CAREER DEVELOPMENT AND WORK EXPERIENCES OF INDIVIDUALS WITH CYSTIC FIBROSIS: A GROUNDED THEORY STUDY

By

PABLO S. SALDANA

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

2012
To my family and partner, you made this accomplishment possible
To the participants in this study, thank you for allowing me into your world. You taught me so much.
ACKNOWLEDGMENTS

Great endeavors are not accomplished individually and this one was no different. I am thankful to so many individuals that helped me along this journey. First, I would like to thank my wonderful committee members for their guidance and support: Dr. Jamie Pomeranz (my chairperson), Dr. Roxanna Bendixen, Dr. Jeanne Repetto, and Dr. Mary Ellen Young. I am fortunate to have such an amazing dissertation committee and I am grateful to each of you for your time, advice, expertise, and patience. I have learned so much from each of you and I thank you.

I would also like to express my appreciation to three other faculty members who helped me: Dr. Tracy E. Barnett, Dr. Barbara Lutz, and Dr. Michael Moorhouse. In your own way, you each supported and helped with this study.

I owe a debt of gratitude to the other essential parties to this undertaking - the study participants. Without your assistance, I would not have been completed this project. I greatly appreciate your time and interest in this study.

Additionally, I want to express thanks to all my friends at Nemours Children’s Clinic in Jacksonville especially Helena Gutierrez-Richards, Kirsten Most, Dr. Bonnie Hudak, Dr. Kathryn Kinyon-Munch, Dr. Mary Belkin, and Dr. Eric Sandler. You encouraged me to go off and attempt this goal and promised I could return one day to apply all I learned. Thank you for allowing me the time to pursue this goal.

Finally, I would like to acknowledge my family and partner for all their love and encouragement. Cusi, Marty, Carlie, Marlene, and Scott: I do not think I can ever completely express my gratitude. You kept me going when I was discouraged and I owe this accomplishment to you. Though my father and grandmother did not live to see this day, I felt their influence and encouragement throughout this journey. Papi y
abuela, espero que ustedes dos estan orgulloso de mi. (Dad and grandma, I hope you are both proud of me.)
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACKNOWLEDGMENTS</td>
<td>4</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>10</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>11</td>
</tr>
<tr>
<td>LIST OF ABBREVIATIONS</td>
<td>12</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>13</td>
</tr>
<tr>
<td>CHAPTER</td>
<td></td>
</tr>
<tr>
<td>1 INTRODUCTION</td>
<td>15</td>
</tr>
<tr>
<td>Background</td>
<td>15</td>
</tr>
<tr>
<td>Pathophysiology of Cystic Fibrosis</td>
<td>17</td>
</tr>
<tr>
<td>Disability Statistics: Prevalence, Employment Rate, and Earnings</td>
<td>19</td>
</tr>
<tr>
<td>Educational Achievement and Employment Outcomes</td>
<td>22</td>
</tr>
<tr>
<td>Employment and Cystic Fibrosis</td>
<td>23</td>
</tr>
<tr>
<td>Toward A Grounded Theory of Career Development with Cystic Fibrosis</td>
<td>25</td>
</tr>
<tr>
<td>Theoretical Frameworks</td>
<td>26</td>
</tr>
<tr>
<td>Rationale for the Methodology</td>
<td>26</td>
</tr>
<tr>
<td>Goal of the Research</td>
<td>27</td>
</tr>
<tr>
<td>Research Questions</td>
<td>27</td>
</tr>
<tr>
<td>Potential Contribution to Rehabilitation Theory and Practice</td>
<td>28</td>
</tr>
<tr>
<td>Summary</td>
<td>29</td>
</tr>
<tr>
<td>2 LITERATURE REVIEW</td>
<td>30</td>
</tr>
<tr>
<td>Cystic Fibrosis and Employment</td>
<td>30</td>
</tr>
<tr>
<td>Disease Severity and Employment</td>
<td>30</td>
</tr>
<tr>
<td>Specific Employment Considerations</td>
<td>34</td>
</tr>
<tr>
<td>Employment Rate and Occupation Type</td>
<td>35</td>
</tr>
<tr>
<td>Vocational Rehabilitation</td>
<td>36</td>
</tr>
<tr>
<td>Employment and Health-Related Quality of Life</td>
<td>37</td>
</tr>
<tr>
<td>Educational Achievement and Employment Outcomes</td>
<td>38</td>
</tr>
<tr>
<td>Disability and Employment Themes</td>
<td>39</td>
</tr>
<tr>
<td>Transitioning to Adulthood and Employment</td>
<td>43</td>
</tr>
<tr>
<td>Vocational Rehabilitation and the Education System: Partners in Transition</td>
<td>44</td>
</tr>
<tr>
<td>Career Development</td>
<td>48</td>
</tr>
<tr>
<td>Models of Disablement</td>
<td>55</td>
</tr>
<tr>
<td>International Classification of Functioning, Disability, and Health</td>
<td>58</td>
</tr>
<tr>
<td>International Classification of Functioning Applied to CF</td>
<td>62</td>
</tr>
<tr>
<td>Emerging Adulthood</td>
<td>66</td>
</tr>
</tbody>
</table>
Emerging Adulthood Applied to CF................................................................. 69

3 METHODOLOGY....................................................................................... 74

Overview........................................................................................................ 74
Qualitative Research....................................................................................... 74
Grounded Theory............................................................................................ 75
Sampling Strategies....................................................................................... 78
Data Collection............................................................................................... 83
Data Analysis................................................................................................. 85
Data Interpretation......................................................................................... 87
Goal of the Research....................................................................................... 88
Research Questions........................................................................................ 89
Methods.......................................................................................................... 89
Inclusion and Exclusion Criteria for Participants........................................ 89
   Inclusion criteria......................................................................................... 89
   Exclusion criteria....................................................................................... 90
Procedures...................................................................................................... 90
   Protection of Participants and Confidentiality........................................ 90
   Recruitment and Participants................................................................. 91
Instrumentation............................................................................................... 91
   Interviews and the Use of an Interview Guide......................................... 91
   Career Development Inventory............................................................. 92
   Data Analysis and Interpretation Procedures........................................ 92
Reflexivity....................................................................................................... 94
Personal Bias Statement................................................................................ 95

4 PARTICIPANT CASE HISTORIES.................................................................. 98

Overview...................................................................................................... 98
Participant Demographics........................................................................... 98
The Participants............................................................................................. 98
   Ann......................................................................................................... 98
   Bob...................................................................................................... 99
   Chris.................................................................................................... 100
   Debbie................................................................................................. 101
   Elsie.................................................................................................... 102
   Fred..................................................................................................... 103
   Grace................................................................................................... 103
   Hal...................................................................................................... 104
   Ingrid................................................................................................. 104
   Jackie............................................................................................... 105
Descriptive Attributes.................................................................................. 106

5 FINDINGS.................................................................................................. 108

Research Overview...................................................................................... 108
Career Development and Disability: An Ecological Approach................................. 109
Ecological Model of Career Development in CF .................................................. 113
Individual Characteristics ................................................................................... 113
Age, Gender, and Disease Severity ................................................................. 113
Altruism, Illness Appraisal, and Persistence .................................................... 115
Personal Contextual Factors .............................................................................. 118
Parents’ Influence ............................................................................................... 118
Education ........................................................................................................... 119
Health Care System Involvement ...................................................................... 121
Treatment Burden .............................................................................................. 122
Mediating Factors .............................................................................................. 124
The Meaning of Work: Independence and Purpose ........................................ 124
Downplaying CF and Occupational Compromise ............................................ 127
The World of Work Environment ....................................................................... 129
Employer and Co-worker Support .................................................................. 129
Disease Disclosure ............................................................................................... 130
Workplace Concerns .......................................................................................... 132
Outcome – Employment/Career Patterns ......................................................... 133
Grounded Theory of Career Development in CF ............................................. 134
International Classification of Functioning, Disability, and Health .............. 136

6 CAREER DEVELOPMENT INVENTORY .................................................................. 137

CDI Results ........................................................................................................ 138
Ann ...................................................................................................................... 139
Bob ..................................................................................................................... 139
Debbie ................................................................................................................ 140
Fred ...................................................................................................................... 141
Grace .................................................................................................................. 141
Hal ...................................................................................................................... 142
Ingrid .................................................................................................................... 142
Jackie ................................................................................................................... 143
Summary ............................................................................................................. 143

7 CONCLUSIONS .................................................................................................. 145

Overview ............................................................................................................ 145
Summary of Findings ......................................................................................... 145
Findings Regarding the Meaning of Work ...................................................... 146
Findings Regarding the Career Development Inventory ................................ 147
Findings Regarding Career Development ....................................................... 148
Grounded Theory of Career Development in CF ............................................ 150
Limitations of this Study .................................................................................... 151
Implications for Service Providers ................................................................ 153
Recommendations for Future Research ........................................................... 154
Conclusion .......................................................................................................... 155
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTERVIEW GUIDE</td>
<td>157</td>
</tr>
<tr>
<td>INFORMED CONSENT FORM</td>
<td>159</td>
</tr>
<tr>
<td>DEMOGRAPHIC INFORMATION SHEET</td>
<td>167</td>
</tr>
<tr>
<td>LIST OF REFERENCES</td>
<td>168</td>
</tr>
<tr>
<td>BIOGRAPHICAL SKETCH</td>
<td>190</td>
</tr>
</tbody>
</table>
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3-1</td>
<td>Typology of purposeful sampling strategies</td>
<td>83</td>
</tr>
<tr>
<td>4-1</td>
<td>Participant demographics</td>
<td>107</td>
</tr>
<tr>
<td>6-1</td>
<td>CDI terms and descriptions</td>
<td>138</td>
</tr>
<tr>
<td>6-2</td>
<td>CDI results by participant</td>
<td>139</td>
</tr>
</tbody>
</table>
## LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2-1</td>
<td>The ICF framework and cystic fibrosis</td>
<td>64</td>
</tr>
<tr>
<td>5-1</td>
<td>Conceptual Model: Key factors that influence work experiences and career</td>
<td>112</td>
</tr>
<tr>
<td></td>
<td>development in individuals with cystic fibrosis</td>
<td></td>
</tr>
</tbody>
</table>
## LIST OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF</td>
<td>Cystic Fibrosis</td>
</tr>
<tr>
<td>FEV₁</td>
<td>Forced Expiratory Volume in 1 Second</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability, and Health</td>
</tr>
<tr>
<td>VR</td>
<td>Vocational Rehabilitation</td>
</tr>
<tr>
<td>WD</td>
<td>Work Disability</td>
</tr>
</tbody>
</table>
Many qualitative studies have examined the lived experience of individuals with cystic fibrosis (CF) but the role of work and career development have previously received only cursory investigation. Individuals with CF are living into adulthood with a regularity that was unknown a generation ago. As a result, more people with CF are now entering the workforce. Despite the growing population of working adults with CF, little is known about their employment experiences and career development. This exploratory study utilized the grounded theory method of qualitative inquiry to investigate the employment implications of CF. The primary goal of the study is to achieve an understanding of the personal meaning of work to, and the employment experiences of, people with CF and ultimately develop a substantive grounded theory of career development applicable to individuals with this disease.

The researcher utilized semi-structured qualitative interviews with ten participants to explore work experiences and career development processes. Analysis of the interview transcripts followed the constant comparative approach to coding, which identified core themes and sub-themes and culminated in a conceptual framework of variables influencing employment and career development. Additionally, in order to
understand participants’ career maturity and decision making, the researcher administered the Career Development Inventory (CDI) an 80-item instrument comprised of four scales (Career Planning, Career Exploration, Decision Making, and Knowledge of the World of Work).

Four major themes and several sub-themes (1. individual characteristics [age, altruism, gender, disease severity, illness appraisal, and persistence], 2. personal contextual factors, 3. mediating factors [downplaying CF, occupational compromise] and 4. workplace characteristics) that influence employment and career development were identified through analysis of the qualitative interviews. These themes were present for all participants, but specific experiences and outcomes varied by disease severity and gender.

The ecological conceptual model that emerged from the present study proposes that work experiences and career development in individuals with CF are influenced by the interaction of certain individual characteristics, contextual factors, mediating factors, and environmental variables. The majority of participants reported balancing daily treatment demands and employment was difficult. While participants with worse disease also reported greater school and work interruptions. In light of these circumstances, participants utilized two types of coping strategies - downplaying CF and occupational compromises.
CHAPTER 1
INTRODUCTION

Background

Cystic fibrosis (CF) is an incurable, life-limiting, genetic disorder with multiple organ involvement that primarily affects the respiratory, gastrointestinal, and reproductive systems of the body (Cystic Fibrosis Foundation, 2011). Physical manifestations and emotional complications of CF represent numerous theorized barriers to optimal career and employment outcomes (Bevelaqua & Adams, 1993; Falvo, 2005; Gillen, Lallas, Brown, Yelin, & Blanc, 1995; Goldberg, Isralsky, & Shwachman, 1985). Nonetheless, minimal empirical research has been conducted on career development issues and employment experiences in individuals with CF (Burker, Sedway, Carone, Trombley, & Yeatts, 2005; Gillen et al., 1995).

Individuals with CF are living into adulthood with a regularity that was unknown a generation ago hence; many are now joining the workforce. In 1969, the median predicted survival age in CF was 14 years. By 1985, the median predicted survival had reached 26 years and by 2010, the median predicted age of survival had climbed to 38.3 years (Cystic Fibrosis Foundation, 2012). These gains in longevity are attributed to improvements in nutritional and pulmonary therapies and the establishment of specialized CF treatment centers (Kulich, Rosenfeld, Goss, & Wilmott, 2003). Due to the ongoing increase in life expectancy, a child born in the year 2000 would be expected to survive approximately 50 years (Dodge, Lewis, Stanton, & Wilsher, 2007; Elborn, Shale, & Britton, 1991). Increasing survival sustains the prospects for achieving independence and employment. As survival rates improve, the population of adults with CF is growing and they are entering the workforce. The Cystic Fibrosis Foundation
reported that of the 26,272 total patients living with CF in 2010, 12,479 were adults and of them 45% maintained full-time or part-time employment.

Mortality in CF is improving significantly; nevertheless, morbidity is high due to the progressive course of the disease (Ernst, Johnson, & Stark, 2010; Ferkol, Rosenfeld, & Milla, 2006; Sanders et al., 2010; Yankaskas, Marshall, Sufian, Simon, & Rodman, 2004). According to the National Heart, Lung, and Blood Institute, in 2006, CF patients averaged six physician office visits and there were 11,000 hospitalizations with an average length of stay of 9.5 days (National Heart, Lung, and Blood Institute, 2009). In addition, individuals with CF have recurrent pulmonary exacerbations (Cystic Fibrosis Foundation, 2011). These episodes are characterized by a temporary deterioration of lung function evidenced by infection, increased cough and sputum production, a drop in lung function and/or weight loss (Cystic Fibrosis Foundation, 2011). Additionally, the CF Foundation (2011) reports that in 2009 the mean predicted lung function of adults with CF was 64.6% indicating moderate disease severity. Finally, people with CF shoulder an onerous daily treatment burden that requires a large amount of time (Ziaian et al., 2006). Specifically, CF management requires a complex and time consuming daily treatment regimen of airway clearance therapy, nebulized breathing treatments of antibiotics and mucolytic agents, numerous oral medications to treat pulmonary and digestive complications (pancreatic enzymes, vitamins, and antibiotics), dietary supplement drinks, and large meals and snacks (Ziaian et al., 2006; Zindani, Streetman, Streetman, & Nasr, 2006). What’s more, the complexity of the treatment routine escalates with increasing disease severity (Zindani et al., 2006).
In addition to the biological sequelae of the disease, emerging adults with CF face numerous psychosocial challenges while entering the workforce (Abbott & Gee, 1998; Ernst et al., 2010). Several studies have documented higher rates of anxiety and depression in people with CF over the general population (Cruz, Marciel, Quittner, & Schechter, 2009; Modi, Driscoll, Montag-Leifling, & Acton, 2011; Quittner, Barker, Snell, Grimley, Marciel, & Cruz, 2008). Furthermore, diminished health-related quality of life in people with CF is also well documented (Britto, Kotagal, Hornung, Atherton, Tsevat, & Wilmott, 2002; Gee, Abbott, Conway, Etherington, & Webb, 2003; Havermans, Colpaert, Vanharen, & Dupont, 2009; Hogg, Braithwaite, Bailey, Kotsimbos, & Wilson, 2007; Wahl, Rustoen, Hanestad, Gjengedal, & Moum, 2005).

Emerging adults with CF face a complicated journey entering the workplace. En route to achieving employment, they balance competing demands. Specifically they manage disease self-care, along with family, social, and academic obligations and the maturational process of moving from the dependency of adolescence to the independence of adulthood. Furthermore, while navigating towards adulthood, they must traverse complex healthcare, insurance, and educational systems, while making crucial career decisions. This constellation - treatment burden, pulmonary exacerbations, frequent clinic visits, hospitalizations, and psychosocial concerns - may have consequences for career development and gaining and maintaining employment in emerging adults with CF and accordingly warrants further investigation.

Pathophysiology of Cystic Fibrosis

CF is the most common fatal, inherited genetic disease in the United States affecting approximately 30,000 individuals and about one in every 3500 births each year (Cystic Fibrosis Foundation, 2011). In most cases of CF, a mutation of the delta-F508
gene causes abnormalities in electrolytes and the exocrine glands leading to mucus plugs in the bronchial tree, chronic recurrent pulmonary infections, and digestive disorders such as pancreatic insufficiency (Braekeleer, Bellis, Rault, Allard, Milot, & Simard, 2001). Other complications associated with CF include diabetes, intestinal obstructions, cirrhosis, hemoptyisis, and pneumothorax (Cystic Fibrosis Foundation, 2009). CF causes thick mucus to build up in the pulmonary and digestive systems of the body. In the lungs these mucus plugs cause infections which contribute to lung deterioration. The chief treatment procedures for respiratory complications are nebulized medications that thin the mucus, airway clearance therapies to expel mucus from the lungs, and antibiotics to treat bacterial infections (Yankaskas et al., 2004).

The digestive complications associated with CF, which result from pancreatic insufficiency, leave individuals unable to absorb nutrients from their food intake, and often result in severe malnutrition. Digestive complications are treated with replacement pancreatic enzymes taken with each meal, increased calorie intake, oral supplement drinks, enteral nutrition, and vitamin supplementation (DeLambo, Levers-Landis, Drotar, & Quittner, 2004; Dodge & Turck, 2006; Yankaskas et al. 2004). The course of the disease has many variations, which eventually lead to death, with chronic lung infections accounting for the majority of morbidity and mortality (DeLambo et al., 2004; Ratjen & Doring, 2003). Given the multiple organ systems associated with CF, it requires ongoing intensive medical management for life (Yankaskas et al., 2004). There is presently no cure but with advances in treatment, the survival of patients with CF is improving and what was once a childhood disease now affects adults who have a life expectancy of nearly 36 years (Cystic Fibrosis Foundation, 2011).
Disability Statistics: Prevalence, Employment Rate, and Earnings

The United States has a large number of individuals with disabilities. In the December 2008 Current Population Reports, the U.S. Census Bureau noted that, “of the 291.1 million people in the 2005 population of the United States, 54.4 million, or 18.7 percent, reported some level of disability, and 35 million (12.0 percent of all people) reported a severe disability” (Brault, 2008, p. 3). A severe disability is one that interferes with everyday activities, makes it challenging to maintain employment, and renders the person unable to perform or needing help with functional activities (Brault, 2008).

Individuals with disabilities are less likely to be employed than their nondisabled peers. The Bureau of Labor Statistics reported that the workforce participation rate, which is the share of the population working, was 20.9% in 2011 for people with disabilities. In comparison, the percentage of persons with no disability in the labor force was 69.7% (United States Department of Labor, 2012). In addition, the unemployment rate for people with disabilities in January 2012 was higher than for persons with no disability -12.9% versus 8.7% (United States Department of Labor, 2012). What this represents for people with disabilities is a loss of income, and more importantly, a loss of social and economic participation.

Disability statistics compiled by the 2008 American Community Survey further demonstrate the disparities in employment experienced by individuals with disabilities. Among youth ages 16-20 with a disability, an estimated 26.4% were employed versus an employment rate of 41.2% for those without a disability (Erickson, Lee, & von Schrader, 2008). For adults with disabilities, the inequalities in employment are even
more pronounced – in 2008, an estimated 39.5% of individuals ages 21-64 were employed compared to 79.9% without a disability (Erickson et al., 2008).

According to a report by the Center for Economic and Policy Research (2009), the poverty rate for people with disabilities is two to three times higher than for the non-disabled population. A disability can result in income poverty because of unemployment/underemployment, employment discrimination, lack of advancement opportunities, reduced earnings, and barriers in education and skill development (Fremstad, 2009). Moreover, income poverty can limit access to health care and preventive medicine and increases the chances that one will live in an environment that adversely affects health status (Fremstad, 2009).

Additionally, people with disabilities experience workplace discrimination. The National Organization on Disability reports, “36% of employed people with disabilities report encountering at least one instance of discrimination in the workplace due to their disabilities” (Frieden, 2003). The majority of allegations of discriminatory behaviors relate to personnel actions pertaining to discharge, reasonable accommodation, employment terms and conditions, disability harassment, hiring, and discipline not to acquiring employment (McMahon & Shaw, 2005). In the period from July 26, 1992, the effective date of the Americans with Disabilities Act (ADA), to 2003 over 600,000 allegations of discrimination were filed with the Equal Employment Opportunity Commission under Title I of the ADA (McMahon, Edwards, Rumrill, & Hursh, 2005). Workplace discrimination makes it more likely that a person with a disability will terminate their employment (Fong, McMahon, Cheing, Rosenthal, & Bezyak, 2005; McMahon & Shaw, 2005).
Having a disability places emerging adults at a serious disadvantage in the workforce and thereby jeopardizes participation in society and the ability for independent living. Carter et al. (2010, p. 195) reported that, “the pervasiveness and persistence of disappointing post-school employment outcomes for young adults with disabilities have prompted ongoing concerns” and this assertion is supported by other researchers. O'Day and Stapleton (2009) have reported on declining employment rates for youth with disabilities - 57.5% to 40.9% during the period of 1989 to 2000 when the economy was growing. Data about youth with disabilities obtained by the National Longitudinal Transition Study 2 also demonstrate slight declines in employment from 62% in 1990 to 56% in 2005 (Newman, Wagner, Cameto, Knokey, & Shaver, 2010).

Obtaining one’s first job is a milestone and rite of passage for youth in the United States (Blomquist, 2006; Csikszentmihalyi & Schneider, 2000). More importantly, employment is a common experience during adolescence (Kelloway & Barling, 1999; Wagner, Newman, Cameto, Garza, & Levine, 2005) which serves many valuable functions in preparing for adulthood. Rogan, Grossi, and Gajewski (2002) observed, “Work is a central component of a quality adult life. Employment provides a source of income, enhances self-esteem, provides important social connections, and allows people to fulfill their duties as contributing, tax-paying citizens” (p. 104). Early employment opportunities expose young people to the world of work and potential careers while they build confidence, learn skills and earn income. Moreover, the early work experiences of adolescence contribute to favorable long-term employment outcomes in adulthood (O'Day, Stapleton, & Mathematica Policy Research, Inc., 2009). Students with disabilities who lack this experience may encounter lifelong
unemployment, underemployment, or lowered expectations (Carter et al., 2010). Likewise, they also have less knowledge of job responsibilities, inaccurately appraise their skills and qualifications, and experience trouble making career decisions (Ochs & Roessler, 2001).

Among high school students without disabilities, approximately 80% report holding a job at some point during their high school tenure (Cameto, Marder, Wagner, & Cardoso, 2003). Conversely, students with disabilities face obstacles obtaining work and are employed at half the rate of their non-disabled peers (Wagner, Cadwallader, & Marder, 2003). Emerging adults with disabilities face significant disadvantages in the labor market and this may also extend to the population with CF who may face an uncertain path to employment and career success.

**Educational Achievement and Employment Outcomes**

The 2003 National Survey of Children's Health estimated that 20% of all children, aged 6 to 17 have a special health care need (Bethell, Read, Blumberg, & Newacheck, 2008) and 6.5% of children experience a degree of illness severity sufficient to interfere with school activities (Shaw & McCabe, 2008). Thus, youth with chronic illnesses are at elevated risk for poor academic outcomes (Dworkin, 1989; Fowler, Johnson, & Atkinson, 1985; Shaw & McCabe, 2008). The annual high school completion rate for students with disabilities surveyed by the National Longitudinal Transition Study (NLTS) was 72% (Newman, Wagner, Cameto, & Knokey, 2009). Specifically, poor grades and standardized test scores signify lower academic performance and subsequently educational achievement is undermined by lower motivation to do well in school, disruptive behaviors, and frequently being bullied (Forrest, Bevans, Riley, Crespo, & Louis, 2011). The percentage of students with disabilities completing college reported
by the NLTS survey was just 29% (Newman et al., 2009). The 71% of students with disabilities who did not complete degree requirements cited reasons including poor grades, expense, not liking school, health demands, transportation problems, and not getting needed services (Newman et al., 2009).

The majority of school age children with CF have few or no hospitalizations or exacerbations however school absence is a concern because of illnesses related to lung infections (DePaepe, Garrison-Kane, & Doelling, 2002; Strawhacker & Wellendorf, 2004). One study (Wildhagen et al., 1996) reported that children with CF were absent an average 19.5 school days per year. Educational achievement for students with disabilities is significant because it is associated with positive employment outcomes for emerging adults seeking their first jobs (Achterberg, Wind, de Boer, & Frings-Dresen, 2009). Some researchers have even posited that postsecondary education is now a necessary step towards employment in the information age (Carnevale & Desrochers, 2003; Frieden, 2003; Gilmore, Bose, & Hart, 2001; Newman et al., 2010).

**Employment and Cystic Fibrosis**

Many studies have examined the lived experience of CF but career development and the role of work has received only cursory investigation. There is insufficient research in the area of CF and its employment implications (Burker et al., 2005; Demars, Uluer, & Sawicki, 2010; Gillen et al., 1995). Extensive searching of electronic databases uncovered ten studies related to CF and employment conducted in the last thirty years. However, none of the studies explored career development, the meaning or experience of work, or the practical employment implications of CF and thus have limited utility for rehabilitation professionals assisting individual’s with CF in their occupational pursuits. Rather, the majority of the studies investigated diverse medical
aspects of the disease that contribute to work disability. The results of the studies must be cautiously interpreted as sample sizes were small and in each case, the research was conducted at just one or two CF centers.

A number of studies offered guidance as to the role of pulmonary function, expressed as forced expiratory volume in 1 second or FEV₁, in work disability. The results are mixed. Three reports showed that FEV₁ was not predictive of work disability as individuals with CF were working in spite of poor lung function. While two studies demonstrated, that FEV₁ does play a significant role. Regardless, it is evident that people with significant lung damage continue to work. There is much variability in symptoms experienced by individuals with CF and disease severity alone does not predict employment outcomes. Important factors to consider are the presence or absence of depression, frequency of hospital admissions, educational level, type of work, and the number of hours worked.

Work also has a positive effect on quality of life. Two studies examined health-related quality of life and both demonstrated better quality of life in working individuals. These findings are consistent with several studies (Eggleton, Robertson, Ryan, & Kober, 1999; Leduc & Lepage, 2002; Mickelson, Bolund, & Brandberg, 2001; Miller & Dishon, 2006; Phillips & Stuifbergen, 2006) that indicate health-related quality of life is greater when one is employed.

