diagnosis and treatment of CF, the life expectancy of individuals with CF has increased dramatically over the past 30 years. In Canada, the median age of survival has increased from 28.4 in 1987 to 53.3 in 2016 (Cystic Fibrosis Canada, 2014a; 2017). As a result, CF is now as much an adult disease as it is a childhood disease (Wallis, 2003). With this increased life expectancy,
adolescents and emerging adults with CF are facing challenges associated with the transition into adulthood that were relatively unimportant when their average life expectancy was less than 30 years of age (Baker & Coe 1993; Moola & Norman, 2011; Palmer & Boisen, 2002; Pfeffer, Pfeffer, & Hodson, 2003). As such, there is an increased need to understand how families, educators, and mental health professionals can best support emerging adults with CF as they pursue normative tasks of becoming an adult in the context of living with a life-threatening disease.

_Treatment._ For individuals with CF, treatments may include the daily intake of pancreatic enzyme supplements, inhaled medicines (e.g., antibiotics, mucous thinners), and airway clearance (Cunningham & Taussig, 2013). Lung transplantation is an additional form of treatment for individuals with advanced CF. In Canada, 45 individuals with CF received transplants in 2016 (Cystic Fibrosis Canada, 2017). These treatments aim to control lung infections, improve the absorption of nutrients, and to clear or thin mucous (Cunningham & Taussig, 2013). CF treatments can often be time consuming. For example, Sawicki, Sellers, and Robinson (2009) found adults 18 years of age or older spent roughly 2 hours per day completing CF therapies in 10 treatment centers throughout the United States. It is possible that this need to spend so much time and energy in treatment on an ongoing basis would have profound influences on the career choices and employment requirements of emerging adults with CF. Unfortunately, there is limited existing research on connections between CF treatment and emerging adults’ career development.

_Adherence._ Adherence to CF treatments is necessary for individuals to remain healthy. Although treatment adherence is important in the management of this disease,
Modi and Quittner (2006) reported rates of overall adherence were below 50% for children with CF, between the ages of 6 and 13. Levels of adherence tend to vary across treatment components (Faint, Staton, Stick, Foster, & Schultz, 2017; Llorente, Garcia, & Martin, 2008; White, Miller, Smith, & McMahon, 2009). Research on CF patients, between the ages of 1.6 and 40.6, showed greater adherence rates for digestive and respiratory medication and lower compliance for physiotherapy and nutritional supplements (Llorente et al., 2008). Previous studies have revealed a wide array of factors influencing patterns of CF treatment adherence, including disease severity (Llorente et al., 2008; Zindani, Streetman, Streetman, & Nasr, 2006), age (Latchford, Duff, Quinn, Conway, & Conner, 2009; Llorente et al., 2008), disease knowledge (Faint et al., 2017), and treatment recommendations (Modi & Quittner, 2006; Pakhale et al., 2016). However, the results of these studies are mixed, due to differences in definitions and measurements of adherence (Kettler, Sawyer, Winefield, & Greville, 2001). Other common explanations for non-adherence included forgetfulness (Conway, Pond, Hamnett, & Watson, 1996; Modi & Quittner, 2006; Myers & Horn, 2006), time pressures (Askew et al., 2017; Conway et al., 1996; Modi & Quittner, 2006; Myers & Horn, 2006), break in routines (e.g., holidays, time away from school; Askew et al., 2017, Ball et al., 2013), and embarrassment or discomfort associated with treatment (Askew et al., 2017; Myers & Horn, 2006).

In recent years, more research has revealed the importance of the relationship between family functioning and CF treatment adherence. Research suggests that parents provide less supervision to older children, even though more parental supervision increases adherence (Foster et al, 2001; Modi, Marciel, Slater, Drotar, & Quittner, 2008;
Furthermore, DeLambo, Ievers-Landis, Drotar, and Quittner (2004) reported positive family relationships related to greater treatment adherence, specifically airway clearance and aerosolized medications. Family expressiveness, cohesiveness, and structure also contributed to greater rates of adherence in children, adolescents, and emerging adults with CF (Ball et al., 2013; Patterson, 1985; White et al., 2009), as did parental presence, positive attention, and instructions during treatments (Butcher & Nasr, 2015). These findings are consistent with literature on other chronic diseases, such as diabetes and asthma (Gavin, Wamboldt, Sorokin, Levy, & Wamboldt, 1999; Hauser et al., 1990; Lewandowski & Drotar, 2007; Miller & Drotar, 2007; Wiebe et al., 2005). In light of the fact that parental involvement is associated with better treatment adherence, it can be speculated that, for at least some families with a child with CF, a high level of parental involvement in young people’s lives is considered to be positive and normative.

**Psychological functioning.** The general psychological functioning of individuals with CF has been examined in the literature; however, the results have been inconsistent, due to different population samples and measurement instruments (Anderson, Flume, & Hardy, 2001; Duff et al., 2014; Yohannes, Willgoss, Fatoye, Dip, & Webb, 2012). Some research demonstrated relatively healthy psychological functioning (e.g., anxiety, depression, personality, and emotional disorders) in children, adolescents, emerging adults, and adults with CF (Anderson et al., 2001; Askew et al., 2017; Bahali et al., 2014; Besier & Goldbeck, 2011; Blair, Cull, & Freeman, 1994; Brucefors, Hjelte, & Hochwalder, 2011; Duff et al., 2014). However, other research has found elevated symptoms of depression and anxiety within this population (Goldbeck, Besier, Hinz,
Singer, & Quittner, 2010; Olveira et al., 2016; Quittner et al., 2014; Riekert, Bartlett, Boyle, Krishnan, & Rand, 2007; Yohannes et al., 2012). For example, Olveira et al. (2016) reported 12.2% of CF subjects, with a mean age of 28.1, had elevated depression scores and 29.7% had elevated anxiety scores. Previous studies have revealed several risk factors associated with symptoms of depression and anxiety in individuals with CF, including poor lung function (Anderson et al., 2001; Duff et al., 2014; Goldbeck et al., 2010; Quittner et al., 2014; Yohannes et al., 2012), older age (Duff et al., 2014; Goldbeck et al., 2010; Quittner et al., 2014), being female (Anderson et al., 2001; Goldbeck et al., 2010; Quittner et al., 2014), lower medication adherence (Hilliard, Eakin, Borrelli, Green, & Riekert, 2015), negative medication beliefs (Hilliard et al., 2015), changes in health status (e.g., diabetes diagnosis, hemoptysis, pneumothorax, antibiotics; Goldbeck et al., 2010; Quittner et al., 2014), career concerns (Duff et al., 2014; Yohannes et al., 2012), difficulty in interpersonal relationships (Yohannes et al., 2012), and transplant listing (Goldbeck et al., 2010; Quittner et al., 2014). Other risk factors included lack of parental warmth and family cohesiveness, expressiveness, and organization (Szyndler, Towns, van Asperen & McKay, 2005).

In addition, more research is starting to emerge regarding the relationship between parental perceptions of child vulnerability and the psychological functioning of children and adolescents with a chronic disease. Research has demonstrated that greater parental perceptions of vulnerability increased anxiety and depression in children and adolescents with chronic diseases (Anthony, Bromberg, Gil, & Schanberg, 2011; Anthony, Gil, & Schanberg, 2003; Lopez, Mullins, Wolfe-Christensen, & Bourdeau, 2008; Mullins et al., 2004). Research has focused exclusively on differences in parental perceived child
vulnerability across different disease groups, including CF (Bourdeau, Mullins, Carpentier, Colletti, & Wolfe-Christensen, 2007; Hullmann et al., 2010). Findings suggested parental perceptions of child vulnerability may vary as a result of the disease type, with parents of children and adolescents with CF reporting significantly higher levels of perceived child vulnerability than parents of children and adolescents with diabetes or cancer (Hullmann et al, 2010). Hullmann et al. (2010) speculated that the results may be due to the unpredictability and progressive nature of the disease, in addition to, hospitalizations. Nonetheless, this body of literature indicates that the psychological functioning of individuals with CF may be influenced by parental perceptions of vulnerability.

**Psychosocial functioning.** Research comparing individuals with CF to healthy control subjects suggests psychosocial functioning of individuals with CF is similar to that of the healthy population (Abbott et al., 2000; Besier & Goldbeck, 2011; Bregnballe, Thastum, & Schiotz, 2007; Britto et al., 1998; Carew, 2010; Drotar et al., 1981; Kostakou et al., 2014; Palmer & Boisen, 2002; Shepherd et al., 1990; Simmons et al., 1985). Some of this literature reports that individuals with chronic diseases are socially competent (Simmons et al., 1985), have healthy self-concepts (Bregnballe et al., 2007; Kostakou et al., 2014; Lewis & Khaw, 1982; Shepherd et al., 1990; Simmons et al., 1985), and display positive behaviors (Bregnballe et al., 2007; Kostakou et al., 2014). However, a study comparing the quality of life of CF patients, between the ages of 2 and 18, to healthy control subjects found quality of life, including emotional, physical, social, and school performance, to be low (Kianifar, Bakhshoodeh, Hebrani, & Behdani, 2013).
Kianifar et al. (2013) suggest the decreased level of quality of life may be due to the other effects (e.g., psychological, cognitive, and social aspects) of CF being neglected by healthcare providers. Similarly, Wolman, Resnick, Harris, and Blum (1994) found adolescents with CF had lower emotional well-being scores than peers without a chronic condition. Wolman et al. (1994) speculate that the results may be due to body image, family connectedness, and concerns about peer relationships. In addition, family functioning (e.g., maternal trait anxiety and overprotection) has also been found to contribute to self-esteem and behavioral problems in children and adolescents with CF (Cappelli et al., 1988; Cappelli, McGrath, MacDonald, Katsanis, & Lascelles 1989; Lewis & Khaw, 1982).

**Cognitive and academic functioning.** In the existing research on the cognitive and academic development of individuals with CF, the disease has not been systematically associated with any cognitive development deficits (Crews, Jefferson, Broshek, Barth, and Robbins, 2000; Grieve et al., 2011; Koscik et al., 2004; Stewart et al., 1995; Thompson, Gustafson, Hamlett, & Spock, 1992). In fact, in 2016 24.1% of adults with CF 18 years of age and older in the United States had a high school diploma and another 29.8% graduated college (Cystic Fibrosis Foundation, 2017). Even though CF has not been associated with cognitive deficits or academic problems, children and adolescents with CF may still experience a variety of challenges in school. As Thies (1999) discussed, the progression and treatment of CF can result in fatigue, confusion, depressed mood, anxiety, memory difficulties, and hearing impairments, all of which can impact learning, including reading, math, and problem-solving skills. Furthermore,
absenteeism may also interfere with the academic performance of individuals with a chronic disease (Thies, 1999). For example, Grieve et al. (2011) found increased school absences were associated with a lower GPA in emerging adults with CF, with participants on average missing 23.6 days of school per year. It is possible that, for some young people with CF, these academic problems may become a barrier in the pursuit of their career goal.

Since malnutrition is common among individuals with CF (Cystic Fibrosis Canada, 2015), a better understanding of how cognitive development is influenced by nutritional status has been an important focus of research attention. Previous research with other populations (Brockman & Ricciuti, 1971; Kar, Rao, & Chandramouli, 2008; Schoenmaker et al., 2015) and experimental studies with rats (Alamy & Bengelloun, 2012; Braga, Fukuda, & Almeida, 2014; Martinez et al., 2009) show that cognitive functioning deficits are strongly influenced by malnutrition. In the case of individuals with CF, Koscik et al. (2004) found children with vitamin E deficiency performed worse on cognitive outcomes compared to a control group. In addition, a delayed diagnosis of CF and unfavorable family factors (e.g., low socioeconomic status, single parent, less parental education) significantly correlated with lower cognitive scores (Koscik et al., 2004). Koscik et al.’s (2004) findings were similar to earlier research, which suggested that cognitive development may be influenced by growth and nutrition (Stewart et al., 1995).