The existing employment research in CF is limited in quantity and scope. This body of work focused on predicting work disability, employment rates, vocational rehabilitation, and health-related quality of life however excluded work experiences,
career development, and the meaning of work. Moreover, the existing studies largely quantified rather than qualified the experience of work.

Employment is a goal for many with CF and no single factor accounts for employment success or failure (Goldberg et al., 1985; Mungle, Burker, & Yankaskas, 2002). The overarching conclusion is that emerging adults with CF have the desire or intention to work. Along their path to employment, they sometimes encounter barriers related to sequelae of their illness. Aside from managing the demands of the disease, as they mature they attend to typical responsibilities, “employment, living arrangements, getting around the community, financial independence, making friends, sexuality and self-esteem, and having fun” (Wehman, 2001, p. 8). With assistance from parents, school personnel, health care and community resources, they can be successful in these areas.

**Toward A Grounded Theory of Career Development with Cystic Fibrosis**

Little is known about the employment experiences of people with CF and its effects on career development. Specifically, the career development of individuals with CF was investigated in just one long ago study (Goldberg, Isralsky, & Shwachman, 1979). Despite a vast body of career development literature, individuals with disabilities are typically overlooked (Conte, 1983; Curnow, 1989; Szymanski et al., 2003). The majority of the extant career development research was conducted with healthy nondisabled individuals and particularly “middle class White males” (Szymanski et al., 2003, p. 92). Furthermore, there is not a generally accepted model of career development pertaining to people with disabilities (Goldberg, 1992).
Theoretical Frameworks

In order to understand and address the unique employment context of individuals with CF, two theoretical frameworks were relevant - one that places CF within the milieu of a disability framework and one for conceptualizing the particular developmental stage of emerging adults with CF. I adopted the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001) and the emerging adulthood model (Arnett, 2000; Arnett, 2004) as guiding theoretical frameworks.

The World Health Organization (2001) framework, the International Classification of Functioning, Disability, and Health (ICF), is a classification system for the description of health and health-related states that provides a lens by which to understand functioning and disability (De Kleijn-De Vrankrijker, 2003; Stucki & Rauch, 2010). The ICF provides a context for determining the influence of CF on career development and employment. The “emerging adulthood” model is theoretical framework from which to evaluate and understand the co-occurring maturational and employment processes of young adults with CF. Emerging adulthood is a new developmental stage posited by Arnett (2000; 2004) that bridges the period between adolescence and young adulthood. These two frameworks in tandem provided a basis from which to examine employment within the context of CF.

Rationale for the Methodology

In keeping with the exploratory nature of the study, the method used was grounded theory. This qualitative method was most appropriate to this area of research, as no theory exists to explain how emerging adults with CF experience work, make career decisions, and construct the personal meaning of work as they mature. This method allowed for the complexities associated with CF and employment to be
better understood through the development of a substantive theory generated from the very experiences of emerging adults with CF.

The study employed the grounded theory method of qualitative inquiry to gain a deep and rich understanding about the personal meaning of work to, and the employment experiences of, people with CF. Grounded theory explores “the ways in which reality is socially constructed” (Richards & Morse, 2007, p. 59) and so there is congruence between the method and the social situation of employment.

Grounded theory was adopted because it allowed for the thorough examination of this topic from the viewpoint of the individual - my intention being to compile a thick description of the lived experience of CF and its employment aspects. Bowers (1988) states that, “the grounded theory researcher intentionally becomes immersed in the world of the research subjects.” From the grounded theory perspective, it is the individual with CF who can best define what the truths are pertaining to employment.

**Goal of the Research**

The primary goal of the study was to conduct grounded theory research that results in an understanding of the personal meaning of work to, and the employment experiences of, people with CF and ultimately a substantive grounded theory of career development applicable to individuals with this disease.

**Research Questions**

The purpose of the proposed study is to answer these research questions for a sample of emerging adults with CF:

1. What is the personal meaning of work?
2. How has the illness influenced their employment choices and aspirations?
3. What are their lived experiences in the workplace?
4. What is the career development process?
The specific aims of the study were four-fold: (a) to gain a deep understanding about the meaning of work to emerging adults with CF, (b) to give voice to emerging adults with CF to discover how the illness has influenced their employment aspirations, (c) to identify, describe, and analyze the employment experiences of emerging adults with CF, and (d) to identify, describe, and analyze the process of career development in emerging adults with CF.

**Potential Contribution to Rehabilitation Theory and Practice**

Just one study to date has examined career development (Goldberg et al., 1979) and no studies have investigated the work experiences of individuals with CF. The shortage of vocational literature in CF presented an opportunity for further research on the personal meaning of work, on barriers and facilitators of employment, and career development in the context of CF. The current cohort of emerging adults with CF were born at a time when the predicted median survival age was approximately 26 years (Cystic Fibrosis Foundation, 1997) and life prolonging treatments were yet to be discovered thus the prospect of reaching adulthood and attaining employment was not widely considered achievable. Increasing longevity sustains the prospect of entering the workforce. Understanding the interplay of CF and employment informs the rehabilitation knowledge base and is essential in order for rehabilitation counselors to deliver vocational services. Furthermore, knowledge regarding employment implications would allow rehabilitation and medical professionals, educators, and employers to help individuals with CF overcome obstacles and facilitate successful employment.
Summary

“People with disabilities would like to obtain jobs that meet their needs and are suited to their talents, and, like everyone else, they would like to secure promotions and advance in their careers” (Feldblum, 1991, p. 82). Likewise, there is no reason to presume that emerging adults with CF do not place the same value on work as others, however, they could face an uncertain path to employment and career success. Their route is complicated by several factors including: unpredictable disease exacerbations and sequela, a heavy treatment burden, the rigorous demands of treatment adherence, and psychosocial challenges related to having a chronic illness.
CHAPTER 2
LITERATURE REVIEW

Cystic Fibrosis and Employment

Cystic fibrosis and its employment consequences have received little attention within the literature (Burker et al., 2005; Demars et al., 2010). An extensive search of electronic databases discovered just 10 research-related journal articles pertaining to CF and employment were published between 1979 and 2010. The majority of these reports investigated diverse medical aspects of CF that contribute to work disability (WD). None revealed any universally accepted methods of determining vocational capacity or identified employment barriers and facilitators. Additionally, investigations regarding the employment experiences of people with CF and its effects on career development are nonexistent.

Disease Severity and Employment

One often-quoted marker of WD is lung function (expressed as FEV$_1$). Lung function is quantified by the pulmonary function test and is one measure of disease severity often cited within the literature. The CF Foundation issued these guidelines for evaluating lung function:

Severity of lung disease is based on a person’s lung function or FEV$_1$ percent predicted. In CF, the lower a person’s FEV$_1$ the more severe the lung disease. An FEV$_1$ greater than or equal to 90 percent is normal. An FEV$_1$ between 70 and 89 percent means mild lung disease. An FEV$_1$ between 40 and 69 percent indicates moderate lung disease. If the FEV$_1$ is less than 40 percent, severe lung disease is present. (Cystic Fibrosis Foundation, 2009, p. 9)

The results of studies using FEV$_1$ as a marker of WD are mixed. Six studies (Burker, Sedway, & Carone, 2004; Frangolias, Holloway, Vedal, & Wilcox, 2003; Gillen et al., 1995; Haermans et al., 2009; Goldberg et al., 1985 and Hogg et al., 2007)
examined the influence of lung function and other predictors of WD on employment status. Three of the six reports examined disease severity alone as a predictor for employment status. Burker et al. (2004), Frangolias, Holloway, Vedal, & Wilcox (2003), and Hogg et al. (2007) used FEV₁ as a proxy for disease severity and found that moderate to severe lung disease was not a strong predictor of whether one would be employed. For example, Burker et al. (2004) found no difference between FEV₁ of working and non-working groups within a sample of 183 individuals with CF (32.4% versus 32.1% respectively). Instead of FEV₁, elevated depressive symptoms, education level, and optimism had greater influence on determining WD. Burker et al. (2004) found that those who were not working had clinically elevated scores on the Beck Depression Inventory while those who were working had lower depression scores. Furthermore, Burker et al. (2004) reported that the education level was lower in those not working.

Frangolias et al. (2003) noted that FEV₁ results were similar for both employed and unemployed subjects. This study was conducted to determine if the combination of pulmonary function testing and exercise testing were better predictors of work/school status than pulmonary function tests alone. In this sample, the mean FEV₁ was 53.4%. The authors concluded that although FEV₁ was useful in detecting severity of impairment, this measure does not have clinical utility for predicting work status. Specifically, the authors reported it was difficult to control for degrees of impairment as the range of patients who were working had a disease severity ranging from mild to severe. The authors further reported that the lower range of disease severity (FEV₁ < 40% predicted) poorly discriminates between working and non-working individuals.
Hogg et al. (2007) reported a mean FEV$_1$ of 51.8% in their sample of adults with CF, yet they observed that neither the FEV$_1$ nor the S-K score (another measure of lung function) reliably determined disability. Rather, age, frequency of hospitalizations, and disease mastery (a feeling of control over the disease) were better determinants of disability as defined by work participation.

Two reports, Gillen et al. (1995) and Havermans et al. (2009) presented opposing conclusions regarding the predictive power of FEV$_1$ on WD. Gillen et al. (1995) reported the mean FEV$_1$ for the studied sample was 51%. The authors reported that disease severity was associated with WD but added that other factors were also significant. In addition to FEV$_1$, Gillen et al. (1995) noted that being diagnosed as an adult, being female, and being single contributed to WD. Havermans et al. (2009) reported a mean FEV$_1$ of 65.09% for the sample. They found that FEV$_1$ was significantly lower in patients who were not working.

Goldberg et al. (1985) used another measure, the S-K score, as a proxy for severity of illness. The authors reported that disease severity was not significantly correlated with work status or vocational development. However, they did find that disease severity was negatively correlated with educational status. In this study, more severe illness indicated a greater chance of derailing educational plans. Isralsky et al. (1979) also using the S-K scoring system to evaluate disease severity, made the assertion that disease severity was not associated with developing vocational plans. The authors found that youth with more or less severe disease did not have difficulty setting vocational goals.
Studies by Burker et al. (2004), Gillen et al. (1995), and Hogg et al. (2007) indicate that variables other than FEV\textsubscript{1}, for example frequency of hospital admissions, demographic variables, mental health, and education level, have greater influence on employment status. Burker et al. (2004) found that those who were not working had clinically elevated scores on the Beck Depression Inventory while those who did work had lower depression scores. Furthermore, Burker et al. (2004) reported a higher education level among those who were working as opposed to those unemployed.

Gillen et al. (1995) reported that certain characteristics (being diagnosed as an adult, female gender, and marital status) considerably influenced WD. The authors found that these three variables were individually statistically significant risk factors contributing to WD. Additionally, when added to a model of disease severity featuring FEV\textsubscript{1}, S-K score, and hospitalization frequency, the inclusion of the demographic variables enhanced the explanatory power of the model.

Hogg et al. (2007) found that maintaining employment was associated with one’s age, disease mastery (feeling in control over the illness), and frequency of hospitalizations. The authors reported that there was not a significant relationship between working and FEV\textsubscript{1}, S-K score, or gender. Work status depended on frequency of hospitalizations and quality of life domains (mastery of illness, dyspnea, fatigue, emotional functioning, and overall quality of life score).

Based on this body of literature it is evident that individuals with CF and significant lung damage continue to work. There is much variability in symptoms experienced by individuals with CF and disease severity alone does not predict employment outcomes. Other important factors to consider are family support, employer and coworker support,
the presence or absence of depression, frequency of hospital admissions, educational level, type of work, and the number of hours worked.

**Specific Employment Considerations**

The extant literature suggests that individuals with CF place the same value on work as their healthy peers (Goldberg et al., 1979), however, given the progressive disease process and symptoms, they could face an uncertain path to employment and career success. Physical manifestations and emotional complications of CF denote numerous theorized barriers to optimal career and employment outcomes (Bevelaqua & Adams, 1993; Falvo, 2005; Gillen et al., 1995; Goldberg et al., 1985). CF imparts a unique set of conditions that may influence choosing, getting, and keeping employment but these are not well-researched (Gillen et al., 1995; Mungle et al., 2002). The route to employment is complicated by several factors including: unpredictable disease exacerbations and sequela, disclosure to employers, managing the complex treatment regimen while working, managing symptoms at work (for example, coughing spells and bowel problems), frequent clinic visits, and hospitalizations (Elborn, 1998; Demars et al., 2010; Gillen et al., 1995; Mungle et al., 2002). Other concerns are workplaces with airway irritants, exposure to infections, exertion level, and job stress (Orenstein, 2004; Yankaskas et al., 2004). These varied conditions are not well documented in the literature and combined may have consequences for emerging adults in gaining and maintaining employment.

There are no outright prohibitions about career choices, in spite of all the potential employment barriers, and the recommended guidance is to consider intellect, ability, preferences, life goals, and current and future physical limitations (Orenstein, 2004; Yankaskas et al., 2004). Some employment accommodations that individuals seek are
flexible work hours, reduced work hours, flexible use of vacation and sick time, and working from home (Yankaskas et al., 2004).

**Employment Rate and Occupation Type**

The CF Foundation (2011) reported that in 2009, 46% or 5748 adults with CF maintained some level of full-time or part-time employment. Conversely, 22% or 2749 individuals were unemployed or identified as disabled and the remainder of the adult population described themselves as students, homemakers, or retired. This employment rate is comparable to what numerous studies have reported.

Several studies described employment rates and the type of positions held by individuals with CF. Seven studies (Burker et al., 2004; Burker et al., 2005; Demars et al., 2010; Frangolias et al., 2003; Gillen et al., 1995; Goldberg et al., 1985; Hogg et al., 2007) detailed employment rates and the types of employment held by their respective samples. In every study, approximately 50% of the sample was working. In the Burker et al. (2004; 2005) studies (n=183), 53.4% of subjects were employed in professional, technical, or managerial capacities and to a lesser extent (29.5%) in clerical, sales, and services positions. Demars, Uluer, and Sawicki (2010) (n=68) reported a breakdown of hours worked per week: 46% working 0-20 hours per week, 17% working 20-30 hours per week, 23% working 30-40 hours per week, and 14% working >40 hours per week but no information was provided on the type of occupation. Frangolias et al. (2003) (n=73) reported 51% worked fulltime and 34% worked part-time in varied occupations. Gillen et al. (1995) (n=49) reported that the majority of subjects (53%) were employed in professional occupations; followed by sales/clerical work (31%), other occupations (16%), and self-employment (12%). Goldberg et al. (1985) (n=52) reported 66% of the
sample working in entry-level professional occupations. While Hogg et al. (2007) (n=50) reported 40% of the sample working at the time and 94% having had some work history.

**Vocational Rehabilitation**

According to Burker et al. (2005) it is only recently that individuals with CF are considered viable candidates for vocational rehabilitation services. This has to do with the perception among rehabilitation providers of limited life expectancy and vocational potential (Burker et al., 2005). Furthermore, only a small number of people with CF are referred or receiving VR services nationwide (Burker et al., 2005). In 2010, out of 321,791 clients with disabilities nationwide who received VR services, 189 (0.06%) were individuals with CF (J.S. Doyle, Rehabilitation Services Administration, personal communication, May 9, 2011).

Three older studies (Goldberg et al., 1985; Goldberg et al., 1979; Isralsky, Goldberg, & Shwachman, 1979) examined vocational rehabilitation aspects of CF. Goldberg et al. (1979) investigated vocational development and adjustment in CF and drew three major conclusions. First, the CF group scored lower than a healthy peer group in measures of vocational and educational plans and was less realistic in considering their limitations. Second, the CF group scored higher on measures of commitment to vocational choice, work values, and awareness of occupational information. Third, the authors concluded that CF patients held strong work values.

Goldberg et al. (1985) studied the rehabilitation status of young adults with CF. This was a longitudinal study of disease severity and the educational and vocational plans of a group of CF patients. Similar to Frangolias et al. (2003) and Hogg et al. (2007), this study reported on the employment limitations presented by CF. For instance, subjects reported limitations due to poor health, limits on the number of hours
they could work, and the need to avoid extremes in climate. In addition, Goldberg et al. noted vocational status was not predicted by any one clinical or demographic factor. Goldberg et al. (1985) concluded that vocational counseling should begin at an early age and continue through adulthood.

Isralsky et al. (1979) investigated the educational and vocational needs of individuals with CF and made the assertion that disease severity was not associated with making vocational plans. In addition, Isralsky reported that children with CF have less exposure to career information and that career planning has been inadequate because of the limited life expectancy. Furthermore, vocational development stages might not apply to children with CF, who are often absent from school, because this stunts their development process.

**Employment and Health-Related Quality of Life**

Health-related quality of life (HRQOL) is a multidimensional construct that encompasses four domains: “1. disease state and physical symptoms, 2. functional status, 3. psychological/emotional state, and 4. social functioning” (Quittner, Buu, Messer, Modi, & Watrous, 2005, p. 2347). Two studies (Havermans et al., 2009; Hogg et al., 2007) have been reported that focus on the relationship of work and HRQOL. Havermans et al. (2005) (n=57) tested the relationship of disease severity (measured by FEV₁) to HRQOL (measured by the Cystic Fibrosis Questionnaire – Revised) to determine if working or non-working individuals reported better HRQOL. Work was classified as either full or part-time employment or school attendance. They reported three findings: First, higher levels of HRQOL are associated with milder disease severity. Second, milder disease severity was noted in individuals who are working or going to school. Third, higher levels of HRQOL are associated with working. Despite
the fact that work contributes to perceptions of better quality of life, Havermans et al. (2009) also point out the demands of working have a detrimental effect on health status.

Hogg et al. (2007) evaluated disease severity and WD in relationship to quality of life using the Chronic Respiratory Disease Questionnaire for 50 individuals with CF. The authors found that work was related to better quality of life scores. At the time of the study, 40% of the sample was working and 94% reported some work history. Hogg et al. (2007) further reported CF had affected career choice (51% of the sample), the job duties (37% of the sample), quit rate due to CF (35% of the sample), and significant obstacles to employment (68% of the sample). Just 6% reported receiving any formal career counseling. Similar to Hogg et al., Frangolias et al. (2003) reported that CF influenced educational and employment choices with 34% of the sample responding that, CF influenced educational goals and 41% responding that CF influenced career goals.

**Educational Achievement and Employment Outcomes**

The majority of school age children with CF have few or no hospitalizations or exacerbations but school absence is a concern because of illnesses related to lung infections (DePaepe et al., 2002; Strawhacker & Wellendorf, 2004). One study (Wildhagen et al., 1996) reported that children with CF were absent an average 19.5 school days per year. Educational achievement is associated with positive employment outcomes in adulthood (Achterberg et al., 2009) though; just one CF specific investigation of this phenomenon is available (Burker et al., 2004). Burker et al. (2004) reported a higher education level among those who were working as opposed to those unemployed. Additionally, descriptive data published by the CF Foundation is available. Emerging adults with CF, have a high school graduation rate that varies from the
general population and from youth with other disabilities. According to the Cystic Fibrosis Foundation, 26% of adults had completed high school and another 8% of the population had less than a high school education (Cystic Fibrosis Foundation, 2011). This compares to 72% of all students with disabilities completing high school in 2003 (Wagner, Newman, Cameto, Garza, & Levine, 2005) and 89% of the general population completing high school in 2008 (Chapman, Laird, & KewalRamani, 2010).

Secondary school completion and enrollment in post-secondary education is pertinent to later employment outcomes and earnings for youth with disabilities. In addition, as the economy becomes increasingly knowledge-based, attaining postsecondary education is crucial (Newman et al., 2009). For instance in 1959, only 20 percent of workers needed some college for their job whereas by 2000, this had increased to 56 percent (Newman et al., 2009). Furthermore, level of education significantly affects one’s earning potential. According to the National Center for Education Statistics, “In 2008, young adults with a bachelor’s degree earned 28 percent more than young adults with an associate’s degree, 53 percent more than young adult high school completers, and 96 percent more than young adults who did not earn a high school diploma” (Aud et al., 2010, p. 60).

**Disability and Employment Themes**

Given the limited amount of available research pertaining to CF and employment, studies relating to the employment experiences of people with disabilities were examined to discern general themes that may also be applicable to CF. The studies reviewed here detail the experiences of individuals with varied disabilities - physical and sensory deficits, mental illness, HIV, cancer, multiple sclerosis, motor neurone disease, Huntington’s disease, and Parkinson’s disease.
Several key themes emerge from the literature regarding the employment aspects of having a disability. These are barriers, stigma, discrimination, concerns about disability disclosure, negative vocational rehabilitation experiences, and the meaning of work.


Physical barriers are a commonly reported compliant (Conyers et al., 1998; Noonan et al., 2004). This refers to inaccessible environments such as entrances to schools and office buildings and the layout within those facilities. Physical barriers have the unintended consequence of limiting educational and vocational opportunities.

Stigma and discrimination are also widely reported in the literature (Freedman & Fesko, 1996; Hernandez et al., 2007; Noonan et al., 2004; O’Day, 1998; Shier et al., 2009; Yorkston et al., 2003). Many individuals with disabilities report not being offered employment, dismissal from employment, limited opportunities for advancement, and being informed they could not perform certain jobs or tasks. Reasons cited by people with disabilities for not being hired or being terminated were that accommodations were
too expensive, being hired would lead to increases in work related accidents, and a subtle notion that people with disabilities are unable to work. Additionally, they experience what Noonan (2004, p. 69) labeled “anti-disability prejudice” - negative attitudes by coworkers and supervisors.

Disability disclosure figures prominently in several pieces of research (Fesko, 2001; Freedman & Fesko, 1996; Johnson, Yorkston, Klasner, Kuehn, Johnson, & Amtmann, 2004; Shier et al., 2009). Disclosure is often required in order to obtain on the job accommodations yet it has some potential disadvantages. Participants in one study expressed apprehension about disclosing hidden disabilities and thus being eliminated from consideration by prospective employers (Freedman & Fesko, 1996). Self-disclosure is also linked to employer discrimination (Shier et al., 2009). Another study found that being HIV+ carried a greater stigma and potential for anti-disability prejudice such that these workers were less likely to disclose their disability (Fesko, 2001).

There is a concern about when to disclose a disability either prior to an interview, during an interview, or after the offer of employment. Given the high incidence of stigma and discriminatory employment practices noted in multiple studies (Freedman & Fesko, 1996; Hernandez et al., 2007; Noonan et al., 2004; O'Day, 1998; Shier et al., 2009; Yorkston et al., & Dudgeon, 2003), concern is justified. Disclosure could be perceived by some individuals with a disability as self-incriminating rather than empowering. Fesko (2001) suggests that rehabilitation counselors can aide clients by exploring their comfort with sharing their condition and developing a scripted disclosure statement.
Several studies (Benz, Johnson, Mikkelsen, & Lindstrom, 1995; Freedman & Fesko, 1996; Hernandez et al., 2007; O'Day, 1998) cited negative experiences with vocational rehabilitation (VR) services. VR services are intended to be beneficial for individuals with disabilities however, in many instances they hinder rather than help. Freedman and Fesko (1996) noted several deficiencies in the delivery of services including poor counselor follow-up, lack of help with job searches, placement in dead-end jobs, cases being closed prematurely, inconsistent application of guidelines, and inconsistent service delivery that depends on the quality of one’s counselor or assigned regional office. Hernandez et al. (2007) reported similar VR shortcomings and found that clients were placed in low wage, temporary, and menial positions. O'Day (1998) reported that some informants never heard of VR. While other informants in O'Day’s study (1998) reported, it was impossible or difficult to get services and were told there were no funds. Finally, Benz, Johnson, Mikkelsen, and Lindstrom (1995) reported this from their survey,

Students and parents are: (a) confused about the transition process and the different transition resources in the community; (b) intimidated by the VR application process; (c) frustrated with the number of assessments that must be conducted for eligibility determination, and the lack of meaningful information about the reasons for these assessments; and (d) overwhelmed by, and even somewhat embarrassed about, the variety of professionals with whom they must discuss their needs in order to obtain transition information and resources (p. 143).

Work has profound meaning for individuals with and without disabilities (Dutta, Gervay, Chan, Chou, & Ditchman, 2008; Szymanski & Hershenson, 1998) and contributes to life satisfaction (Judge & Watanabe, 1993). In particular, employment conveys a valued social status, gives purpose to life, and represents economic security (Szymanski, Parker, Ryan, Merz, Trevino-Espinoza, & Johnston-Rodriguez, 2003).
Thus, work has great meaning for all individuals. Three studies investigated the meaning of work (Conyers et al., 1998; Freedman & Fesko, 1996; Johnson et al., 2004) in the lives of the participants. Conyers, Koch, and Szymanski (1998) found employment meets important psychological and economic needs while reducing the sense of dependency felt by individuals with disabilities. Freedman and Fesko (1996) observed employment means, “feeling productive and keeping busy” (p. 51) which increases self-esteem and well-being. To others work goes beyond the financial benefit – it is therapeutic, enhances their identity, and increases social contact thereby decreasing isolation (Johnson et al., 2004).

People with disabilities face significant barriers in the workplace. They must cope with, among other things; stigma, discrimination in hiring and promotions, architectural and physical barriers, uncertainty about disclosing their disability, and a poor system of services from vocational rehabilitation departments. It would follow that people with CF encounter similar difficulties in their employment experiences, however; there is no confirmatory research. There is a large gap in the research regarding the career development and employment experiences of people with CF.

**Transitioning to Adulthood and Employment**

Transition to adulthood is a multifaceted process that encompasses employment, education, self-determination, relationships, consumerism, and health care (Repetto, 2003). Examples of some transition tasks are, connecting to primary and specialty health care providers, preparing for post-secondary education and/or work, housing arrangements, transportation, and financial independence (Betz & Redcay, 2005; Repetto, 2003). Halpern (1994) provided the seminal description of transition:
Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in postsecondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult service agencies, and natural supports within the community. The foundations of transition should be laid during the elementary and middle school years, guided by the broad concept of career development. Transition planning should begin no later than age 14, and students should be encouraged, to the full extent of their capabilities, to assume a maximum amount of responsibility for such planning (p. 116).

For emerging adults with CF transition has become a focal point in the past two decades (Reiss & Gibson, 2002; Zack et al., 2003). This attention is due primarily to the gain in longevity, with life expectancy now approaching 36 years. Transition with CF has the added challenges posed by a complicated daily medical regimen that individuals must uphold in order to maintain their health (Palmer & Boisen, 2002). Transition to adulthood can be complex for healthy young adults and especially difficult for those who have a chronic illness as they may encounter additional challenges to negotiating the transition to independence (Hanley-Maxwell, Szymanski, & Owens-Johnson, 1998; Wagner, Newman, Cameto, Levine, & Garza, 2006).

**Vocational Rehabilitation and the Education System: Partners in Transition**

Transitioning to independence with CF includes navigating two complex organizations that operate in tandem – the vocational rehabilitation and education systems. The federal Vocational Rehabilitation (VR) program is “a critical link in assisting youth with disabilities to prepare for education, training, and employment” (Kochhar-Bryant, Bassett, & Webb, 2009, p. 34). VR professionals are ideally suited to assist emerging adults with CF in the transition process with their knowledge of the workplace and disability. School districts collaborate with the VR program to deliver
transition services and additionally have their own federal mandate to assist students with disabilities in the guise of the Individuals with Disabilities Education Act (Benz, Lindstrom, & Latta, 1999; Kochhar-Bryant et al., 2009).

The education system and VR have been collaborating on behalf of youth with disabilities since the passage of two historic pieces of federal legislation in the 1970s - the Rehabilitation Act of 1973 and the Education for All Handicapped Children Act of 1975 (now the IDEA) (National Council on Disability, 2008). Together these laws have made it possible for thousands of children with disabilities to gain the educational and vocational skills required for transition to adulthood. According to Benz, Lindstrom, and Latta (1999) school and VR agency partnerships were emphasized since the passage of the laws,

The need for state and local education and vocational rehabilitation agencies to collaborate in their support of transition-aged youth was recognized and emphasized in the parallel transition-related language and mandates contained in the Individuals with Disabilities Education Act of 1990 (P.L. 101-476) and the Rehabilitation Act Amendments of 1992 (P.L. 102-569) (p. 56).

VR is a federal-state program designed to help people with disabilities to choose, get, and keep employment. The VR program administers school-to-work transition services that include activities to help students with disabilities prepare and plan for employment success after high school. Generally, students served by school-to-work transition services are between the ages of 16 to 24 as this is stipulated in IDEA.

The federal Rehabilitation Services Administration (RSA) is the parent agency of the VR program. RSA dictates school-to-work transition programs offer the following core services: assessment, diagnosis and treatment of impairments, vocational counseling, occupational training, on-the-job training, basic academic and remedial
training, job readiness training, disability related skills training, miscellaneous training, 
job-related services, transportation, maintenance, rehabilitation technology, personal assistance services, technical assistance services, and other services (National Council on Disability, 2008). Ideally, these seventeen core services are implemented with input from the student and their parent or guardian. Services are provided in a variety of settings including schools, VR offices, private practitioner’s offices, and work sites (National Council on Disability, 2008).

The Education for All Handicapped Children Act (renamed the Individuals with Disabilities Education Act or IDEA) was enacted in 1975 to address and rectify the educational inequalities experienced by students with disabilities. Prior to the passage of the act, these students experienced discrimination and exclusion from school. The act was reauthorized in 1990, 1997, and 2004 each time making further improvements for students with disabilities (Smith & Tyler, 2010). In the past twenty years, students with disabilities have made great strides in making the shift from secondary to post-secondary educational environments thanks in part to the benefits of IDEA (Kochhar-Bryant et al., 2009).

Effective transition planning is crucial to the success of students with disabilities after high school (Flexer, Baer, Luft, & Simmons, 2008; Smith & Tyler, 2010). Under IDEA, transition services, “facilitate the child’s movement from school to post-school activities” (Cobb & Alwell, 2007, p. 11) including postsecondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living, or community participation (US Department of Education, 2011). Transition services are documented in the child’s
Individualized Education Plan (Smith & Tyler, 2010). These consist of a broad array of activities designed to facilitate the movement towards adulthood by means of classroom instruction, related services, community experiences, the development of employment and other post-school adult living objectives; and if appropriate, acquisition of daily living skills and provision of a functional vocational evaluation (US Department of Education, 2011).

Transition assessment involves an appraisal of a varied set of competencies needed for adulthood. Assessment of an adolescent’s interests, preferences, strengths, and needs is a necessary component for successful transition. Assessment is, “the ongoing process of collecting data on the individual’s needs, preferences, and interests as they relate to the demands of current and future working, educational, living, personal, and social environments” (Sitlington, Neubert, Begun, Lombard, & Leconte, 2007, pp. 2-3).

Career and vocational assessment in transition is a formal process utilizing a variety of assessments and instruments (Flexer et al., 2008). Assessments are completed in a variety of ways both formal and informal. Information is gathered about career maturity, work behaviors, interests, general abilities, specific aptitudes, career attitudes, and characteristics of the student. Formal assessment using standardized instruments is performed using a variety of norm-referenced tools. Some formal transition assessment instruments are the Becker Reading-Free Interest Inventory, Brigance Life Skills Inventory, Career Development Inventory, Career Maturity Inventory, the COPS Interest Inventory, Knowledge of the World of Work Scale, Kuder Vocational Preference Record, Reading-Free Vocational Interest Inventory, the Self-
Directed Search, the Transition Planning Inventory, and the Wide-Range Interest and Opinion Test (Flexer et al., 2008; National Secondary Transition Technical Assistance Center, 2010).

Informal assessments are not standardized instruments but rather take the form of interest inventories, rating scales, and personal interviews. These might be developed by a teacher or school district or come from many available resources on the internet (Sitlington et al., 2007).

Despite the progress made by VR and school systems serving youth with disabilities, there persists high rates of unemployment, economic instability, and low rates of participation in post-secondary education for emerging adults with disabilities (Wittenburg & Maag, 2002). Additionally, studies by Cobb and Alwell (2007), Estrada-Hernandez et al (2008), and Yeo and Sawyer (2005) demonstrate that youth with chronic illness experience academic and vocational difficulties aside from the challenges presented by their illness. Additionally, children with chronic illness face developmental challenges related to career maturity that their healthy peers do not encounter (Ochs & Roessler, 2001).

**Career Development**

Minimal empirical research has investigated the career development and employment experiences of people with CF (Burker et al., 2005; Gillen et al., 1995). Specifically, the career development of individuals with CF was investigated in just one historic study (Goldberg et al., 1979). Goldberg et al. (1979) investigated vocational development in people with CF and drew three major conclusions. First, the CF group scored lower than a healthy peer group in measures of vocational and educational plans and was less realistic in considering their limitations. Second, the CF group scored
higher on measures of commitment to vocational choice, work values, and awareness of occupational information. Third, the authors concluded that CF patients held strong work values.

The origins of career development date back a century to the work of Frank Parsons with Boston youth at the Vocation Bureau (the first known career counseling program which he founded) and the 1909 publication of his prominent book, *Choosing a Vocation* (Baker, 2009; Hershenson & Liesener, 2003). Parsons coined the term “vocational guidance” (Savickas, 2009, p. 195), the forerunner to career development, which he conceptualized as “personal analysis, job analysis, and matching through scientific advising as the basis of occupational choice making” (Brown & Brooks, 1990, p. 14). In Parsons’ formulation of vocational guidance a person made a single unchangeable occupational choice by early adulthood. He proposed a three-step system of vocational guidance: (a) gathering information about the person, (b) gathering information about the world of work, and (c) matching the two to arrive at a career selection (Szymanski & Hershenson, 1998). This approach constitutes an early trait and factor theory, that is, the method of matching individual traits with environmental factors. Parsons’ guidance model forms the foundation of contemporary career counseling practices (Hershenson & Liesener, 2003).

Parsons presumed that occupational choice was an unalterable one-time event of early adulthood and his notions about career patterns prevailed for the next four decades (Szymanski et al., 2003). Subsequent theories of career development originating in the 1950s and 1960s adopted two novel viewpoints: developmental perspectives that emphasized lifelong career development (e.g. Super's Life Span
Theory) and trait and factor approaches (e.g. Holland’s Theory of Types) that emphasized a person’s traits and the fit with factors present in the labor force (Parker & Szymanski, 1998; Szymanski & Parker, 2003). Brown and Brooks (1990) described the present-day approach to career development as being, “a lifelong process of getting ready to choose, choosing, and typically continuing to make choices from among the many occupations available in our society” (p. xvii).

Career development is a broad construct that according to Hanley-Maxwell, Szymanski, and Owens-Johnson (1998), encompasses “the interaction of individual, contextual, mediating, environmental, and outcome factors throughout the life span” (p. 150). Specifically, “career development focuses on the developmental process of one’s lifelong sequences of occupationally relevant choices and behaviors” (Szymanski & Hershenson, 1998, p. 328). Career development has gradually come to embody two distinct meanings – one pertaining to a process and the other referring to interventions (Herr, 2001). Career development process refers to, “the formation of a work identity or progression of career decisions and/or events as influenced by life or work experience, education, on-the-job training, or other factors” (Chartrand & Camp, 1991, p. 2). A precise process-based definition is espoused by the National Career Development Association (2008), “Career development is the total constellation of psychological, sociological, educational, physical, economic, and chance factors that combine to influence the nature and significance of work in the total lifespan of any given individual” (p. 2). Whereas career development interventions are practices or procedures by counseling professionals aimed at enhancing career development such that they, “enable that person to make more effective career decisions” (Spokane, 1991, p. 22).
Intervention strategies include numerous diverse options, such as, individual and group career counseling, career planning batteries, transferable skills analysis, and experiential interventions (Hershenson & Liesener, 2003).

Despite a vast body of career development literature, individuals with disabilities are largely overlooked (Conte, 1983; Curnow, 1989; Szymanski et al., 2003). The majority of the extant career development research was conducted with healthy nondisabled individuals and particularly “middle class White males” (Szymanski et al., 2003, p. 92). Furthermore, there is not a generally accepted model of career development pertaining to people with disabilities (Goldberg, 1992).

Szymanski et al. (2003) and Szymanski and Hershenson (1998) contend that Super’s Life Span Theory and Holland’s Theory of Types have some utility for people with disabilities. Super’s theory (Super, 1980; Super, Savickas, & Super, 1996) is a developmental approach that views career development as a lifetime process rather than a onetime event. Specifically, the theory views career development as comprised of a series of career decisions that culminate in an occupational choice reflecting one’s self-concept (Swanson & Fouad, 1999). Super identified his theory as a “life-career rainbow” in which personal and situational attributes combine with life stages and roles. Life roles (child, student, leisurite, citizen, worker, and homemaker) interact with life stages (growth, exploration, establishment, maintenance and decline) to influence career development (Sharf, 2002).

Occupational self-concept is central to Super’s theory and refers to “how individuals view themselves and their situation” (Sharf, 2002, p. 154). Occupational self-concept is a product of vocational preferences and competencies that change and
evolve over time with new experiences and learning, and stabilize with age (Swanson & Fouad, 1999). Career maturity, another key feature of Super’s theory, relates to self-concept and refers to the individual’s readiness to make career decisions (Sharf, 2002). Super’s theory partly assumes a person-in-environment stance that is best evidenced by his reflection that, “While making a living, people live a life” (Super et al., 1996).

Super’s theory is among the most prominent in career development research and several vocational instruments owe their lineage to his theory and contributions to the field (Kapes, Mastie, & Whitfield, 1994; Zunker, 1994). These are the Career Development Inventory, the Adult Career Concerns Inventory, the Salience Inventory, and the Values Scale. Each of these tools advanced the science and practice of career counseling as Savickas declared referring to them, “Each of these achievements marked a milestone in the history of vocational psychology and career counseling” (Savickas, 1994, p. 54).

Szymanski and Hershenson (1998) propose that Super’s theory has application for people with disabilities and is particularly appropriate to individuals with genetic disabilities. They note expressly that his concept of career maturity has utility in disability studies. Super’s theory offers a framework for addressing the career development concerns of individuals who may have been restricted by limited early experiences, “including opportunities for play, work-role fantasies, and career related role playing” (Szymanski & Hershenson, 1998, p. 332). Furthermore, Szymanski and Hershenson assert that such early experiences are essential to normal career development. The notable criticism of Super’s theory with respect to people with disabilities is that it does not sufficiently consider the impact of disability on career
development. Specifically career decisiveness and career maturity may be susceptible to disability (Szymanski & Hershenson, 1998).

Holland’s theory (1997) is likewise considered efficacious for people with disabilities (Szymanski & Hershenson, 1998). In contrast to Super’s developmental stance, Holland’s theory is a trait-factor approach (otherwise known as a person-in-environment approach) linking six broad personality types to work environments (Sharf, 2002). In this theory, occupational choices are an expression of an individual’s personality type, which encompasses unique characteristic attitudes, skills, and responses to situations (Swanson & Fouad, 1999). A person’s type leads them to prefer one occupation or another. As Holland stated, “The choice of a vocation is an expression of personality” (1997, p. 7).

The theory has four fundamental assumptions (Holland, 1997). First, Holland proposed that most individuals can be described by six personality types – Realistic (preferring concrete, hands-on activities), Investigative (preferring analytical or methodological pursuits), Artistic (preferring creative and self-expressive pursuits), Social (preferring to work with others), Enterprising (preferring competitive and/or leadership pursuits), or Conventional (preferring orderly/systematic pursuits) (Holland, 1997; Holland, Fritzsche, & Powell, 1994). Second, work environments are characterized by their resemblance to model environments with parallel labels as the personality types, again Realistic, Investigative, Artistic, Social, Enterprising, and Conventional. Third, people search for work environments that complement their knowledge, skills and abilities, in other words, their “type” (Sharf, 2002; Swanson & Fouad, 1999). Fourth, the interaction of personality and environment determine one’s
Holland’s theory is prominent in vocational research and is widely used in career counseling (Sharf, 2002; Szymanski & Parker, 2003). He credits the popularity of the theory to its pragmatic design observing that “longer lists of variables and more elaborate theories are unlikely to succeed and will be less likely to be tested or used” (Holland, 1997, p. 7). There are some criticisms of Holland’s applicability to people with disabilities. The first pertains to the over emphasis of individual’s traits while minimizing the role of social and environmental variables (Conte, 1983). These variables are known to be significant considerations for people with disabilities (Szymanski & Hershenson, 1998). Secondly, people with genetic disabilities may have limited early experiences, which in turn inhibits their career knowledge and restricts their ability to accurately assess vocational preferences (Szymanski & Hershenson, 1998).

Szymanski et al. (2003) assert that the utility of Holland’s theory for people with disabilities rests with the various instruments resulting from the theory. Holland authored or co-authored four vocational instruments based on his theory of types: the Career Attitudes and Strategies Inventory (CASI), My Vocational Situation (MVS), the Self-Directed Search (SDS), and the Vocational Preference Inventory (VPI) (Kapes et al., 1994; Whitfield, Feller, & Wood, 2009; Zunker, 1994). The instruments are all self-rated thus integrating client input and self-determination. The SDS, for instance, involves clients in generating numerous career alternatives and has two versions, one for normal reading level and one for low reading level. Likewise, MVS involves active client participation in determining readiness for career planning.
Career development theories abound but their applicability to people with disabilities is circumspect given the heterogeneity of this population (Szymanski & Hershenson, 1998; Szymanski, Enright, Hershenson, & Ettinger, 2003). Szymanski and Hershenson (1998) contend that career development theories are neither fully applicable nor nonapplicable to people with disabilities. Conte (1983) argued, “these theories have been of dubious utility both in describing and predicting the vocational behavior of disabled populations” (p. 316). Curnow (1989) affirms Conte’s assertion regarding the uncertain utility of existing theories and additionally describes the scarcity of career development literature for people with disabilities. Other authorities maintain that instead of predictive ability, prevailing general-purpose career development theories provide a framework (Szymanski et al., 2003) and offer valuable interventions (Szymanski & Hershenson, 1998). Despite these controversies, one thing is certain, “Disability presents a risk factor for career development” (Hanley-Maxwell et al., 1998, p. 150).

Models of Disablement

Models of disablement enhance knowledge of career development. The last fifty years have borne several advances in the understanding of disability, notably, ever improving models for conceptualizing and describing disability (Brandt & Pope, 1997; Field, Jette, & Institute of Medicine, 2007). Disability models are now regular components of clinical practice in the majority of health-related professions including medicine, nursing, occupational therapy, and physical therapy (Snyder, Parsons, Valovich McLeod, Bay, Michener, & Sauers, 2008). In particular, biopsychosocial models of disability are now “the dominant perspective behind contemporary disablement frameworks in use today” (Jette, 2006, p. 727). Models of disability include
older frameworks, such as, the Nagi model, the National Center for Medical Rehabilitation Research model (NCMRR), the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), and the recently issued International Classification of Functioning, Disability, and Health (ICF).

Brandt and Pope (1997) observed that since the 1950s ideas about the causes of disability have evolved from the medical model to biopsychosocial models. In the medical model, the focus is first on illness or impairment and second on the individual. Disability is thought to be an inherent quality of the individual (i.e. the person is “sick”), who needs to be fixed in the medical model. For this reason, it is sometimes referred to as a deficit model (Jette, 2006) and is most often described in rehabilitation and health care literature (Marks, 1997). Vash and Crewe (2004) mentioned that prior to the shift in paradigms, “virtually all of the emphasis in rehabilitation was on modifying the ‘patient’ to fit into the world as it was” (p. xii). Conversely, biopsychosocial models assume, unlike the medical model, that disability results from the interplay of biological, personal, and social aspects. Disability is not characteristic of the person but rather a characteristic of society or as Jette (2006) describes it, “a socially created problem” (p. 727). Moreover, “the limitations of disabilities are not inherent within individuals, but rather in individuals’ interactions with their environments” (Parker & Szymanski, 1998, p. 332).

Much of the current thinking on disability evolved from the work of sociologist Saad Nagi in the 1960s on what is now called the Nagi model or the Nagi Disablement Model (Jette, 2006; Verbrugge & Jette, 1994). According to Jette (2006), Nagi introduced the term disablement in the early 1960s to refer to the, “various impact(s) of chronic and
acute conditions on the functioning of specific body systems, on basic human performance, and on people’s functioning in necessary, usual, expected, and personally desired roles in society” (p. 727). Nagi’s schema has four interrelated, progressive domains: active pathology, impairment, functional limitations, and disability (Jette, 2006). The model also incorporates the influence of the environment with the inclusion of the factors of family, community, and society (Brandt & Pope, 1997). The Nagi model is a linear model that moves systematically from pathology to impairment to functional limitations to disability (Jette, 2006). With the advent of the Nagi model, rehabilitation professionals started retreating from the medical model (Brandt & Pope, 1997; Jette, 2006; Verbrugge & Jette, 1994).

In Nagi’s framework, disability results in limitations in the performance of socially defined roles (being a worker for example) as the result of the physical or mental condition. Disability may or may not result from the other three domains: active pathology, impairment, or functional limitation. In addition, Nagi stresses that disability is not inherent in the individual (as opposed to the medical model), but rather is the result of the interaction of the individual and the environment.

Nagi’s impact goes beyond the development of his theoretical framework. His efforts also influenced public policy and legislation. According to Cornell University’s Disability Statistics website, “The Americans with Disabilities Act (ADA) rests upon the Nagi framework and recognizes that improvements in the environment (access to public transportation, workplace accommodations, etc.) can reduce disability and thus improve the inclusion of all people” (Cornell University, 2011).
In 1993, the National Center of Medical Rehabilitation and Research introduced their own disablement model – the NCMRR model (Brandt & Pope, 1997). This model is similar to Nagi’s in that it incorporates four domains: pathophysiology, impairment, functional limitations, and disability while adding a fifth component - societal limitation. Societal limitations “refer to the restrictions resulting from social policy or barriers, which limit fulfillment of roles or dent access to services and opportunities associated with full participation in society” (Snyder et al., 2008, p. 431). The NCMRR and Nagi models share concepts, but use slightly different terminology. For instance, where Nagi uses the term active pathology, the NCMRR uses pathophysiology. Where NCMRR differs from Nagi is with the inclusion of societal limitation. Another distinguishing feature of NCMRR is the emphasis it places on the adaptation to functional limitations made by the person with a disability (Snyder et al., 2008). This adaptation occurs in various spheres of the individual’s life including home life, work, and community. Rehabilitation is an aspect of this adaptation process and one in which the individual is thought to be an active participant. The goal of rehabilitation is ultimately an improvement in quality of life (Snyder et al., 2008).

A third biopsychosocial model is the International Classification of Functioning, Disability, and Health (ICF) issued by the World Health Organization (WHO). Initially introduced in 1980 as the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), the model underwent major revision, and in 2001 was reintroduced as the ICF (World Health Organization, 2001).

**International Classification of Functioning, Disability, and Health**

The World Health Organization (2001) framework, the International Classification of Functioning, Disability, and Health (ICF), is a classification system for the description
of health and health-related states. What’s more, it provides a lens by which to understand functioning and disability (De Kleijn-De Vrankrijker, 2003; Stucki & Rauch, 2010). Introduced in its current form in 2001, the ICF, “attempts to provide a comprehensive view of health-related states from biological, personal, and social perspectives” (Field, Jette, & Institute of Medicine, 2007, p. 37). Moreover, it is a biopsychosocial model that set the stage for new ways of considering disability. As Snyder (2006) concluded, “disability no longer means a condition, an incapacity, or lack that belongs to a body, but rather a product of the interactions between self, society, body, and the variety of interactions (from political economies to personal commitments) that they engender” (p. 1xx).

The ICF’s predecessor, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), was a system of classification based on “consequence of disease” (World Health Organization, 2001, p. 5). The innovation embodied in the ICF is its focus on “components of health” (World Health Organization, 2001, p. 5). The revision emphasizes the constituents of health, whereas the previous framework focused on the impact of diseases (World Health Organization, 2001). In a second innovation embodied in the revised ICF, the term “handicap” was eliminated from its title and nomenclature (Field, Jette, & Institute of Medicine, 2007).

The ICF is arranged according to the Health Condition first, from which might spring an impairment, activity limitation, or participation restriction. After health condition, are the domains “Functioning and Disability” and “Contextual Factors”, each of which has two subcomponents (World Health Organization, 2001). The first domain, Functioning and Disability, is comprised of the subdomains Body Functions and
Structures and Activities and Participation. The second domain, Contextual Factors, is comprised of Environmental Factors and Personal Factors. Interacting with the Health Condition, these two domains form the basis from which the characteristics of the body, the individual, and society are classified. The components under Functioning and Disability are expressed as problems (e.g. impairment, activity limitations, or participation restrictions) or in neutral terms as non-problems (World Health Organization, 2001). Specifically, ICF’s terminology refers to, functioning as an umbrella term for body functions, body structures, activities and participation, and represents the positive aspects of the interaction between an individual with a health condition and their environmental and personal factors (World Health Organization, 2001). Disability is the umbrella term ICF uses for impairments, activity limitations, and participation restrictions, and denotes the negative aspects of the interaction between an individual with a health condition and their environmental and personal factors (World Health Organization, 2001).

The ICF presents an elaborate construct of disability. While the earlier models, NCMRR and Nagi, were simplistic in their graphic representations of the disablement process as a linear progression, the ICF represents an innovative approach to displaying and dissecting the concepts of health and disability. The ICF depicts the interaction of its various components in an arrangement of three reciprocal levels (Figure 2-1). On the top level appears the Health Condition, the middle level presents Functioning and Disability (i.e. body functions and structures, activities, and participation), and the bottom level presents Contextual Factors (i.e. environmental factors and personal factors). As a classification framework, the ICF does not model
the process of disability but rather it maps disability related constructs (World Health Organization, 2001). Essentially, under the model, functioning and disability are reflected as the interaction between health conditions and personal and environmental contextual factors (Field, Jette, & Institute of Medicine, 2007).

The introduction of the ICF instituted numerous new constructs by which to evaluate disability and acts as a unifying paradigm for scientific inquiry among various disciplines (Jette, 2006; Jette, 2009; Stucki & Melvin, 2007; Stucki & Rauch, 2010). One of the most dramatic changes brought about by the ICF is in terminology. ICF denotes a positive connotation to describe disability, for example, functional ability rather than handicap (Snyder et al., 2008).

The ICF uses the term health condition in a universal way to encompass the diseases, disorders, injuries, trauma, and aging that are the focus of intervention (World Health Organization, 2001). The domain of body functions and structures encompasses all the physiological and psychological human functions and all parts of the human anatomy from internal organs to limbs (World Health Organization, 2001). The activity domain refers to the completion of tasks or actions, for example, walking, climbing steps, or eating. The participation domain refers to involvement in life situations and society, for example, doing things with friends or attending school (Jette, 2006). Participation is characterized as activity performed in a social setting or context.

Problems of body function or structure that occur because of the health condition, and thus cause a deviation from the normal level of functioning, are termed impairments (World Health Organization, 2001). Individuals may also have activity limitations when they are unable to complete desired activities or they might have participation
restrictions - problems in maintaining involvement in life situations (Jette, 2006; World Health Organization, 2001).

The context of personal existence is incorporated in the ICF via the inclusion of personal and environmental factors (World Health Organization, 2001). Environmental context is the physical, social, and attitudinal environment experienced by the individual with a disability. The personal context are factors associated with the particular individual such as, sex, race, age, health conditions, and so on (Jette, 2006; World Health Organization, 2001). In the ICF, the disablement process is a function of the reciprocal interaction of many factors: health condition, body function/structure, activity, participation, environmental and personal factors.

International Classification of Functioning Applied to CF

The ICF informs my thinking about functioning and disability in cystic fibrosis. The model, “looks beyond mortality and disease to focus on how people live with their conditions” (Jette, 2006, p. 726). This facet of ICF is particularly important with CF, which exerts its effects on a daily basis for the lifetime of the individual (Casier et al., 2011; Staab et al., 1998; Wahl et al., 2005). In this regard, ICF is truly a biopsychosocial model and consistent with the aims of the proposed grounded theory study to understand the meaning and experience of work in CF.

In attempting to comprehend a complex phenomenon, such as, employment experiences within the context of CF, it is useful to apply the ICF framework (Figure 2-1). The ICF presents an intricate construct of disability with its three levels and various domains. It depicts the reciprocal interaction of these domains: Health Condition, Body Function and Structures, Activity, Participation, Environmental Factors, and Personal Factors. CF is a complicated illness that has lifelong influence on all these domains.
As such, to study the interplay of employment and CF requires a multifaceted model such as the ICF.

In ICF terms, the health condition of CF is the most common fatal, inherited genetic disease in the United States affecting nearly 30,000 individuals (Cystic Fibrosis Foundation, 2011). The chronic progressive nature of the disease means it has lifelong health effects (Kraemer & Thamrin, 2010; VanDevanter, O’Riordan, Blumer, & Konstan, 2010). Under the Functioning and Disability domain, CF affects the body function and structures of the pulmonary, endocrine, and gastrointestinal systems. Specifically, CF causes lung damage that inhibits breathing and causes chronic cough (Yankaskas et al., 2004). The gastrointestinal complications lead to abdominal pain, malnutrition and problems with elimination (Yankaskas et al., 2004). The endocrine complications lead to CF-related diabetes and growth impairments (Yankaskas et al., 2004). Activity is impacted as the disease affects the tasks of self-care, looking after one’s health, toileting, breathing, digestion, walking, and climbing stairs among others (Sawicki, Sellers, & Robinson, 2009; Yankaskas et al., 2004). Participation in school, work, and community social events is effected because of the repeated bouts of infection, frequent clinic visits, and frequent hospitalizations caused by the illness (National Heart, Lung, and Blood Institute, 2009; Ziaian et al., 2006). The activity of procreation is impacted as the majority of men with CF are sterile due to congenital absence of the vas deferens and women have diminished fertility (Lyon & Bilton, 2002; Sueblinvong & Whittaker, 2007). The gastrointestinal symptoms of CF are particularly bothersome thus interfering with both activity and participation. These include poor weight gain, insatiable appetite,
frequent foul smelling bowel movements, oily bowel movements, excessive gas, and stomach pain (Borowitz, Baker, & Stallings, 2002; Kreindler & Orenstein, 2006).

Under the Contextual Factors domain, the person with CF copes with the consequences of the disease both environmental and personal. Environmental factors include support of family, friends, and coworkers, workplace attitudes, the stigma of having a life limiting illness, and smokers, and smoky environments. Personal factors include their individual disease severity, level of treatment adherence, disease understanding, race, sex, and age.