**Parent functioning.** Results from the available literature suggest caregivers of individuals with CF have high rates of depression and anxiety (Besier et al., 2011; Besier & Goldbeck, 2011; Driscoll, Montag-Leifling, Acton, & Modi, 2009; Quittner et al.,
Specifically, Besier and Goldbeck (2011) reported elevated symptoms of depression in 26.4% of caregivers, whereas 37.7% of caregivers had elevated symptoms of anxiety. Previous studies revealed treatment regimen (Driscoll et al., 2009; Quittner et al., 2014), concern regarding life expectancy (Driscoll et al., 2009), hospitalization (Vardar-Yagli et al., 2017), changes in lung function (Driscoll et al., 2009), and the age of the individual with CF (Quittner et al., 2014) may be factors that contribute to the psychological functioning of caregivers.

Studies that have examined stress levels in parents of individuals with CF have yielded varied results. Some studies suggest parental stress is not significantly different between control groups and parents of children, adolescents, and emerging adults with CF (Quittner, Opipari, Regoli, Jacobsen, & Eigen, 1992; Walker, Ford, & Donald, 1987; Walker, Van Slyke, & Newbrough, 1992). However, other research has found increased stress levels in parents of children, adolescents, and emerging adults with CF compared to parents of healthy control subjects (Blair et al., 1994; Cousino & Hazen, 2013; Goldberg, Morris, Simmons, Fowler, & Levison, 1990). For example, Ward et al. (2009) reported 34.2% of primary caregivers reported symptoms of stress above the clinical cut-off point. Factors associated with increased levels of stress included insufficient support (Holroyd & Guthrie, 1986; Nagy & Ungerer, 1990), treatment regimen (Cousino & Hazen, 2013), poor parental and child psychological adjustment (Cousino & Hazen, 2013), the progressive nature of the disease (Holroyd & Guthrie, 1986), changes in personal identity (e.g., unable to return to work or reduced hours at work; Hodgkinson & Lester, 2002), disease-related decision-making (e.g., genetic implications; Hodgkinson & Lester, 2002), burden of responsibility (Hodgkinson & Lester, 2002; Holroyd & Guthrie,
1986), demandingness (Goldberg et al., 1990), and hospitalization (Vardar-Yagli et al., 2017). Although the research evidence is inconsistent, there are indications that having a child, adolescent, or emerging adult with CF is associated with elevated parental stress, depression, and anxiety. These are important findings, given statistical analyses of individuals with CF and their caregivers revealed elevated anxiety and depression symptoms in caregivers seem to negatively influence the psychological adjustment in adolescents with CF (Besier & Goldbeck, 2011; Quittner et al., 2014).

**Career development and cystic fibrosis.** Although the existing body of literature on career development and CF is limited, previous studies have examined employment characteristics and experiences of adults with CF, as well as connections between employment and aspects of health in this population.

**Employment characteristics.** Around the world, an increasing number of individuals with CF are entering the labour market. Specifically, 50.6% of adults with CF who are 18 years of age and older are in full or part-time employment in the United States (Cystic Fibrosis Foundation, 2017). This is consistent with research from the United Kingdom, where approximately 50% of the CF population is in full or part-time employment (Taylor-Robinson et al., 2013). Currently employed adults with CF reported working on average 32.7 hours per week (Burker et al., 2004; Burker, Trombley, Sedway, Yeatts, & Carone, 2005). Furthermore, 65% of individuals with CF who were 22 years of age and older reported working over 30 hours a week, in contrast to 24% of individuals with CF who were 21 years of age and younger (Demars et al., 2011). Most (64%) adolescents with CF, between the ages of 16 to 18, also reported working less than
20 hours per week (Demars et al., 2011).

The majority (53.4%) of employed adults with CF were found to be working in professional or managerial occupations, followed by 29.5% in clerical and sales occupations, and the rest were employed in other occupations, including hotel manager, artist, and dental technician (Burker et al., 2004; 2005). Gillen et al. (1995) reported similar findings, with 53% of adults with CF working in professional or managerial occupations. Earlier research on adolescents and emerging adults with CF found those who were currently employed held entry level occupations (Goldberg, Isralsky, & Shwachman, 1985). Despite this encouraging upward trend in employment, there is little existing literature examining career development processes in emerging adults with CF, and no known studies that have examined the emerging adults’ perceptions of parental influences on their career development. Nonetheless, this literature provides some important information about the experience of this population while engaged in their chosen career.

**Employment experiences.** Existing research suggests CF may affect occupational choice, limit or change job duties, and influence salary (Hogg et al., 2007; Laborde-Casterot et al., 2012; Targent et al., 2014). For example, Targent et al. (2014) found 47% of adults felt CF had affected their career choices, while 44% of adults with CF stopped a job and 24% had to change their job because of CF. In contrast, Demars et al. (2011) found CF generally did not affect adolescents or emerging adults’ occupational choices.

Finally, few individuals with CF have received career counselling or employment guidance (Demars et al., 2011; Gillen et al., 1995; Targent et al., 2014). Despite this lack of support, adolescents and emerging adults with CF tend to have high hopes for a
successful career (Higham, et al., 2013). Furthermore, Higham et al. (2013) concluded having a career provided emerging adults with CF a sense of purpose in life. In light of the relatively low number of published studies, it is evident that more research is needed to understand the career development of emerging adults with CF.

**Health and employment.** Results from previous research found a relationship between employment status and health-related quality of life in adults with CF (Havermans et al., 2009; Hogg et al., 2007; Targett et al., 2014). More specifically, Havermans et al. (2009) found participants who worked reported higher levels of health-related quality of life compared to those who were not working. In addition, higher levels of health-related quality of life were associated with decreased disease severity (Havermans et al., 2009). Similarly, research examining the employment in adults with CF revealed a strong association between employment status and health-related quality of life (Targett et al., 2014). Previous research has also found a relationship between higher quality of life scores and determinants of workforce participation (Hogg et al., 2007).

Multiple studies have examined the influence of lung function on employment status; however, results have been inconsistent as different analytic strategies were used (Laborde-Casterot et al., 2012). Some studies suggested that lung function is associated with employment status or vocational plans (Gillen et al., 1995; Havermans et al., 2009; Laborde-Casterot et al., 2012; Taylor-Robinson et al., 2013). However, additional factors contributing to employment status were also acknowledged, including education level (Laborde-Casterot et al., 2012), hospitalizations (Taylor-Robinson et al., 2013), social deprivation (Taylor-Robinson et al., 2013), a late diagnosis (Gillen et al., 1995), and being female and single (Gillen et al., 1995). Other research suggests that lung function is
not associated with employment status (Burker et al., 2004; Frangolias et al., 2003; Hogg et al., 2007). Instead, age (Hogg et al., 2007), time in hospital (Hogg et al., 2007), disease mastery (Hogg et al., 2007), elevated depression (Burker et al., 2004), education level (Burker et al., 2004), and optimism (Burker et al., 2004) had a greater influence. Based on this literature, it is apparent that several factors influence the employment status of individuals with CF. Relationship with parents is another important factor that needs to be considered.

**Relationship attachments and processes in career development.** A large amount of research has been conducted on the career development and attachment relationships in healthy populations (e.g., Domene et al., 2012; Kvitkovicova, Umemura, & Macek, 2017; Wolfe & Betz, 2004; Young et al., 2006). Of particular relevance to the present study, Kvitkovicova et al. (2017) examined the role of attachment relationships with parents, friends, and romantic partners in emerging adults’ career development. Using a longitudinal study design, results revealed all attachment relationships were associated with emerging adults’ career development; however, romantic partners were the only kind of attachment relationship that was associated with the career decision-making process over time (Kvitkovicova et al., 2017). Additional research, focusing on the process of career through joint actions, has found parents and youth engage in a variety of career development projects during the transition to adulthood (Domene, Arim, & Young, 2007; Marshall et al., 2011; Young et al., 2001a; 2001b; 2006; 2008; 2011; Young, Ball, Valach, Turkel, & Wong, 2003). These included projects focused on promoting relationships, autonomy, and independence (Domene, Arim, & Young, 2007),
as well as taking on responsibilities, life experiences, and skills (Young et al., 2008). However, the existing literature on relational processes in career development has not explored the potentially distinctive aspects of career development in emerging adults with CF, which may exist due to the specific experience of growing up with this disease.

**Conclusion**

With an increased life expectancy, in the 21st century emerging adults with CF can plan on leading adult lives much like their peers, but with the unique experience of doing so while managing a life-threatening disease. Due to the unpredictable nature of the disease, transitions, such as career, may raise questions of identity and/or purpose of life at the forefront. Given emerging adults with CF are engaging in normative tasks with the reality that their bodies carry a life-threatening condition that requires careful monitoring and time-consuming, on-going medical attention, there may be common as well as distinct patterns of joint action that uniquely influence career development in this population. In order to expand the literature on how families and professionals (e.g., universities, career counsellors, mental health counsellors) can best support these transitions, this study focused on exploring the kinds of career development focused, goal-directed processes emerging adults with CF engage in with their parents using the framework of CAT.
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Chapter 2: Career Development Projects and Actions of Emerging Adults with Cystic Fibrosis and their Parents: A Qualitative Exploration

Consistent with the UNB School of Graduate Studies’ regulations and guidelines for manuscript style theses, Chapter 2 has been written in the form of a journal article manuscript. Specifically, it has been written to conform to the submission requirements of the journal Qualitative Health Research, which can be found at https://us.sagepub.com/en-us/nam/journal/qualitative-health-research#submission-guidelines

Abstract

This study explored the ways in which emerging adults with cystic fibrosis (CF) engage in joint goal-directed processes related to career development with their parents, from the perspective of the emerging adults. The conceptual framework of contextual action theory (Young, Valach, & Domene, 2005), as well as the methodological procedures of Stake’s (2005) multicase study approach and Young et al. (2005) action project method, were used to address the following research question: How do emerging adults with CF describe their career development in terms of joint goal-directed actions in the context of their relationship with their parents? Analyses revealed several unique processes and experiences, as well as two common themes in the career development process of the three emerging adults with CF who participated in the study: parental support and health.

Key Words
Career development, cystic fibrosis, emerging adulthood
Career Development Projects and Actions of Emerging Adults with Cystic Fibrosis and their Parents: A Qualitative Exploration

Cystic fibrosis (CF), a disease mainly affecting the lungs and the digestive system, was historically known as a childhood disease, as few children with CF survived into adulthood (Palmer & Boisen, 2002). Medical advances in diagnosis and treatment have increased survival rates among those living with CF, with Canada’s current median age of survival being one of the highest in the world (Cystic Fibrosis Canada, 2017). With this increased life expectancy, more individuals with CF are able to reach emerging adulthood and pursue education and/or employment.

Career development is an important aspect of emerging adulthood, the developmental period from 18 years to 29 years of age, in which individuals form their vocational identity and explore educational and occupational possibilities (Arnett, Zukauskiene, & Sugimura, 2014; Domene, Landine, & Stewart, 2015). For healthy individuals, emerging adulthood can be a challenging period of time, as behavioral problems and psychological disorders increase (Arnett, 2015). Having a life-threatening disease, such as CF, may further complicate emerging adulthood, as emerging adults try to manage the demands of their disease, as well as the transition to adult medical care, all while attending to the typical developmental tasks in this distinct phase of the life span (Baker & Coe, 1993; Gravelle, Davidson, & Chilvers, 2012; Palmer & Boisen, 2002).

The limited existing body of research on career development in adolescents, emerging adults, and adults with CF provides important information about the experiences of this population. For many adults, the unpredictable and progressive nature of this genetic disease may influence the type of work they pursue (Hogg, Braithwaite,
Employment may also be complicated by disclosure to employers (Demars, Uluer, & Sawicki, 2011; Higham, Ahmed, & Ahmed, 2013), clinic appointments (Demars et al., 2011; Targett et al., 2014), hospitalizations (Askew et al., 2017; Demars et al., 2011), and management of symptoms and complex treatment regimens at work (Askew et al., 2017; Demars et al., 2011). Despite these challenges, few individuals with CF receive any formal career counselling or guidance (Demars et al., 2011; Hogg et al., 2007; Gillen, Lallas, Brown, Yelin, & Blanc, 1995). However, research suggests that adolescents with CF hold strong work values compared to their healthy peers (Goldberg, Isralsky, & Shwachman, 1979).

There is an extensive body of research on how relationships influence career development (Whiston & Keller, 2004). Similarly, research examining transition to adulthood tasks with parent-adolescent dyads without CF revealed that career development is constructed in part through the joint goal directed actions and projects of parents and adolescents (Domene, Arim, & Young, 2007; Marshall et al., 2011; Young et al., 2001; Young et al., 2006; Young et al., 2008; Young et al., 2011; Young, Ball, Valach, Turkel, & Wong, 2003). Specifically, Young et al. (2006) found families who experienced substantial challenges (e.g., chronic disease, unemployment, single parent) identified parent-adolescent relationship projects, a shift from career development to relationship projects, and communication projects as some of the ways by which the dyads worked toward career development goals. Although awareness of the centrality of relationships in career development continues to grow (Young et al., 2011b), the potentially distinct aspects of how emerging adults with CF formulate and pursue career
goals in relationship with other members of their family has yet to be addressed. This gap in the literature is problematic, in light of the fact that parents of emerging adults with CF are involved in the lives of those individuals in ways that are distinct from how parents typically are involved in the lives of emerging adults without CF (Ball et al., 2013; Besier & Goldbeck, 2011; Hullmann et al., 2010; Iles & Lowton, 2009). The unique relational parent-emerging adult dynamics that occur in the context of CF may extend to how parents and emerging adult children with CF engage with each other around the emerging adult’s career development.

The Present Study

It is evident that there is a need for more in-depth examination of the relational processes involved in the career development of emerging adults with CF. Grounded in contextual action theory (CAT), the present study explored this phenomenon by conceptualizing career development as a joint, goal-directed process that occurs between emerging adults and their parents. Using the multicase study approach (MSA; Stake, 2005) and action project method (APM; Young, Valach, & Domene, 2005), this study examined how three emerging adults with CF perceived the ways in which they engaged with their parents in joint goal-directed processes related to career development. Therefore, the guiding research question for this study was:

_How do emerging adults with CF describe their career development as joint goal-directed action in the context of their relationships with their parents?_
Method

Methodological Framework

This study aimed to increase knowledge and understanding of career development in emerging adults with CF by investigating joint career development processes in the parent-emerging adult relational context from the perspective of emerging adults with CF. Given the lack of existing research on the subject an exploratory, qualitative method was used. Specifically, this study was informed by CAT (Young et al., 2005) and conducted using procedures drawn from Stake’s (2005) MSA and Young and colleagues’ (2005) APM.

CAT holds underlying assumptions that position it within the paradigm of constructivism, including relativist, socially-constructed ontological and epistemological assumptions, and an acknowledgement that the researcher’s values will enter into the research process (Socholotiuk, Domene, & Trenholm, 2016; Young et al., 2005). The specific MSA and APM methods that were used to collect and analyze the data are also both located within the constructivist paradigm, which allowed the two sets of procedures to be used together with minimal conflict. CAT also assumes that goal-directed action is central to human experience. Specifically, the theory proposes that human experience can be understood from the levels, perspectives and systems of action described in Chapter 1.

Participants and Recruitment

The cases that made up the sample consisted of one woman and two men, all of Caucasian descent. All three participants received an introductory letter (see Appendix
A), and underwent a telephone screening interview (see Appendix B) to ensure they met the inclusion criteria: (a) have a CF diagnosis, (b) aged 19 to 29, (c) live in the lower mainland of British Columbia, and (d) be fluent in English. Participants’ ages ranged from 22 to 28 years \( (M = 25.33, SD = 3.06) \). Age at diagnosis with CF ranged from before birth to 2 years of age. Two participants lived with their parents and one participant lived with her son. One participant had completed a bachelor’s degree, one participant had a high school diploma, and one participant did not graduate from high school. All participants were employed. None of the participants had ever received career counselling, even though two participants indicated that living with CF has required them to change their work schedules.

After completing institutional ethics review, participants were recruited through posters (see Appendix C) and advertisements (see Appendix D) on the Facebook account of Cystic Fibrosis Canada, Western Canada, and to the volunteer section of Craigslist in communities throughout the lower mainland region of British Columbia. Other recruitment strategies included word of mouth and snowball sampling. A purposive recruitment strategy was used, where only those individuals with CF who met the inclusion criteria were selected. Participants were offered remuneration in the amount of a $25 prepaid credit card after the initial interview, as an expression of gratitude for their involvement and to offset the cost of travel and time away from other activities.

**Research Team**

The research team for data collection included the first author and two research assistants. The first author was involved with interviewing all three participants. The first
The first author is a master’s student in a Counselling program located in New Brunswick. She has 5 years of experience and training in data collection and analysis using a range of qualitative and quantitative research methods through her involvement as a research assistant. Her research supervisor trained her in CAT, APM, and MSA for this study. The first research assistant was a male student in a Counselling Psychology master’s program in British Columbia. This research assistant was using CAT, APM, and MSA for his own research, and was trained by the research supervisor in regards to its application for this study. The second research assistant was a female social worker practicing in the lower mainland of British Columbia. This research assistant was not familiar with CAT, APM, or MSA and was trained by the first author.

The research team for data analysis included the first author, a research assistant, and the research supervisor. The research assistant was a female master’s student in a Counselling program located in New Brunswick. She learned CAT, APM and MSA from the research supervisor for this study. The research supervisor was a male professor in the Faculty of Education at the University of New Brunswick. The professor has over a decade of experience using APM in career development research with adolescents and emerging adults (e.g., Domene et al., 2007; Domene et al., 2015; Domene et al., 2012; Domene, Socholotiuk, & Young, 2011). Apart from the first author, none of the analysis team was involved in data collection.
Data Collection

Data were collected through multi-part individual interviews that focused on participants’ manifest behaviour, internal processes, and social meaning (Young et al., 2005). These interviews took place at locations that were mutually convenient—the public library (n = 1) and participants’ homes (n = 2). The primary interview consisted of four stages: warm-up, joint conversation, self-confrontation, and debrief. The average duration of each part of the interview is presented in Table 1.

Table 1

Duration (hours/minutes/seconds) of Research Interviews

<table>
<thead>
<tr>
<th>Case</th>
<th>Warm-up</th>
<th>Joint Conversation</th>
<th>Self-confrontation</th>
<th>Member Check</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>00:13:53</td>
<td>00:18:25</td>
<td>00:40:40</td>
<td>00:03:38</td>
<td>1:16:36</td>
</tr>
<tr>
<td>2</td>
<td>00:12:40</td>
<td>00:25:36</td>
<td>01:08:38</td>
<td>00:07:28</td>
<td>1:54:22</td>
</tr>
<tr>
<td>3</td>
<td>00:07:35</td>
<td>00:17:50</td>
<td>00:40:24</td>
<td>00:06:21</td>
<td>1:12:10</td>
</tr>
<tr>
<td>Total</td>
<td>00:34:08</td>
<td>01:01:51</td>
<td>02:29:42</td>
<td>00:17:27</td>
<td>4:23:08</td>
</tr>
</tbody>
</table>

Warm-up. In the first stage of the primary interview, participants engaged in a warm-up interaction with the first author and a research assistant. At this stage, participants were asked to describe their career to date and explain their career aspirations and goals. The purpose of the warm-up was to elicit information that reflected the participant’s social and life context, while establishing rapport, preparing participants to think about the topic of interest, and giving participants time to become comfortable with the video equipment.
Joint conversation. Next, participants engaged in a video- and audio-recorded conversation with the first author, to discuss their parents’ involvement with their career development process. The interview protocol for the joint conversation consisted of broad questions (e.g., Tell me what it is like to live with CF?), as well as follow-up probes to elicit information reflecting the manifest behavior and social meaning perspectives on action (e.g., Can you tell me the story of how your parents have been involved in your career planning? See Appendix E). During the joint conversation, the interviewer kept track of when the participants began to talk about their experience of their parents in the career development process, as this was the starting point for the self-confrontation procedure.

Self-confrontation. Following the joint conversation, participants reviewed the video recording of their joint conversation with a research assistant, starting at the time when the participant began to talk about his or her experience of parental involvement in the career development process. During this review, the research assistant stopped the video approximately every minute and asked the participant to comment on the thoughts, feelings, and intentions that he or she had experienced during that segment of the joint conversation. This self-confrontation elicited information on the internal processes perspective on action.

Debriefing. At the end of the primary interview, participants were debriefed. This debrief consisted of (a) asking participants if they had any questions; (b) having the participants complete the demographics form; (c) providing the participants with the $25 honorarium; and (d) obtaining information to contact participants for the member-checking interview.
Data Analysis

**Preliminary data analysis.** The first author transcribed the audio and video recordings from all stages of the interview. The recordings were transcribed verbatim, including all pauses and non-word utterances. The first author and research assistant coded the transcripts according to APM data analysis procedures (Young et al., 2005), discussing differences in perspective until a consensus opinion was reached. The interviews were analyzed according to the three levels of action described by CAT: elements, functions, and goals. To begin, the elements of action were identified and coded using an existing list of action elements (see Appendix F), which has been used in previous APM studies (e.g., Socholotiuk, 2015; Wilson, 2015). The transcripts of the self-confrontation interview were also read to identify additional information related to the goals, the functional steps, and levels of action. From the identified elements and functional steps, the individual and joint goals were derived, followed by the overall goals of the entire action sequence. Although this process is described in a linear manner, the actual implementation of the analysis is more circular, with the researchers moving back and forth between the levels of action and, as needed, modifying the codes from earlier stages (e.g., elements) based on the interpretations that emerged at later stages (e.g., overall goals) and using all parts of the interview to inform all parts of the analysis process.

Using the results of this data analysis, the first author wrote a preliminary narrative description of each participant's career development project (see Appendix G), focusing on their joint actions with their parents in the pursuit of these projects. These narratives were reviewed in terms of plausibility and completeness of description by a
research assistant and the professor who were part of the research team. These preliminary narratives were modified using feedback from this review stage.

**Member-checking interview.** Approximately 3 months after the initial meeting, the first author and each research participant met again for a member-checking interview. Two member-checking interviews were conducted over the phone (n = 2) and one at the participant’s home (n = 1). Member-checking included discussing ongoing informed consent and reviewing the content of the participant’s preliminary narrative, using a protocol consistent with previous APM studies (see Appendix H). The aim of reviewing these narratives was to obtain feedback, and to make corrections to the narrative, based on the participant's understanding of what was written and their own understanding of their experience. No major changes were requested, although one change was made to specific factual information in the narrative of Participant 1, based on the feedback from this participant.

**Final data analysis.** In the final stage of analysis, an exploration of themes that were present across all the cases was conducted using a combination of Young et al.’s (2005) APM and Stake’s (2005) MSA. This included reviewing the demographic information, transcripts of all stages of the initial interview, narrative summaries, and the information collected at the member-checking interview using a two-stage process.