Figure 2-1. The ICF framework and cystic fibrosis
Numerous researchers have exercised the ICF framework to examine a variety of conditions. ICF has been applied to brain injury (Bilbaoa, Kennedy, Chatterji, Ustun, Barquero, & Barth, 2003), cognitive disorders (Arthanat, Nochajski, & Stone, 2004), mental health disorders (Baron & Linden, 2008), developmental language impairments (Dempsey & Skarakis-Doyle, 2010), AIDS (Hwang & Nochajski, 2003), Alzheimer’s disease (Muo, Schindler, Vernero, Schindler, Ferrario, & Frisoni, 2005), and spinal cord injury (Rauch, Escorpizo, Riddle, Eriks-Hoogland, Stucki, & Cieza, 2010) to name a few. However, it has not yet been utilized as a framework for examining CF (Mandrusiak, MacDonald, & Watter, 2009). Integrating the ICF as one my guiding frameworks will be an innovative element in my proposed study.

The ICF provides an ideal lens through which to investigate CF and its employment aspects. The ICF map presented in Figure 2-1 demonstrates that functioning and disability are the outcome of the complex interaction between the CF health condition and the physical and social environment. By using the ICF, I can obtain information on body functions and structures, activities, and participation - all of which are important for functioning with CF. Moreover, these three variables contribute to global functioning and combined influence employment. A major goal of CF treatment is to maintain lung function and thereby maintain overall global functioning, well-being, and quality of life (Abbott, Havermans, & Hart, 2009; Ferkol et al., 2006; Hains, Davies, Quintero, & Biller, 2009). The utility of the ICF is that by mapping CF, the researcher can begin to identify and design biopsychosocial interventions targeted at (a.) maintaining global level of functioning, (b.) identifying the barriers or facilitators individuals with CF experience in activity and participation domains regarding
employment, and (c.) identifying environmental barriers or facilitators to employment. Utilizing the ICF structure as a frame of reference will contribute to a meaningful understanding of the experience of working and having CF. As a biopsychosocial model of disability, it can be integrated with the proposed qualitative study. The interplay of the domains of activity, participation, environmental factors and personal factors encompasses the realm of lived experiences that a person with CF encounters as they navigate the world of work.

**Emerging Adulthood**

A second relevant theoretical framework from which to evaluate and understand the co-occurring maturational and employment processes of young adults with CF is the “emerging adulthood” model. Emerging adulthood is a new developmental stage posited by Arnett (2000; 2004) that bridges the period between adolescence and young adulthood. This stage roughly corresponds to the ages between the late teens to the mid- to late twenties; however, Arnett specifically targets the ages of 18 to 25. Five key features distinguish emerging adulthood from the developmental stages before or after,

> It is the age of identity explorations, especially in the areas of love and work; it is the age of instability; it is the most self-focused age of life; it is the age of feeling in-between, neither adolescent or adult; and it is the age of possibilities when optimism is high and people have an unparalleled opportunity to transform their lives. (Arnett & Tanner, 2006, p. 7)

Arnett (2000) contends that emerging adulthood is a distinct developmental period of life between adolescence and young adulthood with its own unique features. It is a phase more evolved than adolescence but not quite as advanced as young adulthood. In emerging adulthood, the individual is no longer entirely dependent on parents but has not reached certain milestones historically associated with adulthood notably enduring romantic relationships, marriage, parenthood, and career establishment (Arnett, 2000).
Arnett (2004) applies the emerging adulthood schema to a variety of circumstances – relationships with parents, romantic relationships, education, employment, and religion. As defined, it is a period of prolonged self-exploration with postponement of adult responsibilities and delay of major life decisions involving academics, career, marriage, and parenthood. Rather than adopting enduring adult roles and responsibilities, emerging adulthood is marked by change and exploration. Arnett argues that traditional markers of adulthood are no longer applicable by today’s standards. Events such as college graduation or marriage once signaled coming of age but these rites of passage are increasingly being delayed to the late twenties.

Arnett (2000) attributes the emergence of this developmental stage to a trend towards getting married and becoming a parent at a later age. In 1950, the median marriage age for women was 20 and for men 22. By 2000, this had risen to 25 and 27 respectively. Likewise, parenthood has seen a shift from early twenties to late twenties (Arnett, 2000). Subsequently, the theory is applicable in industrialized societies, “that allow young people a prolonged period of independent role exploration during the late teens and twenties” (Arnett, 2000, p. 469) versus societies where youth directly enter into marriage and the workforce from high school.

The primary facet of emerging adulthood is identity exploration where individuals are “trying out various possibilities, especially in love and work” (Arnett, 2004, p. 8). The rehearsal process evident during identity exploration leads to making lasting vocational decisions. It is during this period when young people are experimenting with a variety of options for their lives especially regarding their future careers. Arnett (2000) suggests, “During this time, many young people obtain the level of education and
training that will provide the foundation for their incomes and occupational
achievements for the remainder of their adult work lives” (p. 469).

Approximately 80% of adolescents will obtain part-time employment during high
school (Arnett, 2004; Kelloway & Barling, 1999; Wagner, Newman, Cameto, Garza, &
Levine, 2005). Adolescent employment is characterized by tentative forays into the
world of work that are largely temporary and do not influence later career choices
(Arnett, 2004; Greenberger & Steinberg, 1986). In adolescence, the primary benefit of
working is not the acquisition of skills or the potential vocational preparation but rather
the provision of disposable income for leisure activities, clothes, fast food, and personal
items (Csikszentmihalyi & Schneider, 2000; Steinberg & Cauffman, 1995).

It is not until individuals reach emerging adulthood, between the ages of 18 to 25,
when the nature of work takes on additional significance. Whereas previously
employment was often temporary and not indicative of later adult occupational roles,
emerging adults are making employment decisions that will have lasting effects on their
career trajectory. They are struggling to answer the questions, “What kind of work am I
good at? What kind of work would I find satisfying for the long term? What are my
chances of getting a job in the field that seems to suit me best?” (Arnett, 2000). The
transition to employment is particularly important for, as Bynner (1998) has suggested,
“Of all the developmental transitions, entry to employment is probably the most central
to the formation of adult identity” (p. 29).

The theory of emerging adulthood is relatively new and not without some
controversy about its formulation. Bynner (2005) notes that the notion of an extended
transition period between adolescence and adulthood is not a new concept; rather it
was first suggested in 1904 by G. Stanley Hall, a pioneer in adolescent research who proposed adolescence ended around age 25. Furthermore, there is some question as to the need for new terminology to describe the extended transition period (Bynner, 2005). Cote and Bynner (2008) highlight the limited amount of research studies investigating the theory. While there are numerous journal articles on the topic, many of these merely refer to the theory to represent the age group not to investigate its theoretical underpinnings.

**Emerging Adulthood Applied to CF**

A discussion about emerging adulthood in CF might not have been imaginable in 1985 when the median predicted survival age was just 26 years (Cystic Fibrosis Foundation, 2011) but with predicted survival currently approaching 36 years of age (Cystic Fibrosis Foundation, 2011), emerging adulthood assumes great significance. Fundamentally, emerging adulthood addresses the components of transition to independence and so the theory has high relevance for young adults with CF. The model provides a dynamic frame of reference for conceptualizing the particular developmental stage of young adults with CF as they achieve employment. It also highlights the aspects of development where an emerging adult might encounter transition barriers and this then can become a focus of intervention. Emerging adulthood underscores elements that are essential to comprehending the maturational process experienced by young adults with CF. The concepts of the model most applicable to CF are identity exploration, feeling in-between, and the period of instability.

Most of the research on emerging adulthood has focused on healthy young adults and the model has not been widely applied to chronic illnesses (Luyckx et al., 2008). In fact, there are just a handful of articles pertaining to any type of chronic illness. An
extensive search of the EBSCOHOST database uncovered just four reports using emerging adulthood as a framework for interpreting chronic illness: two reports relating to diabetes (Luyckx, Vanhalst, & Seiffge-Krenke, 2010; Luyckx et al., 2008), one report relating to juvenile arthritis (Gerhardt et al., 2008), and one report relating to cancer (Millar, Patterson, & Desille, 2010). The emerging adulthood framework has not been applied to individuals with CF however; the constructs are decidedly generic though individuals with CF may experience the elements differently than healthy peers. Moreover, the limited research about the adjustment and transition to adulthood of individuals with CF is promising. Several reports gauging a variety of measures have demonstrated successful outcomes and normative adjustment of individuals with CF. These include reports of transition to adulthood (Palmer & Boisen, 2002), psychosocial functioning (Pfeffer, Pfeffer, & Hodson, 2003; Smith, Gad, & O’Grady, 1983), quality of life (Ernst et al., 2010), and psychological adjustment (Anderson, Flume, & Hardy, 2001; Szyndler, Towns, van Asperen, & McKay, 2005).

The primary facet of emerging adulthood is identity exploration in which individuals are “trying out various possibilities, especially in love and work” (Arnett, 2004, p. 8). Young adults with CF confront identity exploration while they strive for normalcy and social integration (Admi, 1996; Badlan, 2006; Blair, Cull, & Freeman, 1994). Like their healthy peers, they also struggle with the twin themes of emerging adulthood - vocational and personal developmental concerns (Goldberg et al., 1979; Mador & Smith, 1988; Smith et al., 1983). According to Arnett (2004) work takes on added significance as one enters the period of emerging adulthood. Arnett (2000; 2004) supposes that emerging adults struggle with making lasting choices pertaining to
careers and occupations. They are struggling to answer the questions, “What kind of work am I good at?” and “What kind of work would I find satisfying for the long term?” (Arnett, 2000). The rehearsal process present in identity exploration typically leads to making lasting vocational decisions. However, for people with CF, the disease places certain restrictions on the types of employment environments suited to them (Burker et al., 2005; Demars et al., 2010).

The second aspect of emerging adulthood with utility for CF is instability, which is manifested in romantic relationships, parental relationships, education, and employment (Arnett, 2000; 2004). Emerging adults with CF also face instability. However, they have the added concerns of assuming responsibility for disease management from their parents, transitioning from the pediatric healthcare system to adult health care, and making education and employment decisions within the constraints of their illness (Brumfield & Lansbury, 2004; Burker et al., 2005; Demars et al., 2010; Eickenhorst, 1996; Palmer & Boisen, 2002).

Lastly, the concept of feeling in-between has utility for comprehending young adults with CF. Arnett (2004) has likened emerging adulthood to an age of “feeling in-between” (p. 14), meaning in-between being an adolescent and an adult. Likewise, young adults with CF are feeling in-between and this has great significance. Emerging adulthood, which roughly corresponds to the ages of 18 to 25, coincides with the health care transition of young adults with CF. Aside from the typical concerns of the emerging adult (mainly relationships, school, and work), individuals with CF are assuming responsibility for disease management from their parents and transitioning from
Health care transition is an essential aspect for CF patients. The movement of patients with CF from pediatric focused to adult focused health care has received increasing attention from the medical community in the past two decades. This attention is due primarily to gains in predicted median survival (Zack et al., 2003; Reiss & Gibson, 2002). These gains in longevity necessitate preparation for transition in which the challenge is, “to share responsibility for developing skills to help adult patients who have CF attain their best quality of life” (Parker H. W., 2007, p. 423). The Cystic Fibrosis Foundation (CFF) encourages care centers to promote, starting at an early age, transition activities leading to independence that includes education about adult CF healthcare, career/vocational planning, and higher education options (Yankaskas et al., 2004). The CFF (Cystic Fibrosis Foundation, 2009, p. 16) states, “It is important to help teens transition from depending on their parents or another adult to taking charge of managing their own health.”

Emerging adults with CF face multiple transition points as they mature (Brollier, Shepherd, & Markley, 1994). Transition is a multifaceted process that includes aspects pertaining to both health care and school: connecting to primary and specialty health care providers, preparing for post-secondary education and/or work, housing arrangements, transportation, and financial independence. Preparation for transition in cystic fibrosis has the added challenges posed by the complicated medical regimen that patients must uphold in order to maintain their health. Transition to adulthood can be complex for healthy emerging adults and especially difficult for those who have a
chronic illness as they may encounter additional challenges to negotiating the transition to independence.
CHAPTER 3
METHODOLOGY

Overview

In keeping with the exploratory nature of the study, the method used was grounded theory. This qualitative method was most appropriate to this area of research, as no theory of career development exists to explain how young people with CF make career decisions or experience the world of work. The grounded theory approach allowed for the complexities associated with CF and employment to be better understood through the development of a substantive theory generated from the very experiences of young people with CF.

The study employed the grounded theory method of qualitative inquiry to gain a deep and rich understanding about the personal meaning of work to, and the employment experiences of, people with CF. Grounded theory explores “the ways in which reality is socially constructed” (Richards & Morse, 2007, p. 59) and so there was congruence between the method and the social situation of employment.

Grounded theory was adopted because it allowed for the thorough examination of this topic from the viewpoint of the individual. This approach endorses compiling a thick description of the lived experience of CF and its employment aspects. Bowers (1988) states that, “the grounded theory researcher intentionally becomes immersed in the world of the research subjects.” From the grounded theory perspective, it is the individual with CF who can best define what the truths are pertaining to employment.

Qualitative Research

Qualitative research methodologies are a means of understanding human experience that rely on analyzing words and responses to open ended questions rather
than numbers (Creswell, 2009). Specifically, qualitative research is, “a means for exploring and understanding the meaning individuals or groups ascribe to a social or human problem” (Creswell, 2009, p. 4). Numerous diverse approaches inform qualitative research and the investigator has several research traditions at their disposal including ethnography, grounded theory, and phenomenology. Each of these approaches has distinct origins and unique methods of sampling, making data, coding data, and interpreting data, yet they also share a set of core features. The common characteristics among them are natural setting, researcher as key instrument, multiple sources of data, inductive data analysis, participants’ meanings, emergent design, theoretical lens, interpretive inquiry, and holistic account (Creswell, 2009).

**Grounded Theory**

Grounded theory is the leading method of qualitative inquiry in the social sciences today and has achieved international utilization (Bryant & Charmaz, 2010; Morse, Stern, Corbin, Bowers, Charmaz, & Clarke, 2009; Patton, 2002). Glesne (2011) reminds us it is not a theory per se, but rather a method of developing theory from data. The methodology offers, “a systematic, inductive, and comparative approach for conducting inquiry for the purpose of constructing theory” (Bryant & Charmaz, 2010, p. 1). Hood (2010) proposes the three essential features of grounded theory are, “(1) theoretical sampling, (2) constant comparison of data to theoretical categories, and (3) focus on the development of theory via theoretical saturation of categories rather than substantive verifiable findings” (p. 163). Furthermore, grounded theory is especially appropriate for research where there is limited or no prior information available of an area (Grbich, 2007).
Grounded theory evolved from the work of noted sociologists Barney Glaser and Anselm Strauss in the 1960s (Bryant & Charmaz, 2010; Charmaz, 2009). Initially associated with the field of medicine and an emphasis on the illness experience and caregiving, grounded theory has spread to many other disciplines including education, nursing, business, gerontology, and social work (Morse et al., 2009). Its theoretical underpinnings were influenced by pragmatism and the studies of symbolic interactionism that occurred at the Chicago School of Sociology between 1920 and 1950 (Corbin & Strauss, 1990). Charmaz (2009) defined symbolic interactionism as “a theoretical perspective derived from pragmatism which assumes that people construct selves, society, and reality through interaction” (p. 189).

Whereas, ethnography seeks to understand via analyzing cultures, “grounded theory focuses on the process of generating theory rather than a particular theoretical content” (Patton, 2002, p. 125). Bowers (1988) stressed that the grounded theory approach is not to test or validate existing theories, but rather to generate theory from empirical data. In grounded theory the central question is, “What theory emerges from systematic comparative analysis and is grounded in fieldwork so as to explain what has been and is observed?” (Patton, 2002, p. 125). Within grounded theory two schools of thought have emerged – Glaserian and Straussian (Bryant & Charmaz, 2010; Cooney, 2010; Grbich, 2007). The Glaserian approach is associated with a process of discovery, emergent directions, constant comparison of data, and theory generation. Conversely, the Straussian approach is oriented towards verification, hypothesis testing, data fracturing, strict coding procedures, and theory verification (Bryant & Charmaz, 2010; Cooney, 2010; Grbich, 2007).
Similar to ethnography, “the grounded theory researcher intentionally becomes immersed in the world of the research subjects” (Bowers, 1988, p. 43). In doing so, the researcher must maintain both an insider and outsider perspective. In this way, events can be observed “from the perspective of the subjects while standing back and asking questions about what the subjects take for granted” (Bowers, 1988, p. 43). Charmaz (2009, p. 178) concurs with Bowers and Richards and Morse regarding the role of the researcher, “Researchers are part of what they study, not separate from it”.

Glesne (2011) provides an abridged version of the grounded theory method in action. Initially, the researcher collects data on a topic through interviews and observations. Then the researcher analyzes data for conceptual categories, links the categories in a tentative theory, and then collects more data to see how it fits the theory (Glesne, 2011). This process repeats with the researcher further developing categories and modifying the theory with new data. Theoretical sampling is inherent in the process as it suggests settings and people to sample in order to compare and contrast parts of the theory (Glesne, 2011). As demonstrated by Glesne’s (2011) abbreviated depiction, grounded theory is an inductive, iterative method in which data collection and analysis occur simultaneously.

Grounded theory researchers seek understanding about situations or processes and therefore one of the first questions posed is, “What’s going on here?” (Charmaz, 2009; Richards & Morse, 2007). Moreover, grounded theorists are interested in questions pertaining to studying social phenomena from the perspective of symbolic interaction. Building on this foundation, Richards and Morse (2007) noted that grounded theory’s focus is on, “understanding the ways in which reality is socially
constructed” (p. 59). Grbich (2007) suggests that the best-suited research questions are those relating to interactions between people or between people and specific environments. In addition, Hood (2010) observes that grounded theory research typically illuminates a process or an action. It follows that a grounded theory study might ask a question beginning with a stem such as “How does (...) happen?” or “What process leads to (...)?”

Grounded theory is devoted to understanding the ways that reality is socially constructed (Richards & Morse, 2007). It takes the position that reality is a collaborative process between people and it is constantly changing and evolving. Richards and Morse (2007) note it is this process of steady change and social construction that interests the grounded theory researcher. It is through close observation of these events that the investigator constructs a “theory grounded in data” (Richards & Morse, 2007, p. 59). Likewise, Patton (2002, p. 125) emphasizes that the findings be “grounded in the empirical world”.

**Sampling Strategies**

Three broad considerations are pertinent to sampling strategies in qualitative research: purposeful sampling, theoretical sampling, and issues of sample size. These considerations merge during the research design phase and implementation of the study. Purposeful sampling (sometimes called *purposive* sampling) is the method of choosing specific participants for the study because of their unique characteristics (Patton, 2002; Richards & Morse, 2007). The goal of purposeful sampling is to select *information-rich cases* for in-depth study so that, “one can learn a great deal about issues of central importance to the purpose of the inquiry” (Patton, 2002, p. 230). Specifically, information-rich cases provide insights, detailed understanding, and
illuminate the research questions (Patton, 2002). In qualitative research, purposeful sampling is preferred to random sampling (Morse, 2010). The bias towards nonrandom selection is because, as Morse (2010) asserted, “researchers seek the best examples of whatever it is they are studying. We seek the optimal, rather than the average, experience (p. 234)”. Furthermore, random samples may impede the study if researchers cannot be assured of selecting the best cases (Morse, 2010).

Purposeful sampling for selecting information-rich cases has many variations. Miles and Huberman (1994) proposed a widely cited typology of 16 purposeful sampling strategies (Table 3-1). Creswell (1998) recommends that qualitative researchers, regardless of qualitative orientation, elucidate their purposeful sampling criteria and rationale for selecting participants.

Creswell (1998) offered guidance on the types of purposeful sampling strategies applicable to ethnographic, phenomenological, and grounded theory projects. For example, in ethnographic research the investigator first selects a particular cultural group and decides on certain aspects to be studied. Creswell (1998) suggests the researcher utilize opportunistic sampling to follow leads as they occur. Otherwise, an investigator might utilize a criterion-based approach to pursue the previously specified aspects of the cultural group. In phenomenological inquiry, it is necessary that all participants have experience with the phenomenon under study. Thus, Creswell (1998) recommends criterion sampling is suitable in phenomenology because all participants have experience with the phenomenon. Finally, in grounded theory the researcher selects participants based on their ability to contribute to evolving theory (Creswell,
1998). This is what Creswell (1998) describes as a *theory based* sampling strategy or in grounded theory terminology, *theoretical sampling*.

Theoretical sampling is a second area of consideration regarding sampling strategy. It is traditionally applied in grounded theory, but has utility for the other qualitative traditions and according to Richards and Morse (2007) must be treated “as a necessity” (p. 84). Theoretical sampling is the selection of participants consistent with the needs of one’s emerging analysis (Richards & Morse, 2007) and achieves “representativeness and consistency” (Corbin & Strauss, 1990, p. 9). Strauss and Corbin (1990) also endorse theoretical sampling, but unlike Richards and Morse (2007), they propose that *concepts* are the unit of analysis in grounded theory research. They characterize theoretical sampling as, “sampling on the basis of concepts that have proven theoretical relevance to the evolving theory” (Strauss & Corbin, 1990, p. 176).

In grounded theory, Glaser (1978) and Corbin and Strauss (1990) posit that sampling proceed on theoretical grounds rather than solely drawing specific samples of individuals. Essentially, “representativeness of concepts, not of persons, is crucial” in grounded theory (Corbin & Strauss, 1990, p. 9). A sample includes individuals and additionally conditions, concepts, their properties, dimensions and variations (Corbin & Strauss, 1990). In other words, anything that might represent the phenomenon under study is selected such that “One varies or contrasts the conditions as methodically as possible in order to determine what has an impact on the phenomenon in question” (Corbin & Strauss, 1990, pp. 8-9).

Charmaz (2009), expanding on Corbin and Strauss, adds that theoretical sampling continues, “until no new properties emerge” (p. 96). Charmaz (2009) also distinguishes
between initial sampling and theoretical sampling. A researcher starts a grounded theory project with initial sampling, establishing sampling criteria for people, cases, and situations before entering the field (i.e. a criterion based sampling strategy). However, initial sampling is a beginning point but does not establish “theoretical elaboration and refinement” (Charmaz, 2009, p. 100) - an investigator cannot identify categories in advance. Grounded theory presumes that categories will emerge through the constant comparative method of analysis. Differentiating between initial and theoretical sampling Charmaz (2009) observes, “Initial sampling in grounded theory is where you start whereas theoretical sampling directs you where to go” (p. 100).

Sample size is the third consideration concerning sampling strategies. Patton (2002) stated firmly, “There are no rules for sample size in qualitative inquiry” (p. 244) and Guest, Bunce, and Johnson (2006) concurred asserting, “Guidelines for determining nonprobabilistic samples are virtually nonexistent” (p. 59). Though there are not firm methodological rules pertaining to sample size, nonetheless guidance does exist. Sandelowski (1995) observes that sample size in qualitative research is not computed by power analysis, as is done in quantitative research, but rather by employing the researcher’s judgment that the data are rich enough and cover the dimensions of interest. Similarly, Charmaz (2009) adds that in grounded theory the aim of sampling is theory construction, not to achieve a representative sample. Moreover qualitative research, “typically focuses in depth on relatively small samples, even single cases (N=1), selected purposefully” (Patton, 2002, p. 230).

According to Morse (1994, p. 230), “Adequacy is attained when sufficient data have been collected that saturation occurs and variation is both accounted for and
understood.” Saturation is, “the discovery that additional interviews are yielding so little new information that more interviews would be a waste of time” (Hood, 2010, p. 161). Nevertheless, some theorists have suggested specific guidelines for sample sizes in ethnography, grounded theory, and phenomenological studies. In phenomenology, Morse (1994) suggests at least six participants while Creswell proposes five to twenty-five (Guest et al., 2006). Morse proposes approximately thirty-five participants for ethnographic and grounded theory research. Creswell (1998) recommends twenty to thirty participants for a grounded theory project. Given all this variation, Patton (2002) surmises that sample size depends on several factors; namely, the study purpose, research question, what is useful, what lends credibility, available time, and available resources.
Table 3-1. Typology of purposeful sampling strategies

<table>
<thead>
<tr>
<th>Sampling Strategy</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combination or mixed</td>
<td>Triangulation, flexibility, meets multiple interests and needs.</td>
</tr>
<tr>
<td>Confirming and disconfirming cases</td>
<td>Elaborate on initial analysis, seeks exceptions, looking for variation.</td>
</tr>
<tr>
<td>Convenience</td>
<td>Saves time, money, effort. Least desirable strategy – low credibility and information-poor cases.</td>
</tr>
<tr>
<td>Criterion</td>
<td>All cases meet some criterion. Useful for quality assurance.</td>
</tr>
<tr>
<td>Critical case</td>
<td>Permits logical generalization and maximum application of information to other cases. If it is true of this one case, it follows to be true of all other cases.</td>
</tr>
<tr>
<td>Extreme or deviant case</td>
<td>Learn from highly unusual manifestations of the phenomenon of interest. For example notable successes or failures.</td>
</tr>
<tr>
<td>Homogeneous</td>
<td>Focuses, reduces variation, simplifies analysis, and facilitates group interviewing.</td>
</tr>
<tr>
<td>Intensity</td>
<td>Information-rich cases that manifest the phenomenon intensely but not extremely.</td>
</tr>
<tr>
<td>Maximum variation</td>
<td>Documents diverse variations and identifies important common patterns</td>
</tr>
<tr>
<td>Opportunistic</td>
<td>Follow new leads during fieldwork and taking advantage of the unexpected.</td>
</tr>
<tr>
<td>Politically important cases</td>
<td>Attracts desired attention or avoids attracting undesired attention.</td>
</tr>
<tr>
<td>Random purposeful</td>
<td>Adds credibility to sample when potential purposeful sample is too large.</td>
</tr>
<tr>
<td>Snowball or chain sampling</td>
<td>Identifies cases of interest from people who know people who know what cases are information-rich.</td>
</tr>
<tr>
<td>Stratified purposeful</td>
<td>Illustrates characteristics subgroups and facilitates comparisons.</td>
</tr>
<tr>
<td>Theory based</td>
<td>Find examples of a theoretical construct and thereby elaborate on and examine it.</td>
</tr>
<tr>
<td>Typical case</td>
<td>Highlights what is normal or average.</td>
</tr>
</tbody>
</table>

Note: Adapted from Miles & Huberman, 1994

Data Collection

Richards and Morse (2007) observe that the practice of grounded theory does not require a particular data source, providing the theory can be grounded in the data. They
further assert that data must be exceedingly detailed as, “the records must support the probing and friction of constant comparison and reflection” (Richards & Morse, 2007, p. 61). Additionally, Richards and Morse (2007) caution against attempting grounded theory with structured data records as this may be restrict what is learned from questioning participants. Moreover, Charmaz admonishes the researcher to, “gather rich data” meaning data that are “detailed, focused, and full” (Charmaz, 2009, p. 14). Grounded theory data can take the form of memos, field notes, interviews, transcripts of interviews, audio tapes of interviews, or information obtained from records and reports (Charmaz, 2009). Glaser, one of the founders of grounded theory, says, “All is data” (Charmaz, 2009, p. 16).

Richards (2009) provides guidance applicable to any qualitative research tradition on data collection activities. She advises the researcher to consider not just ways of making data but ways of recording data. Data analysis will depend largely on the quality of the records made (Richards, 2009). High quality data contains these elements: accuracy (records are checked against recall, notes, tapes), context (include descriptions of setting, social context, body language, tone), thick description (detail of recall and imagery, interpretative comment and contextual knowledge), usefulness (carries all pertinent information about the research event, the respondent, or the setting), and reflexivity (consider the ways in which you are part of the study) (Richards, 2009).

Finally, the social interaction between the researcher and the researched generates data in grounded theory. The role of the researcher and the participant are intertwined as Richards (2009) explained, “qualitative data are not collected, but made
collaboratively by the researcher and the researched (p. 49). Thus, the researcher, having a particular frame of reference, influences the process as much as the participant does. Reflecting on the researcher’s role and the method by which data are made is reflexivity. This is the act of comprehending how the researcher, the participants, and the circumstances influence one another (Glesne, 2011). Robson (2002, p. 22) described reflexivity as, “An awareness of the ways in which the researcher as an individual with a particular social identity and background has an impact on the research process.”

In addition, theoretical sensitivity contributes to the data collection process and is enriched by personal and professional experiences (Strauss & Corbin, 1990). Professional experience provides a “knowledge base and insight” (Strauss & Corbin, 1990, p. 42) for research. While personal experiences offer “a basis for making comparisons that in turn stimulate the generation of potentially relevant concepts and their relationships” (Strauss & Corbin, 1990, p. 43). McGhee, Marland, and Atkinson (2007) and Neill (2006) propose a researcher make explicit their background (in the form of a reflexivity statement) to avoid prior knowledge unduly influencing the research process.

**Data Analysis**

There are both tradition-specific and general analytic strategies for data analysis. All three qualitative traditions have strategies and procedures that are similar for identifying and categorizing themes that emerge from the data. However how coding is done differs with each method. According to Richards and Morse (2007), “Each method demands that the researcher think about data in a particular way” (p. 169). The differences in the approaches become apparent when “the researcher thinks about the
data and subsequently *conceptualizes*, that is, ‘thinks up’ from data” (Richards & Morse, 2007, p. 48).

DeWalt and DeWalt (2002) referenced a general model of data analysis proposed by Miles and Huberman (1994) that specified three activities: data reduction, data display, and interpretation and verification. Data reduction involves, “the process of selecting focusing, simplifying, abstracting, and transforming the data that appear in written up field notes” (Miles & Huberman, 1994, p. 10). Data display follows data reduction. Data (typically direct quotes) presented in tables, diagrams, or matrices, “allows the analyst to review large amounts of data efficiently, make comparisons, summarize patterns, draw conclusions, and present an effective argument” (DeWalt & DeWalt, 2002, p. 181). The last step is interpretation and verification. This involves making inferences from the data (how things are patterned, what they mean, and what causes them) and then returning to the data for verification (DeWalt & DeWalt, 2002).

Glaser and Strauss (1967) promoted the constant comparative method of analysis in grounded theory. Comparing pieces of data is a place to begin, not end, the process of constant comparison. Glaser and Strauss’s description of constant comparison process is:

While coding an incident for a category, compare it with the previous incidents in the same and different groups coded for the same category … This constant comparison of incidents very soon starts to generate theoretical properties of the category (Glaser & Strauss, 1967, p. 106).

Creswell (2009) and Patton (2002) both note that what grounded theory offers for a structure are systematic steps or coding procedures - coding being the fundamental process of analysis in grounded theory. Beginning with *open coding* where categories are generated. This is followed by *axial coding* wherein a category is linked to all the
subcategories that contribute to it, and ending with selective coding where a story is
generated about the interconnected categories (Creswell, 2009). Patton (2007)
described the process as starting with a basic description, followed by conceptual
ordering, and finally, theorizing. Bowers (1988) observes that the phases of research
(i.e. the literature review, question generation, data collection, and analysis) happen
concurrently rather than in discrete steps. This serves the purposes of allowing for
flexibility and adaptation of the grounded theory project.

According to Charmaz (2009), grounded theory offers a flexible set of set of
guidelines rather than prescriptive rules and requirements. The research process is
nonlinear where sometimes the multiples avenues of inquiry may develop or
researchers may find themselves returning to the field after work is nearly completed
(Ccharmaz, 2009). Both Patton (2002) and Creswell (2009) acknowledge that the
primary characteristic of grounded theory design is the continuous making of theoretical
comparisons of data and categories. Two other tenets of this method are striving for
objectivity and the inductive nature of inquiry.

**Data Interpretation**

Information becomes data when, “we record it and try to make sense of it”
(Richards, 2009, p. 33). Data becomes germane to the research project when we
establish how the data answers our research questions. Consequently, “The test is to
handle these data well” (Richards, 2009, p. 33). Handling the data well is accomplished
by abstracting up from the data through the steps of classifying, coding, distilling, and
seeking themes (Richards & Morse, 2007). In addition to the aforementioned steps,
analyzing qualitative research also, “relies on inductive reasoning processes to interpret
and structure the meanings that can be derived from the data” (Thorne, 2000, p. 68).
According to Richards and Morse (2007) the qualitative researcher needs to “think abstractly” (p. 153) in order to transform data from individual occurrences, to general categories, to explanatory concepts, and finally into theory. Richards and Morse (2007) describe data transformation in qualitative research as a process of abstraction. The first steps of “abstracting up from the data” (Richards & Morse, 2007, p. 154) are coding, categorizing, and conceptualizing. Coding is a technique used to generate categories of concepts, themes, and patterns (Richards & Morse, 2007).

After categorizing, the next step of abstraction is conceptualization. In conceptualization, the researcher develops concepts or mental images that are more general and abstract than categories (Richards & Morse, 2007). As categories are developed into concepts, the research theory continues to evolve from descriptive to analytical (Richards & Morse, 2007).

Abstraction, according to Richards and Morse (2007) will occur at various points in the process depending on which qualitative tradition is employed. In ethnographic studies, abstraction occurs as data is collected in the field. Abstraction in grounded theory is developed from the data but can also be developed from other pre-existing theories. In phenomenology, abstraction occurs only after previous ideas are bracketed and data is collected.

**Goal of the Research**

The primary goal of the study was to conduct grounded theory research that resulted in an understanding of the personal meaning of work to, and the employment experiences of, people with CF and ultimately develop a substantive grounded theory of career development applicable to individuals with this disease.
**Research Questions**

The purpose of the study was to answer these research questions for a sample of emerging adults with CF:

- What is the personal meaning of work?
- How has the illness influenced their employment choices and aspirations?
- What are their lived experiences in the workplace?
- What is the career development process?

The specific aims of the study were four-fold: (a) to gain a deep understanding about the meaning of work to emerging adults with CF, (b) to give voice to emerging adults with CF to discover how the illness has influenced their employment aspirations, (c) to identify, describe, and analyze the employment experiences of emerging adults with CF, and (d) to identify, describe, and analyze the process of career development in emerging adults with CF.

**Methods**

I sought approval for a pilot study from the Institutional Review Board (IRB) at the University of Florida prior to the conduct of any research. The protocol for the pilot study was approved on December 29, 2010 and five participants were subsequently interviewed in the spring of 2011. On July 14, 2011, the IRB approved a project revision to recruit 15 additional participants and the inclusion on an instrument (Career Development Inventory).

**Inclusion and Exclusion Criteria for Participants**

**Inclusion criteria**

The target population was:

- Adults (18 years or older) with a diagnosis of cystic fibrosis
- Currently working in paid employment (full-time or part-time) or who have worked in the past twelve months
Exclusion criteria

Subjects who did not meet the above criteria were excluded; this included those who were not diagnosed with cystic fibrosis; those who were self-employed and who had no employment history in the last twelve months.

Procedures

As the principle investigator, I interviewed ten adult participants with CF who were employed at the time or who had worked in the past twelve months. Similar sample sizes were utilized in the studies inspected in the literature review section (Conyers et al., 1998, Johnson et al., 2004, Noonan et al., 2004, O'Day 1998). Sample size in qualitative research is not computed by power analysis, as is done in quantitative research, but rather by employing the researcher’s judgment that the data are rich enough and cover the dimensions of interest (Sandelowski, 1995). According to Morse (1994, p. 230), “Adequacy is attained when sufficient data have been collected that saturation occurs and variation is both accounted for and understood.” After analyzing data from the 10th interview, the researcher conferred with his committee and ended participant recruitment based on the researcher’s judgment that saturation of existing categories was achieved.

Protection of Participants and Confidentiality

The confidentiality of all participants was protected throughout all phases of the study. After obtaining informed consent, participants were assigned an identifying pseudonym. This pseudonym was not linked to the signed informed consent. Therefore, there was no way to link the interview recordings or transcripts to the signed consents. Transcripts of individual interviews were kept in a locked file cabinet when
not in use. All audio recordings of interviews were destroyed after the contents had been transcribed and verified.

**Recruitment and Participants**

The sampling method was a criterion-based strategy as described by Miles and Huberman (1994) to obtain a sample in which all cases meet the criterion of CF and having experience with employment. Moreover, a purposive sampling method was utilized in order to obtain information rich cases with a broad array of ages, gender, and work experiences.

Ten participants were recruited from the Cystic Fibrosis Foundation North Florida office and the CF center at UF/Shands. At the CF center, two social workers assisted with identifying and recruiting potential participants. These individuals had contact with potential subjects through normal routine outpatient care at the CF center. The executive director of the Cystic Fibrosis Foundation North Florida office also assisted with identifying and recruiting potential participants. The executive director is in contact with potential participants through her duties with the foundation.

**Instrumentation**

**Interviews and the Use of an Interview Guide**

The primary instrument of data collection was an in-depth interview conducted in a conversational style to elicit rich narrative data. Participants were asked to submit to an initial interview and possibly a follow-up interview. The purpose of the follow-up interview was to clarify information obtained at the first interview and verify themes identified during the analysis of the transcripts.

The interviews are designed to be lengthy and elicit a narrative rich in detail from the participants. The interviews will be semi-structured in nature with open-ended
questions and strike a conversational tone. An interview guide will serve as the framework to conduct interviews however; this will be a flexible document such that it might be revised after each interview.

**Career Development Inventory**

In order to understand participants’ career decision-making the researcher administered the Career Development Inventory (CDI) (Thompson, Lindeman, Super, Jordaan, & Myers, 1981) an 80-item instrument comprised of four scales of 20 items each: Career Planning (CP), Career Exploration (CE), Decision Making (DM), and Knowledge of the World of Work (WW). These scales measure vocational attitudes and competencies critical to career decision-making. The CDI has been widely used as a career development tool and has utility for physically disabled populations (Eby, Johnson, & Russell, 1998).

The CDI and its subscales have been found to have adequate reliability (Thompson, Lindeman, Super, Jordaan, & Myers, 1981). Pinkney and Bozik (1994) reported acceptable internal reliability coefficients for three scales: CP (.89), CE (.78), and WW (.84) but urged caution regarding the fourth - DM (.67). Furthermore, the CDI demonstrates evidence of predictive validity (Hartung, 1997). After reviewing the literature and psychometric properties of the CDI Savickas and Hartung (1996) concluded that, “the CDI strongly supports the sensitivity and specificity of the inventory as a measure of readiness to make educational choices, vocational choices, or both” (p. 185).

**Data Analysis and Interpretation Procedures**

Interviews were audiotaped and transcribed verbatim. The interview transcripts were then verified against the audio recordings. Following that, the transcripts were
read several times and the audio recordings will be listened to several times to get a sense of the whole. Additionally, interviews were entered in NVivo software to facilitate managing and organizing the data.

The interview recordings and transcripts were analyzed using the constant comparative method as elucidated by Glaser and Strauss (1967). In this technique, continuous comparisons are made of the entirety of the interview data collected. Comparisons are made within a single interview and among the set of interviews collected for the study (Boeije, 2002; Charmaz, 2006; Glaser & Strauss, 1967).

Data from the interview transcripts were coded and examined for emergent themes. These data were then grouped into categories and themes that could be used to describe the experiences of the study participants with regard to career development, and the personal meaning and experience of work.

The researcher took field notes during the interviews and later augmented them immediately following the conclusion of the meetings. Field notes captured both personal reflections and the context of the interview. Later these field notes contributed to analytic memos about concepts that emerged from the data. The researcher also compared transcripts, audio recordings and field notes for any inaccuracies.

Furthermore, the researcher documented the analysis process in an audit trail in a project journal. As the data analysis proceeded, the researcher logged observations and interpretations about the data, keep track of coding decisions and reasons for categories, revisions, and analytical conclusions.

Peer debriefing was utilized as an added crosscheck and analysis mechanism. The researcher consulted with the qualitative data group within the College of Public
Health and Health Professions on the development of an interview guide. Additionally, the researcher sought consultation and feedback on data interpretations from faculty skilled in qualitative research and feedback from the qualitative data analysis group on emerging themes and the conceptual model.

**Reflexivity**

The role of the researcher and the participant are intertwined as Richards (2006) showed, “qualitative data are not collected, but made collaboratively by the researcher and the researched (p. 49)”. The researcher, having a particular frame of reference, has an impact on the process. Reflecting on the researcher’s role and the method by which data are made is *reflexivity* and it is the act of comprehending how the researcher, the participants, and the circumstances influence one another (Glesne, 2011). Robson (2002, p. 22) described reflexivity as, “An awareness of the ways in which the researcher as an individual with a particular social identity and background has an impact on the research process.”

In addition, theoretical sensitivity, guided by the literature review, is enriched by personal and professional experiences (Strauss & Corbin, 1990). Professional experience provides a “knowledge base and insight” (Strauss & Corbin, 1990, p. 42) for research. While personal experiences offer “a basis for making comparisons that in turn stimulate the generation of potentially relevant concepts and their relationships” (Strauss & Corbin, 1990, p. 43).

McGhee et al. (2007) and Neill (2006) propose a researcher make explicit their background to avoid prior knowledge unduly influencing the research process. Following this tenet, reflexivity was completed prior to embarking on any data collection, analysis, or interpretation. I reflected on my experiences to reveal anything that might
inform my research or influence data analysis and interpretation. An ongoing reflexive process will inform my interpretation of findings.

**Personal Bias Statement**

I wish to share how people with CF came to define my research. I began working with individuals with CF as a social worker and rehabilitation counselor never contemplating that I would embark on a research career where they would figure prominently. Now, however, my professional and personal life has been touched by people with CF and along the way, I found my purpose.

In the fall of 2005, I was employed in a non-clinical position performing administrative social work duties at a state agency. I was also in the final semester of a master’s degree in Rehabilitation Counseling and eager to find a position where I could apply the knowledge, skills, and abilities I had acquired in the program. It was in September 2005 that my connection with CF began when I obtained a position as the social worker in a pediatric CF center that serves youth from birth to age 21. Prior to starting this position, I had not encountered anyone with CF and today I estimate I have worked with 150. I jumped into the world of CF wholeheartedly and I was warmly received. Aside from performing my duties in the clinic, I assisted patients when they were hospitalized and I raised money for pharmaceutical research by organizing a team for Great Strides – the annual CF fundraising walk.

As I soon learned, there is much to know about CF. It is a complicated illness affecting the pulmonary, gastrointestinal, and endocrine systems. Fortunately, my patients were willing to teach me how CF affects them - not just physically but emotionally, socially, academically, and vocationally. I discovered that my patients and families had many unmet needs including emotional, financial, school issues, insurance,
and employment. As I became acquainted with them individually, I developed a greater appreciation for my good health and ability to attend school and perform work, two challenges for some individuals with CF.

Speaking with numerous emerging adults about work spurred my curiosity about employment experiences in CF. Many expressed a desire to work or attend postsecondary education but encountered limitations engendered by their illness. Some have experienced vocational success but too many have not. Their triumphs and struggles in choosing, getting, and keeping employment fostered my desire to study the personal meaning and experience of work. The information I acquired, especially about the vocational consequences of CF, set me on the path to research this issue. I also have a strong desire to advocate for people with CF in employment issues and design interventions that might be beneficial.

I feel that my previous knowledge of CF is an advantage in my research. CF is a complex, multifaceted illness that creates some unique conditions pertaining to employment that I now know firsthand. Moreover, my intimate connection to the world of CF gives me a theoretical understanding and sensitivity. This will help me to construct meaning from data that someone unfamiliar with CF might not ascertain.

I foresee one drawback to my dual role as social worker and researcher. My previous training as a social worker and rehabilitation counselor may at times conflict with the research role of gathering data in an interview. There is the potential for a quasi-therapeutic relationship as I would be tempted to fall into the helping role. This is why I choose to do my research at a different CF clinic than my own employment setting so that I do not duplicate the social work role.
I did not initially set out to become a CF researcher. Nevertheless, after spending time assisting individuals with CF and learning about their experiences at school and work I arrived at the conclusion that research in this area could potentially be of benefit.
CHAPTER 4
PARTICIPANT CASE HISTORIES

Overview

In order to provide a context for the data analysis, this chapter presents background information on each participant. These case histories are essential to understanding the unique career development and work experiences of individuals with CF. The researcher assigned pseudonyms to the participants to maintain confidentiality and protect their identities in the reporting of results therefore only pseudonyms are used in the sections that follow. The case histories are presented in the order in which each individual was interviewed.

Participant Demographics

Ten individuals with CF between the ages of 18 and 27 agreed to participate in the study. Demographic information was collected via a demographic information questionnaire and through interviews. Table 4-1 provides a summary of participant demographics. The sample was comprised of six females and four males, and efforts were taken to include diversity in age, gender, disease severity, education, and work experience. However, as CF primarily affects people of Caucasian decent (Yankaskas et al., 2004), all the participants were white.

The Participants

Ann

Ann was an 18-year-old female college student who was employed part-time and living with her parents and siblings. Her CF was mild as evidenced by no history of hospitalizations or CF complications, such as malnutrition or CF-related diabetes. She described making employment and educational decisions influenced by CF. At one
time, Ann had been a daycare teacher but left on her pulmonologist's advice as she was getting sick frequently from interactions with the children. She spoke of the difficulty resigning given her attachment to the children. At the time of interview, she was employed part-time in retail sales in a small independently owned establishment that specialized in serving children. Ann discussed her two positions with great fondness expressing that she felt supported by her employers and co-workers whenever she was sick. For example, while working at the store, coworkers would cover for her if she had a coughing fit, needed to take medicine, felt fatigue, or needed to use the restroom.

Ann was in her first year at a community college with the intention of becoming a teacher. However, teaching was not her first choice. She had originally intended to become a registered dietician working with children with CF. Her own dietician advised her against this given the concern about infection control. Ann spoke of the effect CF has had on her employment and career choices. She verbalized that being a teacher might be incompatible with her condition but she wanted to try.

**Bob**

Bob was a 21-year-old male college student who was employed part-time and living with his parents and siblings. He declared that his education and work history were unfazed by CF hospitalizations or exacerbations. Bob's condition is mild as evidenced by his report of no hospitalizations as an adult and no CF exacerbations. He was hospitalized as a child when he received surgery to remove nasal polyps.

Nonetheless, CF influenced his employment choices. At the time of interview, he was employed in a movie theater as an usher taking tickets and cleaning up the theaters. He had been at this position for over three years working part-time during the school year and full-time in summer. Previously he had worked in a restaurant as a
cook. He shared that he did not think being a cook was a good idea because he would cough a lot and did not want to be coughing on people’s food. Furthermore, he reported being slower than the other cooks because he was continually stopping to wash his hands after coughing. He shared that his current position was more compatible with his condition since the duties are not as taxing and he could excuse himself without being noticed to cough or use the restroom. He has concern about his contact with the public and acquiring infections and thus he avoids individuals he suspects are sick. Bob is selective about disclosing his condition and has only shared with a few of the staff.

Bob was a junior at a state university where he was majoring in electrical engineering. He spoke of his early career interests, such as wanting to be in the medical field, but surrendered this pursuit to a realization that it was unsuited to his having CF.

Chris

Chris was an 18-year-old male college student who was employed part-time and living with his parents and siblings. He was working in an ice cream shop (his first job). He disclosed some negative work experiences related to CF. At the shop, he was responsible for making the various ice cream flavors; therefore, he does not work directly with the public. He expressed overall satisfaction with his duties but did not feel supported by his manager or coworkers. Chris did not initially disclose having CF during the hiring process, however other workers observed his frequent cough. He eventually disclosed in confidence to one worker and this individual told the manager, which created some conflict for him. Subsequently he started trying to suppress his cough and he acknowledged that his physician discourages cough suppression. Additionally, the cold environment of the store freezer aggravates his CF by giving him
chest tightness. As a result of these experiences, he is selective about disclosing his CF at work.

Chris is a full-time freshman at a state university where he is a pre-med student. His goal is to become a dermatologist and he said this was out of a desire to help others. Chris’ CF is mild as evidenced by no history of hospitalizations or CF-related complications.

Debbie

Debbie was a 21-year-old female college student who was working part-time and living with her parents and siblings. She had severe disease evidenced by two double lung transplants, numerous hospitalizations, and the complication of pancreatic insufficiency. Debbie expressed that her education and employment choices as having been significantly influenced by CF exacerbations and hospitalizations.

Debbie had first worked for two years as a cashier for a major grocery store chain. As her disease progressed, she found she did not have the stamina and endurance necessary and she resigned from this position. Debbie shared she needed something less physically demanding and with more flexibility. This is what prompted her to seek employment as a nanny. She noted the benefit of working in this capacity is that her employers have been more understating when she has been sick or hospitalized. At the time of the interview, she was a nanny and baby sitter for numerous families.

Debbie was attending a state university where she was majoring in psychology with the intention of becoming a counselor specializing in children. With her exposure to hospitals, she felt she had the necessary compassion to help children with behavioral health needs. Debbie had originally been interested in journalism but found this ill
suited to her because it was fast paced, stressful, and the work environment too demanding.

**Elsie**

Elsie was a 23-year-old female high school graduate who was not working and lived with her mother. She had severe disease evidenced by numerous hospitalizations, pancreatic insufficiency, and malnutrition. Elsie described an educational and work history often disrupted by CF exacerbations. At the time of her interview, Elsie was not in school and had not worked for 4 months. Most recently, Elsie was a seasonal sales associate with a major department store chain during the holidays. After a week on the job, she developed pneumonia and was hospitalized for one month. Returning to work in mid-December, she felt alienated as though she was treated differently and viewed as sick. Her hours were cut and she sensed management had no understanding or sympathy. Her last day of work was Christmas Eve 2011. Elsie’s first job was at age 17 with a chain restaurant doing food preparation and later she was promoted to assistant manager. Her experience at the restaurant was positive and she noted they were understanding of her frequent illness related absences. She worked briefly for a doctor’s office at the same time as the restaurant job but this was short lived as she was hospitalized and subsequently terminated.

Elsie expressed a desire to pursue vocational training, such as cosmetology or dental hygiene, and has made three unsuccessful attempts since graduating high school. She has decided to wait until she feels well enough to complete a program without interruption before trying again.
Fred

Fred was a 27-year-old male college graduate who was working full-time and attending graduate school. He lived with his significant other and a roommate. Fred stated that CF did not complicate his educational and work history, as he was already an adult at the time of his first hospitalization. At the time of the interview, he was working full-time teaching English as a second language to adult foreign exchange students. Prior to this, he was a middle school teacher for two years. He was enrolled at a university pursuing a master’s in education. Fred characterized his work experiences as positive. Fred has milder disease evidenced by a history of one hospitalization several years ago for a mild CF exacerbation.

Grace

Grace was a 22-year-old female high school graduate who lived with her significant other and roommates. At the time of the interview she was not working. She has severe disease as demonstrated by a history of multiple hospitalizations, pancreatic insufficiency with poor nutritional status.

Grace described the impact of CF exacerbations, which contributed to work disruptions. Grace has a work history consisting of one year in retail, nearly a year in a restaurant, and most recently three years as a nanny. However, illness related absences compromised her retail and restaurant employment, which lead to her last employment setting. Grace had most recently worked as a nanny and found this rewarding. Moreover, she found this type of work afforded her the flexibility she needed to cope with unpredictable disease exacerbations. Grace was not enrolled in college at the time of the interview but had earned some college credits. She cited her financial
circumstances as the reason she could not return to school. Her career aspiration is to become a kindergarten teacher.

**Hal**

Hal was a 21-year old male college graduate working part-time and living with his parents and younger brother. Hal’s CF is mild as evidenced by his report of no hospitalizations or CF exacerbations. His employment history consists of working five summers as a lifeguard, swim instructor, and athletic coordinator at a county recreation department. Additionally, he was a research assistant while an undergraduate. He characterized CF as non-consequential to his education or employment history and expressed positive feelings about his employment experiences. Nevertheless, CF shaped Hal’s career aspirations. He originally majored in biology with the goal of pursuing a career in medicine. Later he decided that the physical demands of medical school and risk of exposure to infection were too great. He switched to psychology and earned a bachelor’s degree from a state university. At the time of this interview, he was in the process of applying to masters programs in counseling psychology with the goal of becoming a therapist.

**Ingrid**

Ingrid was a 21-year-old female college student employed part-time and living with her parents. Ingrid’s CF is severe as demonstrated by her reports of numerous hospitalizations, lung colonization by a particularly harmful bacteria, and CF complications. She disclosed an education and employment history disrupted by unpredictable CF exacerbations. She missed much of the 12th grade and later a semester of college with illness and hospitalizations. In addition, Ingrid shared that CF influenced her career choice.
At the time of the interview, she was working three part-time jobs (retail, line dance instructor, and waitressing) while attending community college. Ingrid has been working since high school when she took her first position as a server with a large restaurant chain. She characterized her work experiences positively by virtue of having supportive employers and coworkers. Ingrid is majoring in public relations at a community college. She expressed a desire to pursue a career in which she could be an advocate for others with CF.

**Jackie**

Jackie was a 21-year-old female college student living with two roommates. Jackie’s CF is more severe as evidenced by numerous hospitalizations and CF exacerbations. She reports a history of education and work disruptions prompted by CF exacerbations. She was not working at the time of the interview and had last worked about three months prior.

Jackie had an extensive work history consisting of retail, restaurant, and clerical positions. She worked as a sales associate in a clothing store for a year followed by being employed as a grocery store cashier. She worked briefly in a clerical position at an engineering firm and most recently as a server in a restaurant. She spoke of the adjustments she had to make to her work schedule to accomplish her CF treatments and changes in employment to accommodate her decreasing stamina and endurance.

Jackie was in college pursuing a bachelor’s degree but had not declared a major at the time of this interview. She was interested in nursing or teaching and she had to miss a few semesters due to illness and stated this put her behind in completing her degree.
Descriptive Attributes

In order to make comparisons, the researcher grouped participants by various attributes. First, participants were grouped by disease severity either having less severe or more severe disease (assessed by their reports of hospitalizations and/or CF-related complications or a lack thereof). In this sample, five of the ten participants were judged to have more severe disease and these were all older, female, participants. The fact that females in this sample had worse disease was not surprising. Gender differences in disease severity and mortality, with females at a disadvantage, are well documented (Kulich et al., 2003; Mogayzel & Flume, 2011).

Second, participants were grouped by age range (age 20 or younger and age 21 and older). Two participants were under age 20 and eight were age 21 or older. Older participants were the ones reporting more severe disease and greater disruptions to education and work pursuits.