**Within-case analysis.** APM and MSA both emphasize the importance of developing an understanding of the phenomenon as it occurs within an individual case prior to exploring patterns across different cases. In CAT, uniqueness within a project is assumed, while the MSA aims to display the exceptionalities of each case (Stake, 2005). This involved understanding the specific career development project that each participant
reported engaging in with his or her parents, as it occurred within the specific life context of that individual (Stake, 2005). The within-case analysis involved close re-reading of the preliminary data analysis notes and narrative descriptions, to identify key patterns of action and the career development project that the participant experienced.

**Cross-case analysis.** Although the APM and MSA emphasize the importance of within-case analysis, both methods also include procedures for identifying patterns that are present across a set of cases. Using procedures from APM and MSA, a cross-case analysis was implemented to reveal additional information about the jointly enacted processes of career development in emerging adults with CF and their parents. This was accomplished by reviewing the entire set of information for all three cases to identify similarities and salient unique processes throughout the experiences described in each case. The cross-case analysis yielded two themes that were common across the three participants, as well as several noteworthy experiences that were unique to one participant (see Findings).

**Rigour and Validation**

**Sufficiency of information.** Constructivist methods require a sufficient amount of information to be collected for meaningful interpretations to be made (Socholotiuk et al., 2016). In the present study, multiple sources of data were used, including demographic information, transcripts of conversations, video-recordings, and transcripts of participants’ self-confrontations. These multiple sources of data permitted an in-depth understanding of the phenomenon of interest.
Adequacy of interpretation. Issues surrounding the credibility of a qualitative study often depend on the engagement of the researcher (Morrow, 2005; Socholotiuk et al., 2016). The first author was involved in all aspects of this study, including recruitment, screening, data collection, transcribing, and data analysis. The first author’s personal experience of growing up with a sibling who had CF and parents who were involved with that sibling’s career development also informed her understanding of the jointly enacted projects involved in career development, as reported by emerging adults with CF.

Addressing subjectivity. Since constructivism assumes a values-mediated approach to research (Socholotiuk et al., 2016), the first author’s relationship with the topic needs to be considered. The first author’s relationship with the topic and underlying values assumptions are presented below, for readers to assess the trustworthiness of the findings in light of her values/experience.

Relationship to the topic. The first author’s interest in the topic of career development among emerging adults with CF stemmed from growing up with a sister who had CF, and who dropped out of post-secondary education due to the progressive nature of the disease. As the first author was not diagnosed with CF, she does not have first-hand knowledge of what it is like to pursue a career with CF. However, based on her experience living with an emerging adult who had CF, at the beginning of the study she assumed the parental relationship would be an integral part of these emerging adults' career development. This assumption was based on conversations with her own parents, as well as comments from other individuals with CF whom she has met. Overall, the first author believed that parents tend to influence the career development of this population
by being overprotective, which limits their ability to develop career-related interests, skills, and abilities needed to enter fields of work. She also believed that parents may try to influence the type of careers pursued by this population. More specifically, she thought parents may encourage emerging adults with CF not to pursue careers in construction, health care, or social services, due to the symptoms associated with the disease.

Due to the small CF community in the lower mainland of British Columbia, the first author’s family knew the families of 2 of the participant’s through the CF parent support group. Specifically, the author’s mother developed a close friendship with the mother of one participant, as they often worked together at fundraising events for many years.

Findings

The cross-case and within-case findings are presented below to ensure confidentiality; all personal identifying information has been removed or altered. During the discussion of informed consent, all the participants chose not to be identified by a pseudonym. However, to comply with the policies of this journal, numbers were assigned to each participant in lieu of their own names.

Within-case Analysis: Participant 1

At the time of the first interview, Participant 1 was a 26-year-old man who had been diagnosed with CF when he was 6 to 8 months old. Participant 1 was born in Canada and was living at home with both of his parents. He had received a Bachelor’s degree in journalism and was working full-time as a marketing coordinator. Having CF
caused Participant 1 to make changes to his work schedule. Despite these changes, Participant 1 had not received any career counselling.

**Patterns of action.** Early in the joint conversation portion of the interview, Participant 1 explained that when he first agreed to participate in this study he believed that CF did not affect his career development too much, due to the instrumental role that his parents played. Participant 1 went on to note that CF has played a minor role in his occupational choice and the need for accommodation in the workplace. Other topics discussed included how the participant and his parents generally think alike. Participant 1 went on to note that, even when they disagree, he felt that his parents supported the decisions he made. For example:

...they’ve always tried to, um, reassure me that we’re not, we may not always agree and ultimately what you decide is what you decide, but...we’re just going to do everything in our power to help guide you...to a better place.

Further into the conversation, Participant 1 explained the discussions he has had with his parents. During this conversation, he mostly talked about his mother, but corrected himself at the end to also include his father. Participant 1 acknowledged this afterwards, and came to the realization that his mother may be more involved in his career development, “I feel it might be true to say that my mom has been a lot more involved in the care than my dad.” Participant 1 seemed to struggle with finding the words to accurately describe the career-related conversations he has had with his parents, but after thinking out loud and processing his thoughts, he stated that open conversations were one of the most important things he did with his parents, in regards to his career
development, “my parents have always been open that way…[they] really embody the principle of there are no stupid questions.”

Participant 1 continued to acknowledge the collaborative nature of his discussions with his parents in other ways. For example, he reported talking with his parents about the advantages and disadvantages of situations. Despite the collaborative nature of these discussions and his desire to present his parents in a positive light, Participant 1 also seemed to experience some conflict, noting how his parents’ involvement can be irritating at times, “so there was part of that was like, um, I want to present my parents in a nice way…but at times I might be understating that it can be very irritating.” Even with this conflict, Participant 1 described how grateful he was to use his parents as a sounding board.

**Career development project.** The joint project that was presented to Participant 1 for validation at the member-checking interview was: *Maintaining an open and collaborative relationship with his parents.* Participant 1 did not request any changes to this career development project.

**Within-case Analysis: Participant 2**

At the time of the first interview, Participant 2 was a 22-year-old man who had been diagnosed with CF when he was 2 years old. Participant 2 was born in Canada and was living at home with both of his parent’s. He had received a high school diploma and co-owned a dance studio with his mother, where he was working full-time as a dance teacher. Having CF caused Participant 2 to make changes to his work schedule. Despite these changes, Participant 2 had not received any career counselling.
Patterns of action. Early in the joint conversation, Participant 2 noted that there were times when his career negatively impacted his treatment adherence, “…like I was talking to you earlier about [dance] we go till like 1am in the morning sometimes, so when I get home I’m obviously not trying to for like a hour long session of physiotherapy.” However, Participant 2 explained that his mother played an instrumental role in helping him manage CF, while he pursued and advanced his career. In addition to helping him initiate career opportunities,

as soon as I knew that I wanted to start teaching she’s like all right I got you like one to two jobs already…she took the initiative to let me know the information, so I was able to contact them.

At first, Participant 2 had some difficulty selecting one example that encompassed everything his mother did to help him in his career development “I was just trying to think of a good, one example out of like 100s and 100s of things that she helps me with,” but eventually Participant 2 reported feeling emotional after reflecting upon the help he had received, “it’s always a little emotional…knowing that you’re getting a lot of help that hasn’t been asked for.” Other topics discussed in the joint conversation included the amount of work Participant 2 has put into the company where he works, and the seriousness with which he takes his work responsibility. Participant 2 viewed this as a way of honoring and paying back his mom’s support, “I try to give back to her in the effort I put into the studio.”

Further into the joint conversation, Participant 2 explained the collaboration between him and his mother, specifically involving owning a company together. During this conversation, Participant 2 explained how he and his mother play off each other’s
strengths. Participant 2 went on to note how grateful he was for the amount of collaboration he has engaged in with his mother, in regards to running the company, and how this relationship made him feel comfortable expressing his own opinions, “we’re not afraid to tell each other when something is a bad idea, um, we’re also not afraid to put our ideas forth.” Participant 2 explained that this collaborative relationship is the reason why their company is flourishing.

Participant 2 also acknowledged the importance of communication between him and his mother. Their communication included (a) listening to one another, (b) giving each other a different perspective and (c) being assertive. Participant 2 identified communicating with respect as one of the most important things he did with his mother, in regards to running a business together:

the respect factor is huge too because me understanding that she’s had like 30 something years of doing this, so her opinion is not anything to be taken lightly.

Despite being able to effectively communicate with his mother, Participant 2 acknowledged that they still have disagreements. Participant 2 went on to explain that, even when he and his mother disagree, they are able to work through it and he feels supported by his mom in the decisions that he has made.

Career development project. The joint project that was presented to Participant 2 for validation at the member check interview was: Maintaining a collaborative relationship with your mom that was built on trust and strong communication. Participant 2 did not request any changes to the career development project.
Within-case Analysis: Participant 3.

At the time of the first interview, Participant 3 was a 28-year-old female who had been diagnosed with CF during her mother’s pregnancy. Participant 3 was born in Canada. She was living with her nine-year old son and was divorced. Participant 3 did not graduate high school, but completed a make-up program. At the time of the interview, Participant 3 was a full-time stay at home mom and was debating whether she wanted to pursue a career as an aesthetician or go back to school for bookkeeping. She had not received any career counselling.

Patterns of action. Participant 3 explained how it was challenging to pursue a career once she graduated from a make-up program, while trying to balance motherhood and her treatment regime. Furthermore, Participant 3 stated that it was difficult having CF and raising her son before she had a double lung transplant, “it was difficult for sure because I was so sick and then you’re trying to take care of a child, it was, it was hard.” Participant 3 also noted that she received a lot of assistance from her parents, “She helps out a lot, they both helped out a lot with my son when I was sick.” Participant 3 went on to explain how her parents influenced the way she has raised her son, and that she shared a lot of parenting similarities with her dad. Participant 3 reported that both of her parents served important and positive roles in her life, despite their different parenting styles. Participant 3 explained how difficult it was for her parents to raise two children who had CF, and seemed to perceive that the person she has become was partly due to their strength. For example:

P: ... like when you have a sick child it can tear parents apart,

I: Mhmm.
P: right, like it’s so hard, right. And they stuck through it, so. I think it’s pretty amazing.

I: Yah and it, I can hear when you’re saying it, like the strength that they had

P: Yah.

I: you’re carrying, you’re carrying

P: Mhmm.

I: some of that strength and

P: Yah.

I: it’s, it’s been a part of who you are.

P: 100%, yah. No, definitely.

I: It’s like really established who you are now.

P: Yah, absolutely.

Other topics Participant 3 discussed included the valuable role volunteering has played in her life.

Further into the joint conversation, Participant 3 described what her parents have done to support her. This included looking after her son, “she was a huge help in that regard. She would, you know, watch him usually a couple hours after school for me” and respecting her parenting practices “they’ve always been a huge support with my parenting.” Participant 3 expressed appreciation for her parents’ help, noting how she would not have been able to do what she has done without them.

Participant 3 initially struggled with finding the words to accurately describe the kinds of discussions she has had with her parents, but after thinking out loud and processing her thoughts she was able to briefly recollect conversations regarding the
General Equivalency Diploma, future careers, and motherhood. Participant 3 explained she was generally on the same page as her parents, “I always wanted to go back and get my grade 12, like that’s what they really wanted me to do and I, I did want to do that,” but they also had discussions in which they had different opinions “so my dad was like, didn’t want me to have the baby.” However, even when her and her parents did not agree initially, she still felt accepted and supported by them afterwards, “like they were obviously not super stoked in the beginning, but they accepted [the pregnancy] and they were, they were great about it.”

Career development project. The joint project that was presented to Participant 3 for validation at the member check interview was: Raising and parenting your son, with the support of your mom. Participant 3 did not request any changes to the career development project.

Cross-case Analysis

The cross-case analysis revealed two overarching themes that were relevant to all of the participants: (a) parental support and (b) health. In addition, the cross-case analysis revealed four unique processes that were distinct to individual participants, but were nonetheless informative in understanding how emerging adults with CF and their parents may engage together around career development.

Parental support. Parental support was a theme that was described by all of the participants as central to their career development. Support seemed to be initiated by parents in response to a perceived need or a direct request. This theme is demonstrated in the following statements from Participant 3:
I: And with the babysitting, um, like did they offer to babysit, was there a conversation around...

P: Um, I think most of the time I would just ask them, like you know

I: Mhmm.

P: they, they were totally like that, like

I: Right.

P: anytime I needed help just ask, so.

I: Right.

P: Yah, I’m sure they would of offered, they probably offered too, like it was a general offer, like hey if you ever need help or whatever, so.

Although participants’ career development projects included the experience of parental support, the type of support that was provided (i.e., treatment-related, tangible, emotional, informational support) varied with each case. Treatment-related supports included reminding emerging adults about treatments and picking up medications. Examples of tangible support included transportation to and from appointments and/or work, meal preparation, babysitting, and help navigating the medical system, whereas emotional support included listening to job prospects, being respectful, and providing encouragement. Parents also provided informational support, such as suggestions or new perspectives. Furthermore, in understanding the nature of parental support, it should be noted that the relationships between these emerging adults with CF and their parents included descriptions of disagreements that participants experienced on occasion. However, all participants explained that they felt supported by their parents after these moments of disagreement.
All of the participants also described experiencing internal processes characterized by feelings of gratitude in response to parental support. This theme and its associated internal processes were evident in the conversation with Participant 2:

P: *I think without her help*

I: *Mhmm.*

P: *I probably wouldn't be in the position that I am because I just, I don't think I would be able to handle all these physiotherapy sessions and everything and do the amount of practice and teaching I need to do to sustain the career that I have*

I: *Right.*

P: *If I didn't have her help with just things like oh having some food ready to go when I wasn't even expecting*

I: *Hmm.*

P: *to eat that day.*

I: *Hmm.*

P: *Or, uh, giving me rides to places when she very well could just be like no take the bus because I have stuff to do today, but she, she’s really given just as much to helping me achieve what I want to achieve, uh, as I have.*

Although feelings of gratitude were observed in the support projects of all the participants, the support that Participant 2 experienced was associated with internal experiences of gratitude and guilt. Feelings of guilt for this participant were identified in reference to the high degree of support that he had received from his mother. For example:
I: And have you asked your parents for help?

P: Oh yah, plenty of times. I’ve asked them for even just those little things. I’ve asked her like, I feel bad about it, but sometimes you just have to and it’s like can you please just like cook some food.

Health. Intertwined with all of the career development projects was an overarching theme focused on the emerging adult’s health. This theme typically included exploring and discussing information around accommodations in the workplace, how CF may affect occupational choice, the challenges of travelling for work, and balancing work with complex health needs specific to CF. As Participant 1 stated:

P: It would be like hey I found this really cool job, um, and I was thinking of applying, and my mom would be like okay well tell me more about it.

I: Right.

P: So I would be like oh well it’s in this location, this is what I would be doing, and this is like, you know, whatever salary or, and she’d be like okay well, you know, would this in any way like affect your health, like is it in a warehouse, is it somewhere that you’d have to travel a lot, is it, so it’s kind of that back and forth conversation.

Unique processes. All participants’ career development projects included a focus on the parent-emerging adult relationship; however, the role that parents played in the career development project varied with each participant. In one case, the participant focused on the relationship with her mother and father, despite the death of her father 3 years ago. The influence of both relationships was particularly important to Participant 3 because of the different functions that her mother and her father served in her life. In the
other two cases, the participants mainly focused on the relationships with their mothers. Participant 1 explained that his mother may be slightly more involved in his care than his father, while Participant 2 stated that his father’s primary role was to assume financial responsibility for the family. As a result, the father was often out of town for work and less available to provide supports beyond financial support.

Another process that varied among the cases was the emergence of internal conflict related to receiving parental support. This internal conflict was uniquely experienced by Participant 1; this contrasted with the narratives of the other two participants, whose internal processes primarily reflected gratitude and pleasure. To demonstrate this career development process, a quote from Participant 1 has been included:

P:  *Am I doing my exercise, am I doing my, you know, she asks me all the time are you doing this, are you doing that, are you taking your medicines, did you remember to do your physio, did you remember to do your polyzynme, and, you know, which sometimes obviously as irritating as that is...*

I:  *Yep.*

P:  *I also, it’s like no it’s because you care, you want me to be healthy.*

I:  *Mhmm.*

P:  *And sometimes I do forget things.*

I:  *Yah, life gets busy.*

P:  *So, you know, so I’m okay with that.*

In this instance, Participant 1 expressed irritation in regards to his mother’s support, while simultaneously acknowledging and appreciating her effort. Upon reflection,
Participant 1 shared how this conflict was facilitated by the desire to portray his parents in a positive light.

Additionally, a variety of processes emerged for Participant 3 that contrasted with the career development processes of the other two participants in this study. Unlike other participants for whom parents were the primary source of support, Participant 3’s support system included her parents, ex-husband, and in-laws. Participant 3 referred to this support system as a “village.” The presence of a village may be connected to the fact that she was the only participant who had a child (and therefore, had an ex-husband and in-laws). Participant 3 also differed from the other participants in terms of volunteer work. She explained volunteering gave her a sense of purpose and the ability to look outside of her own situation while she was not able to pursue work. It also is worth noting that Participant 3 was the only participant in this study who had received a double lung transplant, and thus may offer a case example of some of the career development processes and projects that can occur between parents and emerging adults with CF who also received a lung transplant.

**Discussion**

The findings of this study indicate that emerging adults with CF engage with their parents in joint goal-directed processes related to career development. Additionally, participants worked together with their parents on projects related to their career development. The joint nature of the career development process was also reflected in participants’ actions, with all participants actively discussing their career with their parents. This is consistent with previous findings reported in the literature, that career
development in adolescence is a family project (Domene et al., 2007; Young et al., 2003; Young et al., 2001b).

Several relevant studies highlight the ways in which immediate family members (e.g., parents, siblings; Schultheiss, Kress, & Manzi, 2001; Young, et al., 2011a; Young et al., 2008) and other important individuals (e.g., counsellors, friends, neighbors, coworkers, relatives, teachers, romantic partners; Domene et al., 2012; Schultheiss et al., 2001) play a role in the career development of individuals without chronic illnesses. The findings of the present study extend this body of work by demonstrating that relational factors are also important to consider in the career development of emerging adults with CF. All three participants in this study identified parents as an important relational influence in their career development. From the emerging adults’ perspective, their parents supported and collaborated with them as they planned for their future careers. One participant also described her ex-husband and former in-laws as a core part of her support system. Relational influences beyond parents may be particularly important for emerging adults with CF who are recovering after a lung transplant. Alternatively, it could be that relational influences beyond parents may be particularly important for emerging adults with CF who also have children. Or the factors contributing to emerging adults’ decision to involve their ex-spouses and in-laws in their career development may not have been revealed in the interviews. Future research, using methods designed to establish causality among variables, is necessary to explore this issue further.

Parental support was described by all of the participants as central to their career development projects. Monitoring treatments, picking up medications, transporting participants to and from appointments and/or work, preparing meals, babysitting, and
navigating the medical system were commonly cited activities by parents, from the emerging adults perspective. Participants explained that such activities supported their disease management and treatment tasks, impacting their ability to work. Consistent with the present research, Barker, Driscoll, Modi, Light, and Quittner (2012) and Graetz, Shute, and Sawyer (2000) found families provided treatment related support to adolescents with CF. Despite these findings, parental support for disease management and treatment tasks is largely absent from the career development literature. Instead, this literature emphasized activities that facilitated career development, such as giving information, advice, suggestions, discussions, assistance, and feedback (Young, Friesen, & Pearson, 1988). Although similar activities, such as giving suggestions and new perspectives, were found among parents and emerging adults with CF, the results from this research highlighted the importance of parental support activities related to disease management and treatment tasks in the facilitation of career development for emerging adults with CF.

Existing literature suggests that health-related projects are intertwined in both parenting projects (Young et al., 2000; Young et al., 2001a) and work projects (Young et al., 2011b). For example, research has found parents and youth work together on health related projects, including recovery from adolescent depression (Wilson, 2015), weight restoration in adolescent anorexia (Socholotiuk, 2015), skin cancer prevention (Young, Logan, Lovato, Moffatt, & Shoveller, 2005), and recovery from addiction (Graham, Young, Valach, & Wood, 2008). In the present study, the desire to remain healthy guided the way in which parents and emerging adults with CF jointly engaged in career
development projects, which reveals a need to consider health projects together with work projects for emerging adults with CF.

This study illustrates the strong connection between communication and action in CAT (Young & Valach, 2016). For all three participants, career development was facilitated by communication, characterized by collaborative, open discussions between parents and emerging adults with CF. Consistent with the present study, Young and colleagues (2006) found adolescent career development was enhanced through communication between adolescents and their parents of families with and without challenges (e.g., chronic disease, unemployment, divorce). Consequently, these findings further emphasized the view of CAT that communication is a means through which goals are reached (Valach, Young, & Lynam, 2002).

While all participants in this study identified parents as an important influence, the specific role parents played in the career development projects of emerging adults with CF varied. Based on existing literature about the parental experiences of caring for a child with a chronic disease (e.g., Goble, 2004, Hovey, 2003), it is not surprising that two of the three participants’ mothers were more involved than their fathers in their career development projects. Research has revealed mothers and fathers of children with a chronic disease typically assume the roles of caregiver and provider, respectively (Goble, 2004, Hovey, 2003). This finding is further supported by broader literature suggesting mothers take on different roles than fathers in regards to occupation choices, future plans, and career interests and abilities (Bryant, Zvonkovic, & Reynolds, 2006; Otto, 2000; Palos & Drobot, 2010; Tucker, Barber, & Eccles, 2001).
Although the present research highlighted the way in which parents and emerging adults with CF work together towards career development projects, living with a chronic disease, such as CF, may change the dynamics of the relationship. One participant appeared to express the desire for more independence around treatment regimen. For example, irritation emerged as one internal process connected to parental support with treatment tasks. However, opposite actions were also identified in regards to parental support, and seemed to be facilitated by the desire to portray his parents in a positive light. Such findings highlight the difficult task of parents of young people with CF, which emphasize both the need to oversee treatment regimens while allowing adolescents to develop independence (Modi, Marciel, Slater, Drotar, & Quittner, 2008; Withers, 2012).

Existing literature also suggests that volunteering may be a viable alternative to paid work as a career path for individuals with a chronic disease. For example, research examining volunteer work of people living with HIV has found volunteering helped participants expand their social network and regain an active lifestyle and a sense of psychological well-being (Samson, Lavigne, & MacPherson, 2009). Of particular relevance to the present study, Edwards and Boxall (2010) found volunteering provided one adult who had CF with the adaptability she needed to remain healthy. In the present study, one participant stated that volunteer work served an important function in her life. She explained that, in addition to being flexible, volunteering gave her a sense of fulfillment. Combined with the results of previous research, the present findings suggest that volunteer work may be valuable for the career development of individuals with chronic diseases, such as CF.
Limitations

There are several limitations that must be taken into consideration when interpreting the findings of the present study. First, it is important to acknowledge that the actions and projects of the participants are not transferrable to all emerging adults with CF. In other words, experiences may be different for emerging adults with CF who did not participate in this study. Since all participants identified as Caucasian in this study, particular caution needs to be considered for individuals from different cultural and ethnic backgrounds. Nonetheless, the presence of two themes across the experiences of all participants suggest that many emerging adults with CF experience parental support for their career development, and that health and career development are sometimes closely intertwined for this population.