Third, participants were classified by RIASEC career categories (Realistic, Investigative, Artistic, Social, Enterprising, or Conventional; Holland, 1997) based on the career aspirations they reported. Of this sample, the majority (9) were pursuing careers in the Social domain and notably, in helping-related professions. The tenth participant was pursuing a career in electrical engineering, which falls in the Realistic domain. Lastly, participants were classified according to their outlook on disclosing CF to employers and coworkers. Six participants were open to disclosure while four had a tendency towards being guarded about disclosing facts about their condition. There are various reasons for disclosing or not disclosing. Some individuals with openness to disclosure noted the feeling of empowerment and disavowed any shame in having CF.
While those with a guarded posture expressed wanting to maintain privacy and voiced concerns about disability related discrimination.

Table 4-1. Participant demographics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Work Status</th>
<th>Highest Education Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann</td>
<td>Female</td>
<td>18</td>
<td>Part-time</td>
<td>SC</td>
</tr>
<tr>
<td>Bob</td>
<td>Male</td>
<td>21</td>
<td>Part-time</td>
<td>SC</td>
</tr>
<tr>
<td>Chris</td>
<td>Male</td>
<td>18</td>
<td>Part-time</td>
<td>SC</td>
</tr>
<tr>
<td>Debbie</td>
<td>Female</td>
<td>21</td>
<td>Part-time</td>
<td>SC</td>
</tr>
<tr>
<td>Elsie</td>
<td>Female</td>
<td>23</td>
<td>Not working at interview</td>
<td>HS</td>
</tr>
<tr>
<td>Fred</td>
<td>Male</td>
<td>27</td>
<td>Full-time</td>
<td>BA</td>
</tr>
<tr>
<td>Grace</td>
<td>Female</td>
<td>22</td>
<td>Part-time</td>
<td>SC</td>
</tr>
<tr>
<td>Hal</td>
<td>Male</td>
<td>21</td>
<td>Part-time</td>
<td>BA</td>
</tr>
<tr>
<td>Ingrid</td>
<td>Female</td>
<td>21</td>
<td>Part-time</td>
<td>SC</td>
</tr>
<tr>
<td>Jackie</td>
<td>Female</td>
<td>21</td>
<td>Not working at interview</td>
<td>SC</td>
</tr>
</tbody>
</table>

Note: SC=Some College, HS= High School Graduate, BA = Bachelor’s degree
CHAPTER 5
FINDINGS

Research Overview

The data analysis and interpretation process advanced through a series of four steps, while employing the fundamental strategy of grounded theory - the constant comparative method of analysis (Glaser & Strauss, 1967). In step one, interviews were transcribed as they were completed. Then transcripts were verified against the audio recordings. Next, the researcher re-read transcripts and repeatedly listened to the audio recordings to get a sense of the complete picture. Subsequently, a project database was created using NVivo 8.0© software to facilitate managing, organizing, and coding the transcripts.

In step two, the researcher performed line-by-line coding in NVivo and compiled a comprehensive list of codes assigning each a brief description. Over the course of the research project, code descriptions were refined to achieve ever-greater specificity of terms. Furthermore, the researcher created memos of impressions after listening to tapes and re-reading transcripts. In step three, the researcher grouped the codes by theme categories and then arranged those themes in a hierarchy. In step four, the researcher continued the constant comparison of codes and categories. Some codes were merged and others moved to new theme categories in a continuous process of building, developing, and refining the project. During the comparison approach, the researcher looked for patterns, relationships, and ultimately identified emergent themes that contributed to a grounded theory of career development of individuals with CF embodied by an ecological conceptual framework. Recruitment for the study ended
when this researcher was satisfied that saturation of the existing categories was achieved.

**Career Development and Disability: An Ecological Approach**

An ecological orientation points to the additional importance of relations between systems as critical to the child’s development (e.g., the interaction between home and school, family and peer group) (Bronfenbrenner, 1974).

The conceptual basis for the model presented in Figure 5-1 is the ecological framework of career development of people with disabilities initially proposed by Szymanski and Hershenson (1998) and later refined by Szymanski et al., (2003). Szymanski and colleagues (1998, 2003) proposed an ecological model to make sense of work and career development. In their model, career development is understood in terms of five nested hierarchical constructs: individual, contextual, mediating, environmental, and outcome factors. The person along with their individual physical/psychological characteristics interacts with contextual, mediating, and environmental factors resulting in employment outcomes (Szymanski & Hershenson, 1998; Szymanski et al., 2003).

Szymanski’s framework borrows from Bronfenbrenner's (1979) groundbreaking ecological model of human development, however; the emphasis is on career development of individuals with disabilities. Bronfenbrenner’s ecological formulation takes a systems approach to development in that the child interacts with various people or systems (initially parents, siblings, grandparents; and later daycare, peers, church, etc.). These systems facilitate development. This interaction is mutual in that the child acts on/influences the environment, and conversely, the environment influences and acts on the child. The immediate environment or system of the child is the *microsystem*, which includes family, daycare/school, peers, neighbors, and the physical
environment among others. The interactions between the various microsystems are known as the *mesosystem*. Broad systems that surround the child are part of the *exosystem* (made up of extended family, friends, and in general the society at large) and the *macrosystem* expresses the influence of culture on the microsystem.

At the core of Szymanski’s version of the ecological model (1998, 2003) is the individual and the context in which they live. *Individual characteristics* incorporate physical and psychological attributes of the person such as gender, race, physical and mental abilities, interests, needs, and values. *Contextual factors* account for the influence of socioeconomic status, family, and education.

*Mediating factors* are three interrelated belief systems that affect the relationship of people and environments that include individual, cultural, and societal beliefs. Individual mediating factors pertain to beliefs about personal abilities and traits such as self-concept, work habits, self-efficacy, career maturity, vocational identity, and adjustment to disability. Cultural mediating factors refer to general worldview, religious beliefs, and racial identity. Societal mediating factors denote stereotypes, discrimination, and attitudes towards people with disabilities.

*Environmental factors* are features of work and other environments that influence individual behavior. These include the culture of the employment setting, the task requirements, the characteristics of co-workers, and the physical environment of the setting. Outcomes, the fifth construct, describe the results of interactions between the other constructs, for example, job satisfaction, persistence, tenure, productivity, and job stress. Szymanski’s ecological framework (1998; 2003) highlights the role of the dynamic interaction between the individual and environmental factors in determining
career development. Moreover, this model emphasizes the fact that through reciprocal interaction between the individual and environment, each one influences the other.
Figure 5-1. Conceptual Model: Key factors that influence work experiences and career development in individuals with cystic fibrosis (adapted from Szymanski, Enright, Hershenson, & Ettinger, 2003)
Ecological Model of Career Development in CF

Analysis of the transcripts revealed the participants' interpretation of their school and work experiences, employment decisions, and career development process. The major themes and sub-themes in the current study unfolded in terms of ecologically based interactions. There is ample research suggesting that the multiple environments in which individuals reside influences career development (Betz, 2002; King & Madsen, 2007; Young, 1983).

For this study, this researcher proposes a model of key influencers of work and career development applicable to individuals with CF derived from the ecological framework of career development of people with disabilities proposed by Szymanski et al. (2003). Within this framework, individual's characteristics, personal contextual factors, mediating factors, and workplace factors combine to shape work experiences and career development. These broad themes were present for all participants, but specific experiences and outcomes varied by disease severity and gender. The results of the current study are reported within the framework of the conceptual model in Figure 5-1.

Individual Characteristics

At the core of the model is the individual with their personal traits. Individual characteristics which were influential in this study were a set of interrelated physical properties (age, gender, and disease severity) and a set of psychological properties (altruism, persistence, and illness appraisal).

Age, Gender, and Disease Severity

Age, gender, and disease severity accounted for some of the variation in the observed career development patterns. The sample of ten participants spanned the
ages of 18 to 27 and was comprised of six females and four males. Participants described their health status as ranging from mild to severe and therefore were grouped by two levels of disease severity for comparison purposes. The levels are defined based on whether individuals have a less severe or more severe disease (assessed by self-reports of hospitalizations and/or CF-related complications or a lack thereof). In this sample, five of the 10 participants were deemed to have more severe disease and these were all older, female participants. The finding that females in this sample had worse disease was not surprising as gender differences in disease severity and mortality, with females at a disadvantage, are well documented (Kulich et al., 2003; Mogayzel & Flume, 2011).

The five participants with less severe disease shared a common pattern of career development – uninterrupted high school attendance, after school and/or summer employment, high school graduation, enrollment in post-secondary education, or entering the labor force. The following statements by three participants exemplify their experiences:

Fred: Well for me, I feel like I’ve always been on the upper percentage as far as you know lung function and, and performance. Growing up I would say it had very little influence on my life. You know a lot of people with CF can’t get overheated and, and things like that. And you have to watch, sweating and stuff, but I was very much an indoor person. Always have been. I’ve always been very academic, and it’s never really been a problem growing up.

Hal: Rarely, even back when I was younger, did I miss school, miss anything. If I did miss something, it would be because of a lack—because I was just too tired so I’d have to stay maybe a day or you know and rest for that day but never was it any prolonged period of time other than surgeries or anything like that.

Ann: But in college, I haven’t because I haven’t really had a problem with it and I don’t. I have never had a tune-up in the hospital or anything like that so I haven’t had to miss school or I haven’t missed any college school.
The following statements from Jackie are illustrative of the interruptions and disruptions experienced by participants with worse disease.

Jackie recalled being hospitalized as early as age 11:
I want to say, I wasn’t really coherent of it until I was like 11. Because that’s my first memories of being in the hospital and things like that.

Jackie reported interruptions during her elementary school years:
As far as like being in and out of school, I want to say that was a little hard, because not a lot of teachers knew how to handle like, some, like a kid being out of school and then coming back. So a lot of the time like when I missed two weeks of school, I just missed two weeks of school.

Jackie experienced interruptions in college, too:
I’m supposed to be graduating in next May, but that’s not happening, because, like with a bachelor’s. But that probably won’t happen for a while, because I’ve taken a lot of semesters off, just because college is a lot harder to coordinate being sick with, I guess. So, I take a semester and then I’ll take a semester off. So, just it’s taking a lot longer to get where I want.

The five female participants with severe disease described a common pattern of career development. One marked by disruption and interruption – frequent illness related school absences, enrollment in hospital/homebound education, withdrawing from post-secondary education for illness related reasons, and losing employment for illness related reasons.

Altruism, Illness Appraisal, and Persistence

Of all the personal attributes identified as important, three variables (altruism, illness appraisal, persistence) stood out in their contribution to career development and work experiences. The researcher described the first, altruism, as desire to be in a career where one can help others. All the participants except one identified a desire to pursue a career where they could be of service to others. Exposure to health professionals from an early age likely accounts for this circumstance as the influence of role models has been shown to be highly significant in career choice (Flouri &
The following statements by Debbie, Grace, Jackie, and Hal are representative of altruistic career aspirations.

Debbie: And so, I wanted to just work with troubled youth. So I’m getting a psychology degree for troubled youth and then um probably also get a biblical counseling degree. So, that’s kind of what I’m going for now.

Grace: I love working with little kids. They’re so much fun. I’ve always loved being around little kids. And I always loved like teaching them things, and watching them learn. And so then whenever I baby sit, because I used to baby sit on the side, and, um, I just decided that that’s what I wanted to do.

Jackie: I’ve always wanted to like be a teacher or be a nurse, or basically just be somebody that helps someone else.

Hal: So I made a decision to switch to psychology because I could pursue still, you know, helping people.

Secondly, the study found participants reported illness appraisals that corresponded accurately with their stated disease severity. In other words, they expressed realistic appraisals of their health status and this was interpreted as indicating adjustment to CF. There were no instances of incongruence between illness appraisal and disease severity noted.

Illness appraisals in individuals with less severe disease:

Bob: I feel like it hasn’t been any different for me. Because outside of keeping the schedule every morning with doing the respiratory clearance, the vest particularly. And younger, the hand clapping. I don’t think it really affected anything.

Hal: It’s gotten easier over time. Yes for sure. Well for one, the inhaled medications that I used to take, specifically Tobramycin which is now gone. Which is better in the fact that my health is actually better than it was since switching to like Pulmozyme for an example, before we had that, I would do Albuterol which was like 45 minutes and it really did nothing. I would get sick maybe three, four times a year. Now I get sick maybe once or twice a year. So definitely since the newer medications have come out, it’s been a lot more helpful.

Illness appraisals in individuals with more severe disease:
Debbie: Um, and so, for me it has been a rocky road. It’s been up and down. Some times are a lot better than others. Most of the time has been in the hospital. I’ve received two double lung transplants.

Grace: A lot of coughing. And a lot of difficulty breathing. It’s hard. And lots of medicine. And then as I’ve gotten older it’s gotten worse. Like it’s gotten a lot harder to breath, and there’s a lot more medicine to take, and it takes up a lot of your time.

Jackie: Um, it’s gotten worse, progressively. I can’t do as much. I sleep all day. Um, well as I’ve gotten like older, I don’t move as fast, just because um my, I just can’t breathe as well. So my oxygen levels decrease when I’m like exercising or like just moving fast. So I walk a little slower and I do things a little slower just so I don’t start like coughing or anything like that.

Realistic appraisal of illness corresponds with better adjustment, acceptance, and adaptation to chronic illness (Bombardier, D’Amico, & Jordan, 1990; Falvo, 2004). As Weinert, Cudney, and Spring (2008) observed, “It is the notion that, realistically, one must accept the illness in order to “get on with living” (p. 369). If for example a participant indicated having severe disease, they used expressions consistent with this disease pattern. Conversely, if a participant had mild disease they used descriptions consistent with having a mild course of the illness. The following remarks are illustrative of each subset of the sample.

Finally, persistence, defined by the researcher as steadfastly and tenaciously pursuing goals, was characteristic of the majority in this study. Participants expressed resolute attitudes about achieving work and school related goals. The following statements are reflective of the persistence expressed by the participants.

Ann: And so just everything that I’ve seemed to want to do has kind of been influenced by CF. And I just want to do education. Whether it’s in high school or middle school or I hope elementary school. But I want to make it work. So I’m not gonna let it stop me.

Chris: And, so, you know, like living with CF is more of living my own daily life. It’s just there’s a few extra things I had to do. And you know I, never really…
try not to let it bother me you know like the only time it really does bother me is when I get sick cause then I can’t breathe or something like that. And that’s the only issue. But, living with CF is normally just living my life. But the thing is, the fact that I have CF kind of pushes me to like okay, I kind of want to finish college. Okay, I want my family. I want, I want to be whatever I turn out to be kind of thing.

Debbie: Most of the time has been in the hospital. I’ve received two double lung transplants. Um, so… I don’t have CF technically in my lungs anymore. Um, but I do deal with all the other issues – sinus issues, and, and you know, gastric issues. Um, but my day-to-day life I try to not let it affect me. Um, I am very active. I go to school. Um, I work part-time. So I am very active. But it has been, you know, hard at times.

Elsie: I think I’ll get to it eventually. You know, I just have to be comfortable with myself knowing that I can do it. And you know, I am not going to be really kind of I guess embarrassed or anything of the fact that I am sick. I just have to know that I can do it. Just you know kind of build myself up for it. So. I think I’ll get there eventually.

Prior research has demonstrated that persistence is both a prerequisite for school to work transition success and highly desired by prospective employers (Lindstrom, Paskey, Dickinson, Doren, Zane, & Johnson, 2007). Perhaps more importantly, persistence apparently mediates the disease severity-career development relationship.

Personal Contextual Factors

Throughout the interviews, the influence of each person’s personal context became apparent. Contextual factors account for the influence of family, education, the health care system, and treatment burden.

Parents’ Influence

The influence of parents primarily extended to encouraging participants to pursue post-secondary education or employment. None of the participants reported that parents influenced them to pursue any specific career or course of action and just one is in a related field. Instead parents promoted post-secondary education or training as a means of achieving economic self-sufficiency. This is contrary to prevailing research
findings that hold that individuals’ career choices are essentially prescribed by their family of origin (Duffy & Dik, 2009).

These statements are reflective of parents who promoted education:

Jackie: I know my mom always wanted me to graduate from high school. And then my dad always expected me to go to college. Like it was never, like a doubt of, oh, if she’s going to. It was always, when you go. So, there was never you’re not gonna go. It was just, you’re going. You’re going. That’s all there is to it. And I feel like the, they don’t expect me to like be straight A student. They just expect me to go, like, want go, and go, and do something to like be proud of myself, I guess.

Hal: Okay well mom has always pushed college very, you know, very much. All I know is I was you know expected to graduate from college, you know, that was a bachelor’s and then it ended up being a master’s then it ended up being a PhD. So I'm pulling back to a master’s for her but she's still wanting the PhD I think in the long run but we'll see. She wants a doctor in the family she says.

In just one case did a participant pursue a career similar to his parents:

Fred: So I guess the connection in the fact that, you know both of my parents are kind of involved in education. I mean my mom and my step dad but that, they’re both involved in education may have some, you know, uh, bearing on my choice of career.

Some parents promoted economic self-sufficiency rather than a particular career:

Elsie: You know. I… whenever I first applied to {fast food restaurant}, you know, I really wasn’t expecting to get the job. I was just, you know, my mom was just starting to, “you know you need to start planning job applications. You’re 17, you’re a senior. Don’t you want your own car?” You know, stuff like that.

Grace: Taught me to work hard. To get what I need. To be able to pay for stuff. To get a good job and be able to support myself.

Education

Educational attainment is an essential component of career development and positive employment outcomes in people with disabilities (DeLoach, 1992; Moore, Konrad, Yang, Ng, & Doherty, 2011). Thus it is promising that all the participants in the
study are at minimum high school graduates. Better still, two have earned their bachelor's degrees and seven have some college credits. One participant attempted post-secondary training but was interuptted by disease exacerbations. Educational disruptions, such as being absent from school, were more common in those participants with greater disease severity than those with less severe disease, but by no means universal. Nevertheless, educational disruptions were unwelcome instrusions as evidenced by the following remarks.

Debbie: I went right to college out of high school the first semester. And did one semester. And then I got really sick after that and took a whole year and a half off and then went back. Did one class per semester really, or two classes or whatever. So, I've been back a year now. Um and, so I don't have many credits at all. Because I didn't do dual enrollment or anything. I just tried to get through high school. So community college and getting my AA will probably take me a little longer. But because I only took like one class the first semester and then two classes the next two semesters.

Elsie: I know that I would have already been through college by now. I would have liked to do something in the medical field but I really can't because, you know, either I'll catch something or you know something will happen you know. I can't be around sick people you know. But like being a nurse, I would love to be a nurse. I know a lot about nursing just being through the whole you know… I, uh, a lot of my friends are nurses and they all love their job but I know I could never do it because I could never be around sick people. I couldn't you know do the demands of the job so… I know that if I didn't have CF to you know always put me in the hospital or something like that I would have already completed and been on my career now. Then, you know, still waiting to even start college.

Ingrid: Of course you have the tune ups and going to the hospital for the 10 to 14 days and when you have that, you end up missing school and work.

All the participants viewed post-secondary education or training as a bridge to their careers. This is a positive finding that challenges Loprest and Maag's (2007) conclusion that childhood disability onset is associated with decreased likelihood of high school completion and entering the labor force.
Health Care System Involvement

Ongoing medical management is essential for individuals with CF and thus contacts with the health care system are frequent. The CF Foundation recommends four routine CF clinic visits per year for preventative care. Contacts increase when one is ill or participating in research studies. The study found that due to frequent contact with the health care system, participants viewed medical professionals as role models and were especially influenced to pursue careers in helping professions as was noted earlier. The following remarks demonstrate the influence of the health care environment.

Ann was influenced by her dieticians:

Mmm hmm. And how much she’s helped and all the other dieticians we’ve had. They’ve been influencing us.

Chris attributes some of his career aspirations to his exposure to health care:

So I mean CF and being around hospitals has influenced a lot but I think just the fact that I like science is really what brings me to wanting to be pre-med. And then also my family. My grandfather is a dentist. My dad is an echo technician. So you know being around them also enhances my ability, or not ability, but my want to be what they are. So, I mean, I think that’s why.

Jackie was influenced by nurses:

For being a nurse, like I’ve always been around nurses and stuff, so I’ve seen like their work routine and stuff. And I’ve always found it fascinating, cool. And like I’m a very much a person who likes to stay busy when I’m like at work. And they’re always busy, they’re always doing something. And then um, I like to help people, so I felt like it was an all-in-one type things, and, um, I feel like that, it has a lot of job security, too. Because you always need nurses.

The majority of participants were pursuing careers in helping-related professions suggesting the influence of health care providers as role models. There is abundant research on career development in childhood (Hartung, Porfeli, & Vondracek, 2005;
(Watson & McMahon, 2005) that supports the assertion that early career exposure is an integral part of an individual’s career development. Hartung, Porfeli and Vondracek (2005) reviewed vocational development literature to explore lifespan vocational development and concluded “what children learn about work and occupations has a profound effect on the choices they make as adolescents and young adults, and ultimately, on their occupational careers” (2005, p. 412).

**Treatment Burden**

The daily medical management of CF is complicated and time consuming such that treatment burden was universally acknowledged by the participants. Each day persons with CF must complete a complex routine of airway clearance therapies, inhaled medications, oral medications, oral pancreatic enzymes, and ingest high calorie meals and nutritional supplements. The treatment burden of CF amounts to two to three hours per day spent on self care. In order to complete all these tasks, adjustments to work and school are often required. The following statements are indicative of treatment burden.

**Ann:** And I just have to get up in the morning before school and do treatments and take my medicine with all my meals. And then I just go about my day whether I’m working or going to school. I mean it kind of gets in the way when I start coughing in front of customers or something like that but for the most part I can try and keep it to myself. But then I have to do treatments at night too so the time management becomes probably the biggest issue.

**Bob:** What happens is, when I am not in school because I work late nights it’s, it’s harder to stick to my routine because I’ll wake up at like 11 or 12. You know, late in the day. And so, the day is already started and you’re trying to catch up with the day you know. You know hanging out with a friend or going to work or something. So, I tend to slack when I don’t have a schedule I can stick to. When I have school in the morning and then I can come home. Like when I have a traditional like wake up in the morning, get something done. You know have lunch at whatever time. And then go home at a certain time... I tend to have better care of myself. So I tend to get my treatment like 100% of the time. I mean... during, you know, the summer when I don’t have
school it’s not like I don’t get my treatment. It’s I don’t get my treatment once or twice.

Chris: Oh, you’re very conscious of your symptoms. You know, you cough, you know you have to take these pills or else you know something doesn’t … just doesn’t come out right. Or… you, you… You mean you know this but it’s more of like an acceptance. You know more than, oh I have CF. Oh I have to do this, oh I have to do this today before this. I mean like I would do this and I would plan my schedule around whatever I needed to do. You know cause as you get older you mature and you realize what you have and, what you don’t need to take care of and I know this is something I need to take care. And even before I was mature, I knew I needed to take care of this. Or else my life would be drastically shorter. I mean it sounds sad but it’s true.

Debbie: And so, when I’m getting ready, I’m like, “oh I still need to do my aerosol” or “I still need to do this or that”. And with me, if I’m not feeling good things take twice as long. So in getting ready for work, I have to take, you know, extra time. Um, and being there on time. And, so, in both jobs I still have to, you know, really think about, okay, what I have to do. Do I have to do an aerosol do I have to do this. And, you know, how do I feel. I have to take that into account as well.

Fred: But, you know I was just thinking how, you know eventually it would be nice if I could maybe just work half time. You know? Largely just to, you know keep my energy level to, you know you spend time working out, and you spend time eating right, and cooking, and you know just taking care of myself. And, you know I may have CF, you know have taken care of myself and CF be a 20 hour a week gig. And, you know have a job that’s a 20 hour a week gig.

A number of studies (Sawicki, Sellers, & Robinson, 2009; Ziaian, et al., 2006) have reported the high treatment burden experienced by individuals with CF which amounts to approximately two to three hours per day spent on disease management. Treatment burden in CF is associated with decreased treatment adherence, which is “the degree to which an individual follows a prescribed medical regimen” (Pai & Ostendorf, 2011, p. 17). Cowland, Yorke, and Carr (2011) reported treatment burden contributed to non-adherence to prescribed medications and treatments with 60% of their sample reporting non-adherence associated with “time constraints and social commitments” (p. 3). Poor

**Mediating Factors**

Mediating factors are beliefs about work, personal abilities, and traits such as self-concept, work habits, self-efficacy, career maturity, vocational identity, and adjustment to disability. In this domain participants identified three essential constructs which shaped their approaches to employment. The personal meaning of work and two coping strategies were identified that mediate the effects of CF on work and career.

**The Meaning of Work: Independence and Purpose**

Participants identified beneficial themes pertaining to the meaning of work – having a purpose, work being therapeutic and economic independence. These themes are similar to previous investigations of the meaning of work to people with disabilities described in Chapter 2. Beyond employment’s significant meaning, the participants described psychosocial benefits they experienced by working. Unexpectedly the subset of participants with worse disease, all expressed a desire to work or return to work in spite of their illness. This reaffirms the notion that work is therapeutic.

For Elsie, Fred, Ingrid, and Jackie work meant having a purpose.

**Elsie:** Just being able to get out, you know, socializing with people. Being able to I guess just have that feeling that, you know, you’re supporting yourself. You’re able to do something for yourself. You’re not you know just wasting away pretty much doing nothing. And, you know, that’s what I liked about work was that I had something to do, I had somewhere to go. You know, I had to do this or I had to do that. I wasn’t just sitting at home and like oh yeah, you know, I’m doing nothing again today.

**Fred:** I think for me it interests me because it gives me a purpose, and it gives me a reason to get out of bed in the morning.

**Ingrid:** And it—like I really enjoy being able to get up and go to work because I mean you have something to look forward to. I mean it’s not like oh hey, I’m gonna
wake up and just sit at home all day and watch TV and of course I got school too but just being able to get up and go and you know you're supporting yourself and making your own money, I think you're doing pretty good.

Jackie: I feel like it’s important because it teaches like me to be responsible for something, maybe. Um like, like more than just like myself, if that makes sense. Like having people rely on me, like it makes me feel better that I can like pull through for people and be there for somebody. So I feel like it, like it teaches me that and you know, it just keeps me busy, it keeps my mind off of things if I’m like stressed out and stuff. Gives me something to do. Something to look forward to. Something to like help the structure of my day and things like that, so. I feel like that, it’s like that for anybody though.

In addition, the benefits of work encompass both tangible and intangible aspects. According to Moos (1986), “A job can provide structure for a person’s life, a sense of satisfaction and productivity that stems from completing meaningful tasks, a feeling of belonging to a valued reference group, a basis for self-esteem and personal identity, and a way to earn one’s economic place in society” (p. 9). The aforementioned benefits are embodied in the following remarks.

Ann and Elsie described the sense of belonging that work imparts:

Ann: But also like it is… It’s a good way to uh like see how even though I do have CF, like I can do normal things like everyone else.

Elsie: Yeah, it did as a teen like you know working kind of makes me feel like there isn’t something wrong with me. And I don’t have all these limitations that other people you know don’t have.

Ann, Fred, Grace, Hal, and Ingrid expressed the ability to achieve economic self-sufficiency:

Ann: I’ve always just seen it as a way to become more independent. And not rely on my parents for money. And I have to pay for my own car and rent and stuff like that. So it, I mean it’s… It’s a way to make money.

Fred: Just the fact I mean the financial fact that, you know I mean I, I’ve traveled a lot. And you have traveled a lot, and I want to, um, you know continue to travel all. And, you know I have a few nice things, and you know nice things for my kitchen. And, you know things that like that so the fact that work is
important just to earn money.

Grace: To be able to pay for stuff.

Hal: Um, I like that I'm able to actually, you know, pay for my own things. I've never really had to pay for anything or want for much, um, but I've always been able to help mom by—because CF costs a lot. So there's not always a lot of money. I mean there is, we're—we're fine as far as money goes but, uh, as far as like clothing or extra things that I wanted, I would purchase those, video games.

Ingrid: Really it's just making my own money and being able to support myself.

Finally, participants spoke of the reward of socialization:

Ann: Well right now like with work I really like the relationships I've built with my boss and with all the other girls that work at the store. And even with customers, like I've become friends with some of them. And I like the environment where I work, too.

Elsie: I never really minded working through my senior year because, you know, I had my friends that I worked with. Other friends came in cause it's a pizza place so you know, I saw everyone anyways. And so you know just I really like had no problems with working it. Just something, that was exciting to me.

Ingrid: And for me but, um, I like—I think my favorite part, the most rewarding part of any of my jobs is actually just being able to socialize with other people because I mean the more you talk to somebody you can learn their story and they learn your story and especially when it comes to the CF, you're spreading that word.

Work is central to individuals with and without disabilities (Dutta et al., 2008; Szymanski & Hershenson, 1998) and contributes to life satisfaction (Judge & Watanabe, 1993). England (1991) characterized the meaning of work as “the importance and significance of work and working in one's life” (p. 111). Work had varying meanings for each participant yet the study confirmed the positive effect of work in their lives.
Downplaying CF and Occupational Compromise

The other mediating factors observed in this study are downplaying CF and occupational compromise, two coping strategies that result from perception of illness. Perception of illness encompasses an individual’s ideas about illness that develop in order to cope with health related difficulties. The concept originated with Leventhal’s self-regulatory model (1997), which describes the ways in which individuals respond to health threats. The self-regulatory model postulates that individuals develop cognitive and emotional representations of their illness that generate problem oriented and emotion-based coping strategies. Therefore, illness perceptions influence how one copes and responds to adverse health conditions like CF. In this study, the resulting coping responses observed were downplaying CF and occupational compromise. The researcher defined occupational compromise as, having to make compromises in career and occupational endeavors owing to CF. Downplaying CF was conceptualized as de-emphasizing the significance of CF on career and life.

Participants in the study downplayed the significance of CF on their daily life. This was especially noteworthy for those five with more severe disease who were working or expressed the desire to work in spite of worse illness. This finding is consistent with previous research reported in Chapter 2 that people with CF are working despite having severe disease.

Furthermore all participants described making various types of concessions or occupational compromises to CF, for example, adjusting work hours to accommodate treatment schedule, changing employment, altering career aspirations, and avoidance of infection. Occupational compromise was widespread in the experiences of the
participants though not viewed as problematic but rather part of life with CF. Some examples of the compromises are given in the following segments.

Ann: And also being around kids during flu season and them hugging me all the time. Like I’m sure I caught so many viruses from that. And it just being in that environment wasn’t helping my health. So... I had to... I was crying when the doctors were like you really need to think about stopping your job. And so then I had to make the decision to do that or else I would continue to be sick. And, I wouldn’t get anywhere with that so I had tell my boss.

Debbie: Well actually it’s funny because I always thought that I was going to be a journalist. I always thought I was going to be a news reporter since I was little, like elementary school. I did news reporting in high school and everything. And then all of a sudden in college, right after I had an internship, at (news agency) um I just, something clicked – I was like, I really don’t want to do this. I just felt like, physically I don’t think I can keep up here you know. So at that point that’s when I changed my major to psychology.

Jackie: No, I usually schedule or ask to be scheduled or have my availability on the correct like uh times so that I have time for everything else. So, because at {grocery store name}, after I told them um, they fixed my schedule to where I didn’t have to come in as early, or I could go home early, or just anything like that.

Hal: And then of course there’s the issue of if you’re in a hospital type setting for most of your life, you’re most likely going to catch something, which could be bacterial infection, and that could be bad for my lungs. So private practice is where I’m kind of leaning towards or you know somewhere where I could— maybe a counseling center or something where I will be less likely to run into the most severe sickly people, more mentally sick than physically sick.

Regardless of disease severity, downplaying CF and occupational compromises were pervasive. These mediating factors are interpreted as coping strategies. Snyder and Dinoff (1999) defined coping as “a response aimed at diminishing the physical, emotional, and psychological burden that is linked to stressful life events and daily hassles” (p. 5). Moreover, coping strategies have been emphasized as an essential component of living with life-threatening diseases (Fok, Chair, & Lopez, 2005). These strategies are therefore adaptive ways of coping with the stressors inherent in CF.
The World of Work Environment

Environment factors are features of work that influence an individual’s behavior. These include such features as the culture of the employment setting, the task requirements, the characteristics of co-workers, and the physical establishment of the setting. At the environment level, which is “the world of work” in the broadest sense, participants identified three constructs of importance to their work life (employer and co-worker support, disease disclosure, and workplace concerns).

Employer and Co-worker Support

All the participants in the study had work experience. Eight were working at the time of the interview and two had recent work experience. Every participant but one reported they perceived support from superiors and coworkers. In fact, sympathetic employers and coworkers were a critical source of encouragement. Having supportive supervisors and coworkers is crucial for maintaining employment and obtaining needed accommodations (Gewurtz & Kirsch, 2009). Furthermore, employers and coworkers who know the disability provide more understanding, acceptance, and support (Gewurtz & Kirsch, 2009).

The following remarks are representative of participants’ views about employer/coworker support.

Ann: Well right now like with work I really like the relationships I’ve built with my boss and with all the other girls that work at the store.

Debbie: The manager actually knew me personally. He went to my church. That was definitely a benefit. But any job that you have, obviously they need to depend on you. You know you can’t just call and be like, oh well I’ll be out for two weeks. You know, that’s a vacation you can’t just, you know, do that. So... when you’re in the hospital it’s really hard to keep a job. But some people are more understanding than others.

Debbie: Obviously I know my body and I know when I have to cough. I know when it’s
coming. So, at {store name} it was a little harder. Because I’m standing there at the cash register. But they, they always said, you know, if you need to use the restroom or if you need a break then let somebody know and somebody will come and relieve me. So I did that on occasion. I would, you know, have somebody come relieve me and I could take a minute or two and go to the restroom. And just cough or whatever I needed to do. So that was always available to me.

**Disease Disclosure**

In order to gain support or accommodations, disability disclosure at work becomes an important consideration as CF is a hidden disability. Attitudes towards disclosing CF were mixed. Six participants were open to disclosure while four had a tendency towards being guarded about disclosing. The reasons for disclosing or not disclosing vary. Some individuals with openness to disclosure noted the feeling of empowerment and disavowed any shame in having CF. While those with a guarded posture expressed wanting to maintain privacy and voiced concerns about disability related discrimination.

A recent study of disclosure practices by patients with CF highlighted this complicated decision. Modi, Quittner, and Boyle (2010) reported that 51% had disclosed to supervisors and 39% disclosed to coworkers. The strongest influences on the decision to disclose are perceived risk of a negative reaction and perceived limitations compared to healthy coworkers.

The remarks that follow are representative of participants’ with a tendency towards openness about disclosing CF on the job. In the cases where participants disclosed reactions were positive and supportive.

**Ann:** If I’m really sick then I won’t go to work. My boss knows everything and completely understands. And just all my bosses have always been really understanding. And then my boss now I... just... I had to come out and tell her in case anything ever happened. She would see me eating and taking pills so I just had to tell her up front and everything.
Debbie: It was a little more difficult but I did inform them of my situation and they were aware. Um, which was a risk that I took of telling them everything but I figured I should tell them up front before I called them one day and say, “hey I’m in the hospital”. And they say, “what’s going on?”, you know, so I did need to tell them.

Elsie: Yeah. {fast food restaurant} - I told them that I had CF. But when I got hired at {fast food restaurant} I was only in the hospital maybe once a year. So I told them you know there might be a time when I’m out for maybe two weeks but that’s it. And they were fine with that. I told the chiropractor because my mom always says, just make sure you tell them you know just so that they know. You know, they can’t say, oh you didn’t tell me. So I had told all of them that you know I had it and there might be a time when I’m out but you know whenever they were hiring me they were like oh yeah that’s fine you know, that’s no problem.

Hal: But the facility leader, he does know and he knew from the beginning. I told him you know listen this is what is going to happen with me. If somebody passes out, I probably will not be able to perform CPR as long as another person will. I probably shouldn't perform it at all just because it could, perhaps be life threatening for me if I was to completely exhaust myself.

So I just informed him of that and everyone knew and I mean, the people I worked with were all friends of mine so they all knew as well. So it really was kind of like an informal, just uh by the way this is what's happening with me you know. I might miss work occasionally because of doctors’ appointments. There’s nothing I can do. I scheduled them three months in advance, and everything worked out with that.

A minority were guarded disclosing CF mainly out of concerns about discrimination.

Bob: I try never to. I try never to. Like I said my friends know because they come over and hang out at my house and they see the respiratory machine. The vest machine. And they’ve seen my medications and stuff like that. So like my friends know but outside my friends I try not to tell anyone. Yeah… it’s, it’s kind of along the lines of, a, people do look at you differently when you first meet them. Like if I were to come up to you and to meet you for the first time and I was like oh I have cystic fibrosis and you find out what it is. It sounds much worse than it is.

Chris: Um, no. I didn’t feel it necessary at all, actually. Um in fact even if I did say it I think she would have still hired me. Because during the interview I wasn’t hacking all over the place. She, she… you know you look at me and you can’t say oh that person has CF. You know. And so, even if I did tell her I
would have said okay, you know, here’s the complications, here’s what happens, here’s what not happens. And so you know, I just never found it necessary to um tell her.

Jackie: Um, I usually don’t tell them, because um, whether you want to think it or not, people look at that as something to think, like, to use, I won’t say against you, but a reason not to like, wanna hire you. But I don’t, usually don’t tell people, because I feel like it’s not an issue until you know, it needs to be brought up. So when the time comes, you bring it up. I bring it up. But until then I don’t usually tell anybody.

After not disclosing, Chris had the negative experience of betrayal by a coworker.

Chris: Apparently it was one day my manager was talking about how I was coughing a lot and then she finally told the manager. And I wasn’t too happy about that. I told my friend, I was like, listen, I’m not mad at you but that’s kind of my place to tell people not really necessarily for you.

Workplace Concerns

Within the workplace participants expressed concerns about job demands and the work environment. For them it was important to have certain accommodations. For instance, flexible scheduling, ability to take breaks, take medication, or perform treatments at work. In the work environment it was helpful to have close access to bathrooms, avoid airway irritants, and avoid risk of infections.

These statements are representative of concerns about job demands:

Elsie: Um… being able to you know rest when you need to. You know being able to you know just kind of relax and not be so, you know, high strung at your job. Worrying about constantly doing something. That’s what I liked about [fast food restaurant] is they were relaxed and you know you could sit down when you needed to. They understood that you know doing all this stuff isn’t, you know, that easy. So you were able to like take ten minute breaks and stuff like that.

Debbie: Yes and no. I… [store name] was very strenuous. Just standing on my feet for so long.

Fred: I think a career in education probably is one that might be a little more difficult for, for CF, or, you know because you are always on your feet. Um, but you know so I’m just very aware like oh I need to weigh 20 pounds more than I do. You know, and I think teaching makes that really hard. You know because
you’re on your feet. You’re spending a lot of energy. You know you’re working, and you don’t have time to just sit down, and just, you know.

The following statements are representative of concerns about avoiding infection:

Bob: It’s kind of sad. Because, like, anytime I see anyone who’s kind of thin or looks kind of sickly I kind of do stay away from them.

Chris: Well… No actually, I never thought of that. But I knew, but like I said previous is that if I ever wanted to be a doctor I would probably never be a respiratory doctor. You know. Cause dealing with CF patients, me being a CF patient myself that’s never good to have cross contamination. So you know, that’s what I thought something different such as dermatology.

Debbie: Then in the job itself, um, obviously I have, even at the babysitting job and at {store name}, I always had hand sanitizer on me. Um, and I would just um if somebody was coughing or really sick or whatever I would just stay away from them. You know, at {store name} I was able to just kind of not get near them. You know, just kind of avoid them.

**Outcome – Employment/Career Patterns**

Outcomes, the fifth construct, describe the results of interactions between the other constructs, for example, job satisfaction, length of tenure, employment patterns, productivity, and job stress. The outcome of interest in this study was the process of career development. Two patterns of career development outcomes emerged from the data - the uninterrupted and the interrupted.

The uninterrupted pattern, closely resembling the path taken by healthy peers, is a seamless transition from school to post-secondary education or work. The five participants with less severe disease had in common, the uninterrupted pattern of career development – continuous school attendance, after school and/or summer employment, high school graduation, enrollment in post-secondary education, or entering the labor force.

The interrupted pattern of career development is marked by interruptions and disruptions in school and work and an uneven transition path from school to post-
secondary education or work. The five female participants with severe disease had in common, the interrupted pattern of career development. One marked by disruption and interruption – frequent illness related school absences, enrollment in hospital/homebound education, withdrawing from post-secondary education for illness related reasons, and losing employment for illness related reasons.

Age, gender, and disease severity are physical attributes that accounted for some of the variation in the observed career development patterns by their effect on stamina and endurance. However, their effects were mediated by influential intrinsic psychological variables (altruism, persistence, coping strategies) and motivational variables (meaning of work). These offsets were especially evidenced in participants with more severe disease who were working or in school or both despite advanced disease.

**Grounded Theory of Career Development in CF**

The preceding sections demonstrated the complex interplay of numerous constructs (individual characteristics, personal contextual factors, mediating factors, and the environment) that collectively influenced career development in this sample and became the basis of a theory grounded in the data. An interactional ecological process that began the same way for all the participants but proceeded along divergent paths illustrates the grounded theory of career development in CF that emerged from this study.

Career development commences early in life and continues during the school-to-work-to-life transition. Initially, parents and caregivers guide the process. Later on, health professionals become an influential set of role models for the developing child. This may correspond with the frequency of visits throughout their formative years. A
child with CF typically makes four routine clinic visits per year and is seen more often when sick. In the current study, the majority expressed a desire to pursue occupations in helping related professions. Medicine, nursing, counseling, and teaching, were cited as career aspirations.

As the child ages, they develop a perception of illness and related coping strategies. This illness perception is a mental representation of the individual’s ideas about the disease that develop in order to cope with health related difficulties. Illness appraisal and disease severity influence perception of illness. These in turn influence how one copes with CF via the formation of coping strategies. The participants in this study employed two coping strategies – downplaying CF and occupational compromises.

Finally, career development patterns will vary based on physical and psychological characteristics of the person. The physical attributes of age, gender, and disease severity along with personal context accounted for some of the variation in the observed career development patterns by their effect on stamina and endurance. However, influential psychological variables (altruism, persistence, coping strategies, meaning of work) and aspects of the work environment (employer support, disease disclosure) mediated their effects. The result of these complex interactions is a career development outcome where one of two possible patterns may occur - the uninterrupted pattern or the interrupted pattern. The former pattern marked by continuous school attendance, after school and/or summer employment, high school graduation, enrollment in post-secondary education, or entering the labor force. The latter pattern
marked by interruptions and disruptions in school and work and an uneven transition path from school to post-secondary education or work.

**International Classification of Functioning, Disability, and Health**

The World Health Organization’s framework, the International Classification of Functioning, Disability, and Health (ICF; 2001), is a classification system for the description of health and health-related states that provides a lens by which to understand functioning and disability (De Kleijn-De Vrankrijker, 2003; Stucki & Rauch, 2010). The ICF provides a context for determining the influence of CF on career development and employment. Similar to the ecological conceptual model that emerged from this study, the ICF model depicts the reciprocal interaction of numerous factors: health condition, body function/structure, activity, participation, environmental and personal factors.

Specifically, the current study highlights four aspects of the ICF model: activity, participation, environmental factors, and personal factors. Activity and participation were reflected in the treatment burden, educational/employment interruptions, and workplace concerns evidenced in the study. Environmental factors were represented by job tasks, the physical environment of the workplace, disease disclosure, and employer and co-worker support. Finally, age, gender, and disease severity represent personal factors reflected in the ICF model. The interplay of the ICF domains of activity, participation, environmental factors and personal factors encompasses the realm of experiences that an individual with CF encounters navigating the world of work which for some of the study participants these factors hindered the career development process.
CHAPTER 6
CAREER DEVELOPMENT INVENTORY

The Career Development Inventory (CDI) was utilized to augment the qualitative interviews and thereby better understand the participants' career development. This measure was included as a secondary information source about the participants rather than for statistical analysis. The CDI (Thompson et al., 1981) is an 80-item instrument comprised of four scales of 20 items each: Career Planning (CP), Career Exploration (CE), Decision Making (DM), and Knowledge of the World of Work (WW). These scales measure vocational attitudes and competencies critical to career decision-making. The CDI also reports on three composite scales: Career Decision Attitudes (the combination of CP and CE), Career Decision Knowledge (the combination of DM and WW), and Career Orientation Total (the combination of CDA and CDK). These composite scales exist to provide a more reliable measure of attitudes toward careers and knowledge of careers and the work world.

The CDI measures an individual's career development and readiness for the tasks of choosing a profession (Savickas & Hartung, 1996). The instrument is recommended for use in career counseling, career planning, and vocational research (Levinson, Ohler, Caswell, & Kiewra, 1998). The CDI and its subscales have been found to have adequate reliability (Leveinison et al., 1998; Thompson, Lindeman, Super, Jordaan, & Myers, 1981). Pinkney and Bozik (1994) reported acceptable internal reliability coefficients for three scales: CP (.89), CE (.78), and WW (.84) but urged caution regarding the fourth - DM (.67). Furthermore, the CDI demonstrates evidence of predictive validity (Hartung, 1997). Descriptions of the CDI scales are presented in Table 6-1.
Table 6-1. CDI terms and descriptions

<table>
<thead>
<tr>
<th>Scale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Career Planning (CP)</td>
<td>Career Planning represents degree of involvement in thinking about one’s future and how well various occupations fit.</td>
</tr>
<tr>
<td>Career Exploration (CE)</td>
<td>Career Exploration represents how well one has used quality resources in planning activities.</td>
</tr>
<tr>
<td>Decision Making (DM)</td>
<td>The scale measures the ability to apply knowledge and insight to career planning and decision making.</td>
</tr>
<tr>
<td>World of Work (WW)</td>
<td>World of Work Information represents the fund of knowledge one has about occupations and the world of work.</td>
</tr>
<tr>
<td>Career Development – Attitudes (CDA)</td>
<td>Composite scale combining CP and CE which reflects career attitudes.</td>
</tr>
<tr>
<td>Career Development – Knowledge (CDK)</td>
<td>Composite scale combining DM and WW which reflects overall career knowledge.</td>
</tr>
<tr>
<td>Career Orientation Total (COT)</td>
<td>Composite scale combining CP, CE, DM, and WW that reflects career maturity.</td>
</tr>
</tbody>
</table>

Note: Adapted from Thompson et al., 1981

**CDI Results**

Eight of the ten participants completed the CDI for this study. The instrument was incorporated in the study (with IRB approval) after five interviews were already completed. Subsequently the first five participants were mailed the instrument however only three responded. The next five participants were administered the instrument immediately after their interview was completed. Results of the CDI were not reviewed with participants.

Scores on the CDI, at and above the 75th percentile are considered high scores indicative of better levels of career development (Thompson et al., 1981). An average score is between the 40th to 60th percentile suggesting the participant’s scores are similar to others on his or her grade level. While scores at or below the the 25th percentile indicate deficits in career development (Thompson et al., 1981). Table 6-2 presents an overview of CDI results and is followed by an individual review of each participant.
Table 6-2. CDI results by participant

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>CP</th>
<th>CE</th>
<th>DM</th>
<th>WW</th>
<th>CDA</th>
<th>CDK</th>
<th>COT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann</td>
<td>26%</td>
<td>53%</td>
<td>94%</td>
<td>34%</td>
<td>34%</td>
<td>77%</td>
<td>57%</td>
</tr>
<tr>
<td>Bob</td>
<td>16%</td>
<td>19%</td>
<td>44%</td>
<td>7%</td>
<td>16%</td>
<td>17%</td>
<td>11%</td>
</tr>
<tr>
<td>Debbie</td>
<td>76%</td>
<td>50%</td>
<td>12%</td>
<td>2%</td>
<td>56%</td>
<td>2%</td>
<td>19%</td>
</tr>
<tr>
<td>Fred</td>
<td>65%</td>
<td>7%</td>
<td>3%</td>
<td>3%</td>
<td>24%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Grace</td>
<td>95%</td>
<td>89%</td>
<td>42%</td>
<td>75%</td>
<td>95%</td>
<td>49%</td>
<td>92%</td>
</tr>
<tr>
<td>Hal</td>
<td>98%</td>
<td>93%</td>
<td>22%</td>
<td>59%</td>
<td>97%</td>
<td>29%</td>
<td>94%</td>
</tr>
<tr>
<td>Ingrid</td>
<td>88%</td>
<td>61%</td>
<td>3%</td>
<td>14%</td>
<td>83%</td>
<td>4%</td>
<td>32%</td>
</tr>
<tr>
<td>Jackie</td>
<td>67%</td>
<td>58%</td>
<td>58%</td>
<td>59%</td>
<td>60%</td>
<td>61%</td>
<td>67%</td>
</tr>
</tbody>
</table>

Note: CP=Career Planning, CE=Career Exploration, DM=Decision Making, WW=World of Work, CDA=Career Decision Attitudes, CDK=Career Decision Knowledge, and COT=Career Orientation Total

Ann

Ann was an 18-year-old employed female first year college student with a clearly defined career goal of becoming an elementary school teacher. She scored in the low range on CP and average range on CE, indicating little career planning and exploration. However, this likely reflects the fact that she is certain about her career choice rather than deficits in these areas. Ann’s high score on the DM scale demonstrates that she is able to make career related decisions with ease. This is consistent with her employment record and the fact that she has made a career choice. Her low score on the WW scale likely reflects her youth and limited work experience. Ann scored in the average range on the COT, meaning that her overall level of career maturity is comparable to her able-bodied peers.

Bob

Bob was a 21-year-old employed male third year college student with a definite career goal of becoming an engineer. His scores were all in the low range on each scale except for DM. He scored in the average range on the DM scale (his highest area) indicating he applies adequate decision-making knowledge and skills to career
problems. It also is reflective of his employment record and the fact that he has made a career decision. He scored low on CP, CE, and WW indicating little career planning, exploration, and knowledge of the world of work. However, his low scores on CE and CP may reflect that he is decided about his career choice thus less exploration and planning are necessary. Bob’s low score on the WW scale is inconsistent with his age and lengthy work history. During the interview, he expressed a defined career ambition and had specific world of work knowledge about his chosen field such as the education and internship requirements. Bob’s performance on the COT was low suggesting his career maturity is lower than others.

**Debbie**

Debbie was a 21-year-old employed female college student. She has a clearly defined career goal of becoming a counselor specializing in children. Debbie performed well in two areas, poorly in two areas, and had a low overall score. She scored high on CP and in the average range on CE. These are consistent with her interview where she expressed knowledge of her chosen field. Debbie had low scores on the DM and WW scales, which indicate she may have difficulty with career or work related decisions and little knowledge of the workplace.

Debbie performed better on the composite attitude scale (CDA) than the composite knowledge scale (CDK) suggesting she has a good attitude about work but has less knowledge of the world of work. This may be related to her work history as a nanny. In addition, she had changed her career path from journalism to psychology at one point, which might indicate some lack of career crystallization on her part, but this would require further exploration beyond the scope of the present study. Debbie’s performance on the COT was low suggesting her career maturity is lower than others.
Fred

Fred was a 27-year-old employed male with a bachelor’s degree. He has a career goal of completing a master’s degree in education and continuing to work as a teacher. His score pattern shows he performed well on the CP scale but low on the CE, DM, and WW. This pattern means that he has a definite career choice without having completed much career research. This corresponds with his interview data where he stated that he had a varied professional history and additionally had changed majors from linguistics to education. Fred’s performance on the COT was low suggesting his career maturity is lower than others.

Grace

Grace was a 22-year-old unemployed female high school graduate with a goal of becoming a teacher one day. Her score pattern shows she performed well in three areas and average on the fourth. Grace was high on the CP scale meaning she had awareness, concern, and involvement in making educational and occupational choices. Her CE scale was equally high denoting effective strategies for seeking information and gathering relevant data about occupations. Grace scored well on a third scale, WW, meaning she engaged in appropriate amounts of information seeking to learn about educational and occupational opportunities. On the DM scale, Grace scored in the average range showing she applies adequate decision-making knowledge/skills to career problems. Like Debbie, Grace performed better on the composite attitude scale (CDA) than the composite knowledge scale (CDK). This suggests she has a good attitude about work but has less knowledge of the world of work. Grace’s COT score was high signifying she has an above average degree of career maturity.
Hal

Hal was a 21-year old employed male with a bachelor's degree. He has a goal of earning a master’s degree in psychology and becoming a counselor. Hal’s score pattern shows he performed well in three areas and below average on the fourth. Hal performed well on the CP scale meaning he had appropriate awareness, concern, and involvement about making his educational and occupational choices. His CE scale was equally high meaning he had effective strategies for seeking career information and gathering relevant data about occupations. Hal scored in the average range on a third scale, WW, meaning he engaged in appropriate amounts of information seeking to learn about educational and occupational opportunities. On the DM scale, Hal scored in the low range showing he lacks adequate decision-making knowledge/skills regarding career problems and this may reflect his work history that is limited to one long-time position. Hal performed better on the composite attitude scale (CDA) than the composite knowledge scale (CDK) suggesting he has a good attitude about work but has less knowledge of the world of work. Hal’s COT score was high signifying he has an above average level of career maturity.

Ingrid

Ingrid was a 21-year-old employed female college student with a clearly stated goal to complete a bachelor’s degree and enter the public relations field. She performed well in two areas and poorly in two areas. Ingrid did well on the CP and CE scales, which are attitudinal measures that demonstrate a good attitude towards career planning activities like finding and using career information. She did poorly on DM and WW. These measures assess knowledge about the work world. Ingrid performed better on the composite attitude scale (CDA) than the composite knowledge scale
(CDK). This suggests she has a good attitude about work but has less knowledge of the world of work. Ingrid’s performance on the COT was low suggesting her career maturity is lower than others.

**Jackie**

Jackie was a 21-year-old unemployed female college student without specific career goal. Her scores on all four scales were in the average range. There is a discrepancy between her scores, which indicate moderately good career orientation and what she verbalized in the interview. She stated she had no certain career plans and was vacillating between two options nursing and teaching. Despite this uncertainty, her scores in the average range may reflect her extensive work history and the fact she has ideas about a career if not a specific choice. Jackie scored in the average range on the COT, meaning that her overall level of career maturity is comparable to her peers.

**Summary**

The results of the CDI demonstrated wide variety among the participants especially on the composite scales. There were no discernible performance patterns on the instrument by age, gender, or disease severity. One notable pattern emerged from comparison of the attitudinal composite scale (CDA) to the knowledge composite scale (CDK) with five participants performing much better on the attitude scale than the knowledge scale. This suggests they had good attitudes about working but lacked knowledge of the work world. This warrants further investigation.