Second, this study was not designed to reveal how career development processes change or evolve over time. The full, longitudinal data collection procedures that are typical of action-project research (Young et al., 2005) were not used, due to the limited scope of this study. As a result, the focus of this study was on the current and previous career development projects of this population from the perspective of a single point in time.

Finally, the findings of this study may be limited due to the fact that parents were not involved in the research. Consequently, the findings were based on the emerging adults’ perspectives of the career development projects and their descriptions of joint actions, rather than on direct observations of how these individuals and their parents engage together around the emerging adult’s career development. This contrasts with the traditional form of APM research, which assesses the joint actions between a participant
dyad (e.g., an emerging adult with CF and a parent). It is possible that additional or different projects, actions, overarching themes, and unique processes would have emerged if the data collection had included conversations between parents and emerging adults with CF.

**Conclusion**

Despite the presence of several limitations, the findings of this study provided important information about the kinds of joint goal-directed projects that parents and emerging adults with CF may engage in around career development. In addition, projects related to career development that were previously found in research with parent-adolescent dyads, as well as interconnected with other features of the emerging adults life with CF were also supported.
Chapter 2 References


Iles, N., & Lowton, K. (2009). What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services? *Health and Social Care in the Community, 18*, 21-29. doi:


Socholotiuk, K. D. (2015). *Understanding weight restoration in adolescent anorexia as a*


Chapter 3: Implications of the Study

This study explored ways that emerging adults with cystic fibrosis (CF) experience their career development as goal-directed action that is jointly enacted with their parents, and revealed common and distinct experiences that some emerging adults with CF encounter as they engage in goal-directed processes with their parents around career development. The findings from this study are directly related to the field of counselling in that the results provide potentially important information for counsellors working with emerging adults with CF and/or their parents. After the counselling implications of the findings are considered, a discussion of potential directions for future research will follow.

Potential Counselling Implications

The purpose of this study was to understand how emerging adults with CF describe how they work together with their parents in the career development process. As emerging adults and their parents work together on the career development of emerging adults with CF, counsellors may be able to provide them with another perspective by conceptualizing career development as a joint goal-directed process that occurs between them. Shifting the perspectives of emerging adults with CF and their parents may strengthen their relationship, as well as help facilitate the emerging adults’ careers.

This study revealed that the career development of emerging adults with CF is constructed in part through the joint goal directed actions with their parents. As a result, it may be beneficial for counsellors to be able to address both relationship and career issues when working with emerging adults with CF. By addressing career and relationship
problems together, the experience of emerging adults with CF may be more fully resolved. Specifically, the career development of all three emerging adults with CF was facilitated through the relational processes with their parents. Therefore, it may be helpful for counsellors to incorporate parents into the counselling sessions to address the dynamics of emerging adults with CF more effectively compared to individual counselling. Furthermore, this study revealed that the career development of one participant was influenced by other relationships apart from her parents. As a result, it may be valuable for counsellors working with emerging adults with CF to explore potential influences of other relationships, including ex-husbands and former in-laws. Taking the relational components of emerging adults with CF into consideration may provide counsellors with a more comprehensive understanding of these individuals, as well as inform counsellors of more appropriate interventions, and help individuals with CF mobilize their relational networks in intentional ways.

Similarly, counsellors must not underestimate the intricate connection between career development projects and other projects in the life of emerging adults with CF. This study suggests that participants’ joint projects related to career development are intertwined with health projects connected to CF. Therefore, when working with emerging adults with CF on their career development, counsellors may be better able to support this population by taking all projects into consideration. Similarly, counsellors and other health professionals who are assisting emerging adults (and their parents) to manage their CF may benefit from exploring the connections between their health maintenance and their career development.
Similarities in projects and patterns of action across participants were also identified, along with findings that were unique to specific cases. As a result, counsellors may be able to use the findings of this study to provide psychoeducation to emerging adults with CF and their parents regarding common patterns of action that could facilitate with career development, including collaborative, open discussions about career and/or transportation to/and from appointments and/or work. Similarly, counsellors may benefit from information about what is important for balancing emerging adults’ needs for independence with adequate parental supervision in regards to treatment tasks and positive relational influences, such as parental support. This kind of prevention-based psychoeducation will allow parents to begin implementing some of the strategies well before their children with CF begin the process of transitioning into adulthood.

**Future Research**

Given the lifelong nature of the career development process, it will be useful for future research to track the career development projects of emerging adults with CF across a longer period of time, using the longitudinal version of the action project method (APM), as described by Young, Valach, and Domene (2005). Furthermore, such research could implement the dyadic interview protocol of the APM to capture the perspectives of other family members, particularly parents. This would generate directly observable data to increase understanding of the project-related actions that other significant people (e.g., parents siblings, friends, spouses) engage in within the career development projects. Confirming and building on the present study using the full APM may also provide additional insight for counsellors and health professionals, regarding important relational
dynamics in the joint projects of emerging adults with CF. Future exploration of family
dynamics would be particularly beneficial for professionals who are working from a
systemic perspective (e.g., family therapists) or attempting to implement the previous
recommendation of integrating a relational focus into career counselling for this
population.

Given the influence of gender on the transition to adulthood that has been
revealed in previous studies (e.g., Domene, Socholotiuk, & Young, 2011; McKinney &
Renk, 2008; Renk et al., 2007; Trees, 2002), another direction for future research is to
explore the role of gender (of both parents and emerging adults with CF) on joint career
development projects. Domene and Young’s (2008) procedures for conducting
comparative qualitative analysis within the APM provides a way to approach this
question. The between-groups comparison with the APM may provide a more detailed
understanding of joint goal-directed processes parents and emerging adults with CF
engage in together around career development. However, “the procedure cannot be used
to draw the conclusion that the grouping construct is responsible for the differences and
similarities that emerge” (Domene & Young, 2008, p. 76). Thus, quantitative research
methods may also be useful, as quantitative methods of inquiry allows the researcher to
establish directions of causality out of emergent pattern in the data (Socholotiuk et al.,
2016). For example, future studies may ask the question, “What is the difference in career
development goals and outcomes for mother-son dyads versus mother-daughter dyads, in
which the emerging adult children have CF?”
Conclusion

The present study increased understanding of how emerging adults with CF describe their career development as joint-goal directed action in the context of their relationships with their parents. Using the framework of contextual action theory, as well as the procedures outlined in the multicase study approach and the APM, the findings generated in this study showed how career development was described by 3 emerging adults with CF. It was revealed that career development is constructed through a series of joint goal directed actions, which were embedded in a relational context. The overarching themes of parental support and health were also found to be present across the three cases. This research provides important information for improving the practice of career counsellors and other professionals who are working with emerging adults with CF to support their transition into adulthood. However, the presence of some limitations in the study and the nature of the research design that was implemented clearly suggests that it would be beneficial to conduct additional research is required to fully understand the relational contexts of career development in emerging adults who have CF.


Appendix A: Introductory Letter

Introductory Letter

Understanding the Career Development of Emerging Adults with Cystic Fibrosis

From a Contextual Action Theory Perspective

Researcher: Caitie Napodi, M.Ed. student
University of New Brunswick, Faculty of Education
(604) 653-4030; caitie.napodi@unb.ca

Supervisor: Dr. Jose Domene, Professor
University of New Brunswick, Faculty of Education
(506) 453-5174; jfdomene@unb.ca

You have indicated an interest in this study. This letter and consent form are designed to provide you with more information about the study, as well as the eligibility requirements required to participate. After reviewing this information, and if you meet the eligibility requirements, please contact the researcher if you are interested in participating or have any additional questions.

Your participation is completely voluntary. In others words, you do not have to participate and can withdraw from the study at any time, without penalty. If you choose to withdraw from the study, any data collected will be destroyed.

Purpose:

We are interested in understanding the career development of young adults with cystic fibrosis. Specifically, we are interested in how young adults with cystic fibrosis and their parents work together in the career development process.
For more information about the study procedures, confidentiality, and risks/benefits please see the included consent form.

**Eligibility Criteria or Requirements to Participate:**

If you meet **all** of the below requirements, you are eligible to participate in this study.

- ☐ You have received a diagnosis of cystic fibrosis
- ☐ You are between the ages of 19-29
- ☐ You are living in the Lower Mainland of British Columbia
- ☐ You are fluent in English

If you are still interested in participating after reviewing the introductory letter and the consent form, please contact the primary investigator, Caitie Napodi, at (604) 653-4030 or caitie.napodi@unb.ca, to discuss the next steps.

Thank you for taking the time to review this information package and for your interest in this study!
Appendix B: Telephone Screening Form

Telephone Screening Interview

Thank you for your interest in this study. Where did you hear about the study?

________________________________________________________________________

As you may know, we are studying the career development of young adults with cystic fibrosis. Specifically, we are studying how young adults with cystic fibrosis and their parents work together in the career development process. We are looking for young adults with cystic fibrosis who are willing to talk to us about their career development and what role their parents have played in this process.

Do you have any questions about this study?

We are looking for young adults who are willing to take part in two interviews. The first interview will consist of participating in a video and audio-recorded interview. Participants will be asked to have a conversation with a researcher about their career development and how they see their parents as being part of the process. In the last stage of the first interview, a research assistant will ask you to recall your thoughts and feelings as you review 15 minutes of the video recording of your conversation with the researcher. In the second interview, you will be asked to review a written summary of the information from the first interview and provide feedback.

Are you interested in participating?

First, you should know that your information, as well as anything you say in the interview, will be kept confidential. Second, due to the purpose of this study, there are some requirements that need to be met before we can determine your eligibility to
participate. We can go through these now or I can call back at a later date if you would like some time to think about participating?

IF THEY WANT YOU TO CALL BACK AT A LATER DATE STATE THE FOLLOWING:

In the meantime, would you like me to send you a copy of the formal consent form for you to review?

☐ Yes

☐ No

Name: _____________________ Date of Screening Call: _____________________

Telephone # and/or email where you can be reached:

____________________________________________________________________

IF THEY WANT TO CONTINUE WITH ELIGIBILITY CRITERIA ASK THE FOLLOWING:

Date of Screening Call: _____________________

Name: _____________________

Date of birth: _________________ Age: _________________

Are you comfortable having a conversation in English: YES / NO

Have you received a formal diagnosis of cystic fibrosis? YES / NO

If yes, how old were you when you received the diagnosis? _________________

What city do you currently live in? _________________

Telephone # and/or email where you can be reached:

____________________________________________________________________

IF INCLUSION CRITERIA IS MET, STATE THE FOLLOWING:
Now that I have gone over the eligibility questions, I will consult with my supervisor and then I will be in touch to arrange the first interview. Do you have any questions?

IF INCLUSION CRITERIA IS NOT MET, STATE THE FOLLOWING:

“Thank you very much for your interest in this study. Unfortunately, you do not meet the eligibility requirements needed for the purpose of this study. If you feel discussing your experience with career development would be beneficial, I encourage you to contact support services at the Cystic Fibrosis Clinic, at (604) 806-8522 or cfclinic@providencehealth.bc.ca. Do you have any questions? Thank you again for your interest. I really appreciate your time.”
Appendix C: Poster

Are you a young adult with cystic fibrosis?

We need your help for a research study!

We need your help to learn about how young adults with cystic fibrosis plan for their future career with their parents.

Who is eligible to participate?
- Have cystic fibrosis
- Be between the ages of 19-29
- Be living in the Lower Mainland of British Columbia
- Be fluent in English

Study Procedures:
Participants will take part in 2 separate interviews.
Total time commitment will be approximately 3 hours.
All participants will be provided with a $25 Visa gift card!

For information, contact Caitie at caitie.napodi@unb.ca or (604) 653-4030

This study has been reviewed by the University of New Brunswick Ethics Board, file #2017-036.
Appendix D: Advertisements

My name is Caitie Napodi and I am a student in the M.Ed. counselling program at the University of New Brunswick. I am conducting my master's thesis research on the career development of young adults with cystic fibrosis. I am particularly interested in how young people with cystic fibrosis and their parents talk about and plan for future careers. If you are eligible, please consider participating in my research.

Who is eligible to participate?

• Have cystic fibrosis
• Between the ages of 19 to 29
• Live in the Lower Mainland of British Columbia
• Fluent in English

Participants will be asked to take part in two interviews. The total time involved for participation in this project will be approximately 3 hours.

In appreciation for your participation, you will be given a $25 Visa gift card.

If you would like to participate in this study, or would like more information, please contact me, Caitie, at (604) 653-4030 or at caitie.napodi@unb.ca.
Appendix E: Interview 1 Protocol Form

Interview 1 Protocol

Participant number: _______  Length of interview: _______

Time, date, and location: ______________________________________________________

Interviewers: ________________________________________________________________

Set-up & Preparation

☐ Get there early to set up and test equipment

☐ 2 photocopies of consent form

☐ Demographics form

☐ $25 prepaid Visa gift card

Preliminary

☐ Build rapport by asking how they heard about the study, did they have any
difficulty finding the interview space, etc.

☐ Read the informed consent

☐ Ask if they have any questions

☐ Remind participants that their participation is completely voluntary and can withdraw their participation at any time, without penalty

☐ Turn on audio and video equipment

As indicated in the consent form, this interview will be audio and video recorded, so if it is okay with you I will turn the equipment on now.

Introduction

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Thank you for participating in this study. The purpose of this study is to learn about the career development of emerging adults with cystic fibrosis. Specifically, we are interested in how emerging adults with cystic fibrosis and their parents work together in the career development process. For this study, career development is broadly defined as things that you and your parents do together to achieve goals related to your school, work and/or identity. Once we have discussed ways in which you engage in joint goal-directed process related to your career development with your parents, you and ____________ will view the video-recording of the conversation you just had with me.

**Warm-Up Interview**

*Before we begin, I would like to take a few minutes to get to know you.*

☐ What was it about this research study that made you want to participate?

☐ Can you tell me a little about your relationship with your parents?

☐ Can you tell me a little about your education and/or career to date?

☐ What are your plans for the future, in regards to education and/or career?

☐ What is it like to live with cystic fibrosis?

☐ Tell me what it has been like to have cystic fibrosis and pursue education and/or your career?

☐ What are some important things you have done/experienced in your career development?

**Joint Conversation**
Research Question: How do emerging adults with cystic fibrosis engage in career development joint actions and projects, in the context of their relationship with their parents?

So, now I am going to ask you to think about cystic fibrosis and your career development, in the context of your relationship with your parents.

☐ Can you give me an example of how your parents have been involved in your career development process?

☐ Can you tell me how you and your parents work together to help you with your career development?

☐ What kinds of things do you do together with your parents that have to do with your career development?

☐ How do these activities usually go?

☐ Can you recall any recent activities or things you have done together with your parents related to your career development?

☐ What kinds of conversations do you have with your parents about your career development, and how do they go?

☐ Can you recall any recent conversations you have had with their parents about your career development?

☐ Have you and your parents had any disagreements or difference in opinion regarding your career development?

  ○ Can you give me an example?

Self-Confrontation

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You and I are going to review the video-recording of the conversation you just had with Caitie. I’m going to stop the recording at 1 minute intervals and ask you to recall your thoughts and feelings occurring at that moment. This portion of the interview will last for approximately 15 minutes.

☐ Stop after each minute

☐ Ask:

  o What do you recall thinking or feeling in that minute?
  o How did it feel to say that in that moment?
  o Is there anything else you recall about what you were thinking or feeling at that moment?
  o Is there anything else you would like to add?

☐ Note start times when you resume the video-play back

1. ______________  2. ______________
3. ______________  4. ______________
5. ______________  6. ______________
7. ______________  8. ______________
9. ______________  10. ______________
11. ______________ 12. ______________
13. ______________ 14. ______________
15. ______________ 16. ______________

Debriefing

☐ Have demographics form completed by participant
☐ Give participant $25 VISA gift card

☐ Obtain information to contact the participant for the second interview
  
  ○ Phone # & Condition for call back:

Again I want to thank you for participating in this study. The information that you have provided will be very helpful in understanding the career development process of emerging adults with cystic fibrosis. In a few weeks I will be contacting you to schedule the second interview, where you will be asked to review the summary of information from today. Do you have any questions or concerns before we finish today’s session?

Reflection on the Interview
Appendix F: Codes for Analysis

Acknowledges

Minimal statements, that acknowledges the statement by the other

“Um-hmmm”

“Yes”

“Sure”

“OK”

Advises

“I think the best idea for you is to get a job in the short term and then think about your educational concerns in the long-term.”

Agrees

“Yes, I agree”

“That’s true”

“You’re right”

“I concur”

“We see eye to eye”.

Ambiguous response

Response is unclear, not readily interpretable, has more than one possible meaning, hazy or fuzzy meaning.

Answers question

Apologizes

“Sorry, I apologize”

“Oops”
“My-bad”

**Approves**

Positive evaluative or judging statement

“It’s a great idea that you’re ________”

**Validates**

“That’s fantastic”, “It’s good”, “It’s fine”)

**Asks for clarification** (further explanation or expansion)

“Can you tell me more about that?”

“I’m wondering which of your dilemmas seems to have the most importance for you right now?” “Can you give me more details about that situation?”

“Can you expand on that?”

**Asks for confirmation**

“Am I getting this right?”

“Is that what you mean?”

“So, you’ll be here for next week’s appointment?”

**Asks for feeling state**

“How do you feel about that?”

“What does it feel like when you _____________?”

“Tell me more about that sadness”

**Asks for information** (more factual in nature)

“When was it that you moved out of your parents’ home?”

**Asks for justification or reasons**

“Why was that?”
“What was your rationale for making that choice?”

**Asks for opinion or belief**

“What do you think about that?”

“What do you believe to be the most important aspect of becoming an adult?”

**Asks for speculation or hypothetical scenario (challenges)**

“What if . . . ?”

“Let’s say ________ happened?”

“How do you think you would handle __________?”

**Clarifies**

Usually in response to asks for clarification. Involves giving more information to clear up an ambiguity or a misinterpretation.

**Complains**

“My employer gives me every crappy shift. It ruins my weekend plans.”

**Confirms**

Response to a request for further information

“So you are coming for dinner tonight?”

**Continues other’s statement**

After an interruption

Continues own statement after a pause

**Demands**

Tells the other what to do

**Describes future**

“My mother will be visiting next week.”
**Describes other** (in the annotation – describe who the “other” is)

“It seems to me that you ____________.” (is usually used with expresses perception)

“It sounds to me that your sister is really trying to work things out with the family.”

**Describes past**

“I told my mother that I was grateful for everything she has done for me.”

“I went to college 5 years ago.”

“When I was a kid, I was bit by a dog and now I can’t seem to get over it.”

“I used to hate my brother.”

**Describes possibility or hypothetical situation**

“If I can’t get into UBC I know I will be disappointed.” (sometimes used with other codes – i.e. describes self, expresses perception)

**Describes self**

“I suck at tennis.”

“I’m a generous person.”

“It really wasn’t like me to behave that way.”

**Describes situation or event**

**Disagrees** (denies)

**Disapprove**

Negative evaluative or judgment statement

“I don’t like them.”

“She really should have known better than to behave like that.”

**Dismissive or diminishing statement**

“Oh c’mon.”
“Don’t be silly.”

“That’s nonsense.”

“Whatever.”

**Elaborates**

Extends a previous statement

Provides more information, adds depth to a previous statement, gives a deeper explanation.

**Encourages**

Give confidence, cheer, hearten

**Evaluative or judging statement**

Focused on a phenomenon, or event, or person with approving or disapproving

**Expresses anger** (irritation, exasperation, rage, disgust, envy, torment)

“I was so pissed off with him.”

“I was furious.”

**Expresses belief or disbelief** (concrete as opposed to tentative)

“I just know things are going to work out.”

“I don’t believe in God.”

“I can’t believe this is happening to me.”

**Expresses desire**

I need, I want, I wish….

**Expresses disgust** (usually more of a facial expression, distaste, expression of not liking or loathing)

“It totally grossed me out. It was disgusting to be in that cell with all those crack addicts.”
Expresses dissatisfaction

“School isn’t what I thought it would be.”

Expression of dissatisfaction sometimes coded with expresses sadness or some other emotion.

Expresses doubt

“I’m not sure I can handle that.”

“I doubt I have the ability to get into university.”

Questioning, has emotional content, not about indecisiveness

“I don’t know about that, I don’t know if that fits for me.”

Possible others - disagrees, dismissive statement

Expresses fear (horror, nervousness)

Overwhelmed or expressing a lot of concern.

Expresses frustration

“It totally sucks that I didn’t get the job I wanted.”

Expresses gratitude

“Thank you.”

“I really appreciate what we are doing here.”

“I’m thankful for this opportunity.”

Expresses humor

Tells a joke

Says something funny (either intentional or unintentional)

Contextual use of humour, use of wit, lightheartedness, kidding around

Expresses joy

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Happiness, cheerfulness, zest, contentment, pride, optimism, enthralment, relief

**Expresses**

Liking of idea, object, person; not love

**Expresses love** (affection, lust, longing)

**Expresses perception or opinion or hunch**

Is usually a tentative statement or interpretation

“It seems to me that you may be quite similar to your dad in that way.”

“Correct me if I’m wrong but I think ______________.”

**Expresses realization**

Client expresses an “ah-ha” moment in the present tense.

“I realize that these people are very important to me.”

“Wow, I’ve never thought about that before.” (add surprise to the code)

“Oh no, really. I hadn’t thought about that consequence before.” (add disappointment to the code)

**Expresses sadness**

Suffering, disappointment, embarrassment, shame, neglect, regret, sympathy

“I was so depressed about it.”

“I was really hurt when my stepmother attacked me like that.”

**Expresses surprise**

More of a facial expression

“I was really surprised that she reacted that way.”

“Oh wow!”

**Expresses uncertainty**
Is about decision-making. Not being able to sort something out. Not able to accurately predict.

“I’m not sure.”

“I can’t decide what option to take.”

**Expresses understanding**

“I get that.”

“I see where you’re coming from.”

“That makes sense.”

“I see what you mean.”

**Expresses worry**

“I’m worried about my exam.”

**Incomplete statement**

Can be questions, statements, or sentences.

**Interrupts**

**Invites or elicits a response**

Use of hand gesture to elicit a response from a client

“You know what I mean?”

“Right?”

**Laughs**

**Paraphrasing**

Repeats previous statement

Repeats a previous statement in your own words

**Partial agreement**
Halfhearted agreement

“Sort of.” (specifying the amount of agreement)

**Pause**

A break in the sentence or dialogue, silence, a pregnant pause

**Praises**

Compliments, admiring remark, accolade, congratulates

“Good for you”

“Look at you!”

“Congratulations.”

“It’s terrific that you have such great insight.”

**Provides information**

“You can get an application on-line if you go to the website.”

**Reflects affect**

Capturing an image that is beyond what was previously stated

Beyond paraphrasing

Advanced empathy, empathy

“You felt disappointment when you didn’t get into UBC this year.”

**Reflects cognition**

Advanced empathy, empathy

“That was a tough situation for you.”

“You didn’t think that was the right way to go.”

“So you’ve been thinking about a number of career options over the last year.”

**Requests**
Asks the person to do something. Asks for

“Could you sign this form?”

**States a plan**

“I’m going to go to school next term.”

“I will be here next week for my appointment.”

**Suggests**

“I’d like to suggest that your father didn’t mean to hurt your feelings.”

**Unintelligible response**

Can’t be understood on tape or through transcription
Appendix G: Participants’ Individual Narratives

Participant 1

This is a summary of the interview and conversation you had with [the first author] and [a research assistant] in [location], on April 22, 2017. At the time of your interview in April, you were a 26-year old man who had been diagnosed with cystic fibrosis when you were 6 to 8 months old. You were born in Canada and you were living in [town] with your parents, and were single. You have a Bachelor’s degree in journalism and are working as a marketing coordinator full-time. Having cystic fibrosis has required changes to your work schedule. Despite these changes, you had not received any career counselling.

A number of topics were discussed during the interview. Early in the conversation, you explained that when you first agreed to participate in this study you believed that cystic fibrosis did not affect your career development too much. You explained that your parents played an instrumental role in that (They never treated me like "oh poor T., you have CF, oh, you know, all this bad stuff’s happened to you." They’ve really just been really like candid about it…). You went on to note that cystic fibrosis has played a minor role in job selection and the need for accommodation in the workplace. Other topics we discussed included how you and your parents generally think alike (they don’t have any specific expectations for me other than are you healthy and do you enjoy life…so do we have any disagreements about what I want to do, not really). You went on to note that even when you disagree, you feel supported by your parents in the decisions you make. For example:
It makes it really easy, for me, um, I never find myself worrying what they’ll think because I know whatever I do they’ll just be honest and they’ve made it clear that it’s okay to disagree, but I also really respect their opinions, so that if they do disagree with me I’m not going to take it personally; ...they’ve always tried to, um, reassure me that we’re not, we may not always agree and ultimately what you decide is what you decide, but...we’re just going to do everything in our power to help guide you...to a better place.

Further into our conversation, your main goal for our interaction seemed to be to explain the discussions you have had with your parents. During this conversation, you mostly talked about your mom, but corrected yourself at the end to include your dad. You acknowledged this afterwards (I realize how much I keep talking about my mom and not so much my dad) and came to the realization that your mom may be more involved than your dad (...I feel it might be true to say that my mom has been a lot more involved in the care than my dad; ...I feel like maybe my mom is more...slightly involved, like, well obviously my dad and I talk too...but I don’t think as much). You seemed to struggle with finding the words to accurately describe the conversations you have had with your parents, but after thinking out loud and processing your thoughts you were able to identify open conversations as one of the most important things you do with your parents, in regards to your career development (...my parents have always been open that way...for anything, like they’re the type of people that are like, really embody the principle of there are no stupid questions).

A second goal during our conversation together seemed to be to acknowledge the collaborative nature of your discussions with your parents. One of the ways you did this
is by talking with your parents about the advantages and disadvantages of situations (...I might have been thinking about going full-time (to school) and I think my mom was the one who said well are you going to keep up your taekwondo...That’s really important for your lungs...so lets consider this too). Despite the collaborative nature of these discussions, you seemed to experience some internal conflict, noting how your parents’ involvement can be irritating at times while also wanting to present them in a positive light (...so there was part of that was like, um, I want to present my parents in a nice way...but at times I might be understating that it can be very irritating...but I didn’t, probably didn’t really want to say that...but that is probably the truth). Even with this conflict, you were able to recognize how grateful you are to use your parents as a sounding board (...it’s always nice to have that fall back; I like to have someone to talk about it with).

Overall, the primary career development project that you were engaged in at the time of the research interview seemed to be about maintaining an open and collaborative relationship with your parents.

**Participant 2**

This is a summary of the interview and conversation you had with [the first author] and [a research assistant] in [location], on May 25, 2017. At the time of your interview in May, you were a 22-year old man who had been diagnosed with cystic fibrosis when you were 2 years old. You were born in Canada and you were living in [town] with your parents, and were single. You have a high school diploma and are working as a dance teacher full-time. Having cystic fibrosis has required changes to your work schedule. Despite these changes, you have not received any career counselling.
A number of topics were discussed during the interview. Early in the conversation, you noted that there has been times when your career has negatively impacted your treatment adherence (…there are times when I’ll have to miss physiotherapy sessions sometimes,…so when I get home I’m obviously not trying to for like a hour long session of physiotherapy…). However, you explained that your mom has played an instrumental role in helping you manage cystic fibrosis, while you have pursued and advanced your career. For example:

*I think without her help…I probably wouldn’t be in the position that I am because I just, I don’t think I would be able to handle all these physiotherapy sessions and everything and do the amount of practice and teaching I need to do to sustain the career that I have.*

At first you had some difficulty picking one example that encompassed everything your mom did to help you in your career development (*I was just trying to think of a good, one example out of like 100s and 100s of things that she helps me with…*), but afterwards you were able to acknowledge feeling emotional reflecting upon the help you have received (…it’s always a little emotional because you kind of, you kind of see what they’re trying to do to help you,…and it’s almost a little bit eye opening…knowing that you’re getting a lot of help that hasn’t been asked for…). Other topics we discussed included the amount of work you have put into the company and the seriousness with which you take your work responsibility. You seemed to view this as a way of honoring and paying back your mom’s support (*C: It sounds like your mom has a lot of trust in you, I mean… R: Yah, yah, I mean thankfully she does, thankfully she knows that I take what we do fairly
seriously; I try to give back to her in the effort I put into the studio; ...if you expect help
you need to show that you’re worthy of the help).

Further into our conversation, your main goal seemed to be to explain the
collaboration between you and your mom, specifically involving owning a company
together. During this conversation, you explained how you and your mom play off each
other’s strengths (...I don’t really do a lot of the business side of it, um, that’s another
thing mom has helped me with, uh, she does all the business stuff). You went on to note
how grateful you are for the amount of collaboration you have done with your mom, in
regards to running the company, and how this relationship makes you feel comfortable to
express your opinions (...gratitude for her allowing me to put like all of my ideas in and
be able to without hesitation...; we’re not afraid to tell each other when something is a
bad idea, um, we’re also not afraid to put our ideas forth...). You explained that this
collaborative relationship is the reason why the company is flourishing.

A second goal that seemed to emerge during our conversation together was to
acknowledge the importance of communication between you and your mom. Ways that
you and your mom do this include (a) listening to one another, (b) giving each other a
different perspective and (c) being assertive. You identified communicating with respect
as one of the most important things you do with your mom, in regards to running a
business together. For example:

...the respect factor is huge too because me understanding that she’s had like 30
something years of doing this, so her opinion is not anything to be taken
lightly,....um, but her also realizing that I’ve been very involved in what is
relevant now...and I’m very up on where things are going, uh where they’ve come from and what’s happening...

Despite being able to effectively communicate with your mom, you acknowledged that you still have disagreements. You went on to note that even when you disagree, you and your mom are able to work through them and you feel supported by your mom in the decisions that you make.

Overall, the primary career development project that you were engaged in at the time of the research interview seemed to be focused on maintaining a collaborative relationship with your mom that built on trust and strong communication.

Participant 3

This is a summary of the conversation you had with [the first author] and [a research assistant] in [location], on July 17, 2017. At the time of your interview in July, you were a 28-year old female who had been diagnosed with cystic fibrosis before you were born. You were born in Canada and you were living in [town] with your nine year old son, and were divorced. You did not graduate high school, but have completed a make-up program. At the time of the interview, you were a full-time stay at home mom. You have not received any career counselling.

A number of topics were discussed during the interview. Early in the conversation, you stated that it was difficult having cystic fibrosis and raising your son before you had your double lung transplant (...it was difficult for sure because I was so sick and then you’re trying to take care of a child, it was, it was hard). You also noted that you received a lot of help from both of your parents (She helps out a lot, they both helped out a lot with my son when I was sick, ....I moved out when I was 19, I got
married, …but they helped me out still tons). You went on to explain how your parents have influenced the way you have raised your son, and that you share a lot of parenting similarities with your dad (…my dad was always like that fun dad who was always playing with us and silly and goofy, so I definitely think I got that sense from him).

Afterwards you reported that both of your parents have served important and positive roles in your life, despite being different. You explained how difficult it was for your parents to raise two children who had cystic fibrosis (…it’s already hard enough raising a child, as I know, right. I couldn’t imagine having a sick child) and seemed to perceive that the person who you have become is partly due to their strength. Other topics we discussed included the valuable role volunteering has played in your life (…because I wasn’t able to work it kind of gave me something to do).

Further into our conversation, your main goal seemed to be to explain what your parents have done in the past and what your mom is currently doing to support you.

Ways your parents did this included looking after your son (…so she was a huge help in that regard. She would you know watch him usually a couple hours after school for me) and respecting your parenting decisions (my parents are very kind of like we’re here if you need us, but they’ve never really like been pushy…so, yah they’ve always been a huge support with my parenting). You expressed appreciation for your parents’ help, noting how you would not have been able to do what you have done without them.

A second goal seemed to be to explain the discussions you have had with your parents. You seemed to struggle with finding the words to accurately describe the kinds of discussions you have had with your parents, but after thinking out loud and processing your thoughts you were able to briefly touch on conversations regarding the General
Equivalency Diploma, future careers, and motherhood. You explained you were generally on the same page as your parents (…I always wanted to go back and get my grade 12, like…that’s what they really wanted me to do and I, I did want to do that…), but there have been discussions in which you and your parents have had different opinions (so my dad was like, didn’t want me to have the baby, really, um, but then my mom’s like so opposite). You went on to note that even when you and your parents did not agree initially, you still felt accepted and supported by them afterwards (…like they were obviously not supper stoked in the beginning, but…they accepted [the pregnancy] and they were, they were great about it, like we, yah. I was living at their house when I was pregnant, so…yah it was good).

Overall, the primary career development project that you were engaged in at the time of the research interview seemed to be focused on raising and parenting your son, with the support of your mom.
Appendix H: Interview 2 Protocol Form

Interview 2 Protocol

Set-up & Preparation

☐ Get there early to set up and test equipment

☐ 2 copies of summary

Preliminary

☐ Review informed consent

☐ Ask if they have any questions

☐ Remind participants that their participation is completely voluntary and can withdraw their participation at any time, without penalty

☐ Turn on audio recording

As indicated in the consent form, this interview will be audio and video recorded, so if it is okay with you I will turn the equipment on now.

Introduction

Thank you for participating in the second half of this study. Today's interview will be much shorter than the last, lasting approximately 15 minutes. The purpose of this second interview is to have you review the summary of our conversation from our previous interview.

☐ Ask if they have any questions

Member-Checking
So, now I am going to read out the summary and at any time if you have any questions, concerns, or want to provide feedback please ask me to stop.

☐ Read narrative, slowly

☐ Pause at each paragraph
  ○ Ask: Does that fit with you?

☐ Is there anything important that we missed?

Debriefing

Again I want to thank you for participating in this study. The information that you have provided will be very helpful in understanding the career development process of emerging adults with cystic fibrosis. Once this study is completed, and if you provided your email on the consent form, you will be emailed with a summary of the results. Do you have any questions or concerns before we finish today’s session?
Curriculum Vitae

Candidate’s full name: Caitlin Alexandria Dinn Napodi

Universities attended (with dates and degrees obtained):

Simon Fraser University
September 2006 – February 2014
BA Psychology

University of New Brunswick
July 2014 – May 2018
MEd Counselling (candidate)

Publications:


Conference Presentations:


to work. Poster presented at the 77th convention of the Canadian Psychological Association, Ottawa, ON.