Additionally, discrepancies arose between the interviews and CDI results. For example, Bob, Debbie, Fred, and Ingrid scored in the low range on the COT an overall measure of career development however they verbalized firm career aspirations and knowledge of the workplace. Their low scores contradict their reports of career choice
certainty and belie their career maturity. Ann, who also expressed career certainty and workplace knowledge, attained an average score. Conversely, Jackie attained an above average COT score however, she reported uncertainty about her career plans. Hence, it would be useful for future qualitative research to review CDI results with participants. This would identify if scores were consistent with participants’ expectations and if they agreed with said results. These considerations were beyond the scope of the current study.
CHAPTER 7
CONCLUSIONS

Overview

This chapter is arranged in four sections that summarize the study findings, study limitations, implications for service providers, and recommendations for future research. The first section offers an overview of significant findings from the qualitative interviews and the instrument. The second section describes the limitations of the study. The third section reviews the implications of the research for CF treatment centers, rehabilitation professionals, and educators. The fourth section discusses recommendations for further research.

Summary of Findings

The purpose of this research study was to examine the personal meaning and experience of employment for people with CF and ultimately develop a substantive grounded theory of career development applicable to individuals with this disease. The study utilized the grounded theory method of qualitative inquiry to investigate the employment implications of CF. Specifically, the researcher performed semi-structured qualitative interviews with ten participants to explore the meaning of work and career development processes. The participants provided rich descriptions of their experiences with employment and career choices in light of CF. Analysis of the interview transcripts followed the constant comparative approach to coding, which identified core themes and sub-themes. A theory grounded in the data, embodied by an ecologically based conceptual model, emerged from these themes. The model reflects the effects of interactions between the person and environment on work experiences and career development.
The researcher administered the Career Development Inventory as a secondary source of information rather than for statistical purposes. This instrument was used to supplement interview data and enhance understanding of the participants’ career maturity.

**Findings Regarding the Meaning of Work**

Numerous studies with varied populations have reported that work is central to individuals with disabilities (Dutta et al., 2008; Freedman and Fesko, 1996; Moore, Konrad, Yang, Ng, & Doherty, 2011) and contributes to life satisfaction (Judge & Watanabe, 1993). These assertions were also substantiated in the current study of employment in individuals with CF. In fact, the study confirmed many positive effects of work in their lives.

England (1991) characterized the meaning of work as “the importance and significance of work and working in one’s life” (p. 111). In the present study, work had different meanings for participants but with commonalities among them. For instance, participants identified beneficial themes pertaining to the meaning of work – having a purpose, work being therapeutic, and economic independence. These themes are similar to previous investigations of the meaning of work to people with disabilities described in Chapter 2.

Super (1982) specified that employment is vital for “self-esteem, identity, and sense of order” (p. 95) and these constructs were echoed by participants. For example, in the subset of participants with worse disease, they all expressed a desire to work or return to work propelled by esteem needs and despite illness complications. This demonstrates persistence and reaffirms the notion that work has therapeutic value for individuals aside from the economic considerations. Notably, employment had great
salience for this set of participants. Work salience refers to relative importance of work and satisfaction with the work role (Naidoo, Bowman, & Gerstein, 1998). High work salience is associated with career maturity, career commitment, and work ethic that in turn contribute to favorable career outcomes.

**Findings Regarding the Career Development Inventory**

The results of the CDI revealed a range of career competencies among the participants, especially on the COT composite scale, where scores varied from very low to high career maturity. This has important implications for career outcomes particularly for those with middle and low scores. Studies by Creed, Patton, and Hood (2010) and Wessel, Christian, and Hoff (2003) reported that higher levels of career development are associated with well-defined career objectives, persistence in post-secondary education, obtaining career-related work experience, and finding employment in a desired field.

One notable pattern emerged from comparison of the attitudinal composite scale (CDA) to the knowledge composite scale (CDK) with five participants performing much better on the attitude scale than the knowledge scale. This suggests they had good attitudes about working but lacked knowledge of the work world. This warrants further investigation because CF may interfere with school attendance, after school jobs, summer jobs, and other activities where one would acquire knowledge of the work world.

There were no discernible performance patterns on the instrument by age, gender, or disease severity. Nevill and Super (1988) reported similar findings in a study of career maturity in university students using the CDI. These researchers reported gender was not associated with career maturity but commitment to work was related to attitudinal and cognitive factors (Nevill & Super, 1988).
It would be useful for future qualitative research projects using the CDI to review the results with participants. This would identify if scores were consistent with participants’ expectations and if they agreed with said results. These considerations were beyond the scope of the current study.

Findings Regarding Career Development

CF has the potential to influence career development outcomes as evidenced by the interrupted and uninterrupted patterns observed in the present study. Specifically, older participants reported having more severe disease and some disruptions in education and work pursuits. Furthermore, the majority of participants reported balancing daily treatment demands with school and/or employment was one of their primary challenges. These findings were not surprising given the progressive course of CF and are consistent with previous research (Gillen et al., 1995). However, participants with severe disease continued to work or desired to work in spite of their complications and numerous studies (Burker et al., 2004; Frangolias et al., 2003; Hogg et al., 2007) have maintained that poor lung function alone is not a marker of work disability.

The majority of participants had positive coping behaviors and favorable perception of illness, which is associated with increased likelihood of academic persistence and maintaining employment. This finding corresponds with reports on the association between positive coping and employment outcomes in people with disabilities (Crisp, 2005; Cunningham, Wolbert, & Brockmeier, 2000). Specific to CF is Abbott, Hart, and Morton’s (2008) investigation of coping wherein the majority of individuals utilized the coping style optimistic acceptance, which was significantly associated with superior quality of life variables such as employment. This suggests
that psychological processes mediate career outcomes as demonstrated in London’s conceptual model (1997) of coping with career barriers. London (1997) posits that emotional and cognitive processes for example accurate appraisal, resilience, and constructive coping affect how individuals respond to career barriers.

The precise manner by which perception of illness influences career development in individuals with CF is not readily discernible in the current study and no research in this area exists. In fact, Sawicki, Sellers, and Robinson’s (2011) investigation of quality of life and Bucks et al. (2009) study of treatment adherence are the only illness perception reports available specific to CF. Future research studies might investigate how the construct of perception of illness is associated with academic achievement, career development, and employment outcomes.

Finally, the researcher classified participants by RIASEC career categories (Realistic, Investigative, Artistic, Social, Enterprising, or Conventional; Holland, 1997) based on the career aspirations they reported. Of this sample, the majority were pursuing careers in the Social domain and notably, in helping-related professions suggesting the influence of health care providers as role models. There is abundant research on career development in childhood (Hartung, Porfeli, & Vondracek, 2005; Watson & McMahon, 2005) that supports the assertion that early career exposure is an integral part of an individual’s career development. Hartung, Porfeli and Vondracek (2005) reviewed vocational development literature to explore lifespan vocational development and concluded “what children learn about work and occupations has a profound effect on the choices they make as adolescents and young adults, and ultimately, on their occupational careers” (2005, p. 412).
Grounded Theory of Career Development in CF

The grounded theory resulting from this study is novel for two reasons. First, there is scant qualitative research on employment in CF and none utilizing the grounded theory method. Second, an ecological approach to the study of employment in CF has never been proposed. Ecological models of career development have been proposed for disability-related populations such as developmental disabilities (Szymanski, 1996), HIV/AIDS (Conyers, 2004), and psychiatric illness (Tschopp, 2001) and minority groups (King and Madsen, 2007; Turner, 2006) but never applied to CF.

A theory grounded in the data related to career development in CF was developed from the analysis and interpretation of the interviews. The theory highlights the complicated interaction of numerous ecological variables (individual characteristics, personal contextual factors, mediating factors, and the environment) that collectively influence career development. The presence of CF alone does not guarantee individuals will experience negative effects on career development. Rather, multiple variables exist that could influence career development. An interactional ecological process that began the same way for all the participants but proceeded along divergent paths illustrates the grounded theory of career development in CF that emerged from this study.

The grounded theory proposes that work experiences and career development in individuals with CF are influenced by ecologically based interactions. Specifically, career development patterns will vary based on physical and psychological characteristics of the person interacting with personal context and the environment. The physical attributes of age, gender, and disease severity along with personal context accounted for some of the variation in the observed career development patterns by
their effect on stamina and endurance. However, influential psychological variables (altruism, persistence, coping strategies, meaning of work) and aspects of the work environment (employer support, disease disclosure) mediated their effects. Laborde-Casterot et al. (2011) investigated employment status and work disability in adults with CF. Unlike the present study, the researchers noted that employment status was significantly associated with pulmonary function and education level and was unaffected by age and gender. Furthermore, Laborde-Casterot et al. (2011) propose the key to employment is achieving the highest level of education possible because this enhances employability.

The result of these complex interactions is a career development outcome where one of two possible patterns may occur - the uninterrupted pattern or the interrupted pattern. The former marked by continuous school attendance, after school and/or summer employment, high school graduation, enrollment in post-secondary education, or entering the labor force. The latter by interruptions and disruptions in school and work and an uneven transition path from school to post-secondary education or work.

**Limitations of this Study**

In qualitative research, the researcher is the primary investigative tool (Richards & Morse, 2007). Thus, trustworthiness is cited as a limitation in qualitative research in that the researcher’s personal bias may affect data interpretation and conclusions (Patton, 2002). As discussed in Chapter 3, the researcher undertook strategies to minimize bias and maintain the trustworthiness of the study. The initial step was to consider reflexivity. This involved reflecting on the role and the method by which decisions about the data are made. This process of self-reflection resulted in the personal bias statement in Chapter 3 and ongoing awareness of personal bias. Aside
from ongoing reflexivity, additional measures undertaken by the researcher aimed at promoting trustworthiness included:

- Extensive course work in qualitative research methods.
- Extensive personal reading of qualitative research literature.
- Attendance and participation in a bi-monthly qualitative data analysis group.
- Professional training in the use of NVivo qualitative software offered by the College of Education.
- Private tutoring in the use of NVivo with a professor who is a qualitative expert.
- Development of an interview guide with assistance from faculty skilled in qualitative research and feedback from the qualitative data analysis group.
- Consulting with the qualitative data analysis group on emerging themes and the conceptual model.
- Consulting with committee chair on themes observed in the data.
- Consulting with a College of Medicine faculty member who is knowledgeable about CF on themes observed in the data.

Other limitations of the study were the small sample size and lack of ethnic diversity. The small sample limits the transferability of the research findings to the population of individuals with CF. Additionally, all the participants were Caucasian. According to the CF Foundation, the population of people with CF is predominantly white, however the foundation also notes that of people with the disease, about 4% are African-American and 7% are Hispanic (Cystic Fibrosis Foundation, 2011). The lack of ethnic diversity suggests that the data collected may not represent the experience of non-white individuals with CF. Additional studies with more diverse samples are necessary to understand how CF may affect the employment experiences and career development of people from other ethnic groups. To the researcher’s knowledge, no existing employment research in CF has included a diverse ethnic sample however;
Quittner et al. (2010) studied the effects of socioeconomic status (SES) and race on health-related quality of life in a large sample of minorities with CF. The researchers found that low SES and minority status contributed to variability in the course of the disease and worse patient-reported outcomes (Quittner et al., 2010).

**Implications for Service Providers**

The CF Foundation recommends treatment centers assist individuals with career planning (Yankaskas et al., 2004). By assuming an ecological viewpoint, CF treatment centers benefit patients by recognizing the meaning of work and importance of career development. Further, by understanding the complex interplay of individual characteristics, personal context, and environmental factors, CF centers can assist individuals with career decisions and making a smooth transition from school to post-secondary education and/or work.

Similarly, rehabilitation professionals can utilize the findings of this study to assist their clients with CF to choose, acquire, and maintain employment. Mungle, Burker, and Yankaskas (2002) reported that adolescents with CF would benefit from career planning and employment services yet this population has been largely overlooked possibly due to misconceptions about limited life expectancy. The fundamental significance of this study is that young adults with CF can and want to work but they need assistance from rehabilitation professionals to navigate contextual and environmental variables. For instance, rehabilitation counselors might assist with identifying suitable employment (for example, free of airway irritants or risk of infection) and in obtaining, needed workplace accommodations.

Finally, education professionals may utilize the findings of this study to assist students with CF. Five participants with more severe disease reported experiencing
educational disruptions due to CF. However, even students with less severe disease will miss some school for medical appointments or illness. As noted in Chapter 5, educational attainment is associated with employment outcomes. School personnel attuned to the complexities of CF could offer interventions to minimize the negative effects of school absences, such as, plans to make up schoolwork, before or after school tutoring, hospital and home education services, and individualized education plans. Early attention to the needs of students with CF may avert later disrupted career patterns observed in this study.

**Recommendations for Future Research**

Results of the present study were concluded from a small, non-diverse sample of individuals with CF. While a rich understanding of the meaning of work and career development was achieved, it was limited by having the perspective of a small number of individuals and thus is not representative of the general population with CF. Thus, future studies with large, diverse samples are warranted.

More importantly, to continue the development of the proposed grounded theory, follow-up studies must test the ecological conceptual model that emerged with a larger sample of individuals with CF and with significant others. Just one perspective was obtained for this study, that of individuals with CF, however, as the ecologically based model suggests, interactions between multiple domains influence employment and career development. Thus, the grounded theory proposed herein would be enhanced by further research obtaining the input of parents, teachers, role models, coworkers, and others involved with the individual.

Another component of future research could involve a longitudinal design with repeated follow-up at regular intervals. The present study was limited to one-time
interviews about work experience and career development. A longitudinal design would allow for observation of the career development process as it unfolds measured by repeated administration of the CDI. Longitudinal studies measuring various aspects of career development in non-disabled high school age students are numerous (Germeijs & Verschueren, 2006; Stringer, Kerpelman, & Skorikov, 2011; Tracey, Robbins, & Hofsess, 2005) but are nonexistent for students with disabilities including CF.

Finally, the current study did not review CDI results with participants. Future studies that administer the instrument to individuals with CF should incorporate a feedback/interview session. A review of CDI results with participants could assess if results are in line with participants’ expectations and if they agree with the results. Furthermore, a large national study incorporating the CDI might compare sample norms to the group norms published in the instrument’s test manual. A single-sample t-test was performed to compare the mean of the sample to normative group data published in the test manual. No significant differences between the population’s mean and the sample’s mean were observed.

**Conclusion**

The present study was conducted to gain a rich understanding about the personal meaning of work, employment experiences, and career development process of people with CF. Data were collected by semi-structured qualitative interviews with ten participants and the use of a career development instrument. A theory grounded in the data, embodied by an ecologically based conceptual model, emerged from these interviews. The model reflects the effects of interactions between the person and environment on work experiences and career development. The present study’s findings suggest that age, gender, and disease severity are physical attributes that
accounted for some of the variation in the observed career development patterns by their effect on stamina and endurance. However, their effects were mediated by influential intrinsic psychological variables (altruism, persistence, coping strategies) and motivational variables (meaning of work). These mediators were especially evidenced in participants with more severe disease who were working or in school or both despite advanced disease.
APPENDIX A
INTERVIEW GUIDE

Interview Guide: The Personal Meaning and Experience of Work to People with Cystic Fibrosis: A Pilot Study

Questions:

- Tell me what it is like to have CF.
  - Probe if necessary: How has it changed over time?
  - Probe if necessary: How did you learn you had CF?
  - Probe if necessary: Tell me about your daily routines
- Anything else you would like to tell me about CF?
- Tell me what school was like for you.
  - Probe if necessary: Discuss how CF influenced your education.
- Tell me about your parents or guardians work history.
- How did their work history influence you?
  - Probe if necessary: What were their expectations for you?
- Tell me about the jobs you have held.
  - Probe if necessary: Tell me about interviewing for positions.
  - Probe if necessary: Tell me about disclosing CF to employers
  - Probe if necessary: How has CF affected your ability to be hired by an employer?
  - Probe if necessary: What does work mean in your life?
  - Probe if necessary: What does work do for you?
  - Probe if necessary: What is it about work that is important to you?
  - Probe if necessary: What about working is hard?
- Probe if necessary: What about working is easy?

- How does CF affect you at work?

- Tell me about your career plans.
  - Probe if necessary: What is it about (blank career) that interests you?
  - Probe if necessary: How did you arrive at this career choice?
  - Probe if necessary: Discuss how CF influenced your career goals.

- Anything else you would like to tell me about your work experiences or your career plans?
APPENDIX B
INFORMED CONSENT FORM

INTRODUCTION

Name of person seeking your consent: _____________________________________________

Place of employment & position: ________________________________________________

Please read this form which describes the study in some detail. A member of the research team will describe this study to you and answer all of your questions. Your participation is entirely voluntary. If you choose to participate you can change your mind at any time and withdraw from the study. You will not be penalized in any way or lose any benefits to which you would otherwise be entitled if you choose not to participate in this study or to withdraw. If you have questions about your rights as a research subject, please call the University of Florida Institutional Review Board (IRB) office at (352) 273-9600.

GENERAL INFORMATION ABOUT THIS STUDY

1. Name of Participant ("Study Subject")

___________________________________________________________________________

2. What is the Title of this research study?

The Personal Meaning and Experience of Work to People with Cystic Fibrosis: A Pilot Study
3. **Who do you call if you have questions about this research study?**
   Principal Investigator: Pablo S. Saldana at 904-652-9622.

4. **Who is paying for this research study?**
   The sponsor of this study is the College of Public Health and Health Professions, Department of Behavioral Science and Community Health.

5. **Why is this research study being done?**
   I want to learn about your work experiences and what work means to people with cystic fibrosis.
   You are being asked to be in this research study because you have cystic fibrosis and work experience.

---

**WHAT CAN YOU EXPECT IF YOU PARTICIPATE IN THIS STUDY?**

6. **What will be done as part of your normal clinical care (even if you did not participate in this research study)?**
   There will be no change to your usual medical care provided by the Cystic Fibrosis Center if you decide to participate in the study or decide to stop being in the study.

7. **What will be done only because you are in this research study?**
   You will be asked to complete a career development survey and be interviewed about what work means to you and your experiences with employment. You can choose not to answer any question for any reason at any time during the interview. The interview will be audio recorded and transcribed verbatim. If you give me permission I may contact you after the interview in order to clarify, expand, and/or validate findings.

   If you have any questions now or at any time during the study, please contact Pablo S. Saldana in question 3 of this form.

8. **How long will you be in this research study?**
   Approximately one to two hours for the length of time it takes to complete the in-depth interview. A brief follow-up interview may be conducted by telephone or in person as appropriate to clarify, expand, and/or validate findings.
9. **How many people are expected to take part in this research study?**

   Fifteen people.

---

**WHAT ARE THE RISKS AND BENEFITS OF THIS STUDY AND WHAT ARE YOUR OPTIONS?**

10. **What are the possible discomforsts and risks from taking part in this research study?**

    Researchers will take appropriate steps to protect any information they collect about you. However, there is a slight risk that information about you could be revealed inappropriately or accidentally. Depending on the nature of the information, such a release could upset or embarrass you, or possibly affect your insurability or employability. Questions 17-21 in this form discuss what information about you will be collected, used, protected, and shared. This study may include risks that are unknown at this time.

    Participation in more than one research study or project may further increase the risks to you. If you are already enrolled in another research study, please inform Pablo S. Saldana (listed in question 3 of this consent form) or the person reviewing this consent with you before enrolling in this or any other research study or project.

    Throughout the study, the researcher will notify you of new information that may become available and might affect your decision to remain in the study.

    If you wish to discuss the information above or any discomforts you may experience, please ask questions now or call the PI or contact person listed in question 3 in this form.

11a. **What are the potential benefits to you for taking part in this research study?**

    There are no anticipated potential benefits of being in this study.

11b. **How could others possibly benefit from this study?**

    The information that the researcher acquires from this study may benefit other cystic fibrosis patients in the future.

11c. **How could the researchers benefit from this study?**

    In general, presenting research results helps the career of a scientist. Therefore, Pablo S. Saldana may benefit if the results of this study are presented at scientific meetings or in scientific journals.
12. What other choices do you have if you do not want to be in this study?

You can refuse to participate in this study. This will not affect your care at the Cystic Fibrosis Center. Participation in this study is voluntary and your usual medical care will continue regardless of whether or not you choose to participate.

13a. Can you withdraw from this study?

You are free to withdraw your consent and to stop participating in this study at any time. If you do withdraw your consent, you will not be penalized in any way and you will not lose any benefits to which you are entitled.

If you decide to withdraw your consent to participate in this study for any reason, please contact Pablo Saldana at 904-652-9622. He will tell you how to stop your participation safely.

If you have any questions regarding your rights as a research subject, please call the Institutional Review Board (IRB) office at (352) 273-9600.

13b. If you withdraw, can information about you still be used and/or collected?

No.

13c. Can the Principal Investigator withdraw you from this study?

You may be withdrawn from the study without your consent for the following reasons:

Administrative reasons.

WHAT ARE THE FINANCIAL ISSUES IF YOU PARTICIPATE?

14. If you choose to take part in this research study, will it cost you anything?

There will be no costs to you for participating in the study.

15. Will you be paid for taking part in this study?

You will be provided a $50.00 Wal-Mart gift card for participating in the study.

16. What if you are injured because of the study?

Please contact the Principal Investigator listed in question 3 of this form if you experience an injury or have questions about any discomforts that you experience while participating in this study.
17. How will your health information be collected, used and shared?

If you agree to participate in this study, the Principal Investigator will create, collect, and use private information about you and your health. This information is called protected health information or PHI. In order to do this, the Principal Investigator needs your authorization. The following section describes what PHI will be collected, used and shared, how it will be collected, used, and shared, who will collect, use or share it, who will have access to it, how it will be secured, and what your rights are to revoke this authorization.

Your protected health information may be collected, used, and shared with others to determine if you can participate in the study, and then as part of your participation in the study. This information can be gathered from you or your past, current or future health records, from procedures such as physical examinations, x-rays, blood or urine tests or from other procedures or tests. This information will be created by receiving study treatments or participating in study procedures, or from your study visits and telephone calls. More specifically, the following information may be collected, used, and shared with others: your diagnosis of cystic fibrosis to determine eligibility for the study and descriptive data will be collected such as age, gender, race, education level, and employment status.

This information will be stored in locked filing cabinets or on computer servers with secure passwords, or encrypted electronic storage devices.

Some of the information collected could be included in a "limited data set" to be used for other research purposes. If so, the limited data set will only include information that does not directly identify you. For example, the limited data set cannot include your name, address, telephone number, social security number, photographs, or other codes that link you to the information in the limited data set. If limited data sets are created and used, agreements between the parties creating and receiving the limited data set are required in order to protect your identity and confidentiality and privacy.

18. For what study-related purposes will your protected health information be collected, used, and shared with others?

Your PHI may be collected, used, and shared with others to make sure you can participate in the research, through your participation in the research, and to evaluate the results of the research study. More specifically, your PHI may be collected, used, and shared with others for the following study-related purpose(s):

To determine your eligibility to be in the study and to be able to contact you regarding the study.

Once this information is collected, it becomes part of the research record for this study.
19. Who will be allowed to collect, use, and share your protected health information?

Only certain people have the legal right to collect, use and share your research records, and they will protect the privacy and security of these records to the extent the law allows. These people include:

- the study Principal Investigator, Pablo S. Saldana and research staff associated with this project.
- other professionals at the University of Florida or Shands Hospital that provide study-related treatment or procedures.
- the University of Florida Institutional Review Board (IRB; an IRB is a group of people who are responsible for looking after the rights and welfare of people taking part in research).

20. Once collected or used, who may your protected health information be shared with?

Your PHI may be shared with:

- the study sponsor (the College of Public Health and Health Professions, Department of Behavioral Science and Community Health).
- United States and foreign governmental agencies who are responsible for overseeing research, such as the Food and Drug Administration, the Department of Health and Human Services, and the Office of Human Research Protections.
- Government agencies who are responsible for overseeing public health concerns such as the Centers for Disease Control and federal, state and local health departments.

Otherwise, your research records will not be released without your permission unless required by law or a court order. It is possible that once this information is shared with authorized persons, it could be shared by the persons or agencies who receive it and it would no longer be protected by the federal medical privacy law.

21. If you agree to take part in this research study, how long will your protected health information be used and shared with others?

Your PHI will be used and shared with others three years from the time you enter the study.

You are not required to sign this consent and authorization or allow researchers to collect, use and share your PHI. Your refusal to sign will not affect your treatment, payment, enrollment, or eligibility for any benefits outside this research study. However, you cannot participate in this research unless you allow the collection, use and sharing of your protected health information by signing this consent and authorization.
You have the right to review and copy your protected health information. However, we can make this available only after the study is finished.

You can revoke your authorization at any time before, during, or after your participation in this study. If you revoke it, no new information will be collected about you. However, information that was already collected may still be used and shared with others if the researchers have relied on it to complete the research. You can revoke your authorization by giving a written request with your signature on it to the Principal Investigator.

**SIGNATURES**

As an investigator or the investigator’s representative, I have explained to the participant the purpose, the procedures, the possible benefits, and the risks of this research study; the alternative to being in the study; and how the participant’s protected health information will be collected, used, and shared with others:

______________________________  __________________________
Signature of Person Obtaining Consent and Authorization  Date

You have been informed about this study’s purpose, procedures, possible benefits, and risks; the alternatives to being in the study; and how your protected health information will be collected, used and shared with others. You have received a copy of this Form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask questions at any time.

You voluntarily agree to participate in this study. You hereby authorize the collection, use and sharing of your protected health information as described in sections 17-21 above. By signing this form, you are not waiving any of your legal rights.

______________________________  __________________________
Signature of Person Consenting and Authorizing  Date

**AUDIO TAPE ADDENDUM TO CONSENT FORM**

You have already agreed to participate in a research study entitled: The Personal Meaning and Experience of Work to People with Cystic Fibrosis: A Pilot Study conducted by Pablo Saldana. I am asking for your permission to allow me to audio tape
the interview as part of the study.

The recording(s) will be used for analysis by the researcher.

The recording(s) will include your first name only.

The recording(s) will be stored in a locked file cabinet and linked with a code to subjects' identity; and will be destroyed upon completion of the study procedures.

Your signature on this form grants the investigator named above permission to audio record you as described above during your participation in the study. The investigator will not use the recording(s) for any other reason than stated in the consent form without your written permission.

**SIGNATURES**

As an investigator or the investigator’s representative, I have explained to the participant the purpose, the procedures, the possible benefits, and the risks of this research study; the alternative to being in the study; and how the participant’s protected health information will be collected, used, and shared with others:

_____________________________    ____________________________
Signature of Person Obtaining Consent and Authorization    Date

I have been informed about this study’s purpose, procedures, possible benefits, and risks; the alternatives to being in the study; and how my protected health information will be collected, used and shared with others. I have received a copy of this Form. I have been given the opportunity to ask questions before signing, and I have been told that I can ask questions at any time.

I voluntarily agree to participate in this study. I authorize the collection, use and sharing of my protected health information as described above. By signing this form, I am not waiving any of my legal rights.

_____________________________    ____________________________
Signature of Person Consenting and Authorizing    Date
APPENDIX C
DEMOGRAPHIC INFORMATION SHEET

Demographic Information
Thank you for providing the information below. It allows the researcher to describe participants and make comparisons to other groups.

Age: ________

Gender:
_____ Male
_____ Female

Race:
_____ American Indian or Alaska Native
_____ Asian
_____ Black or African American
_____ Native Hawaiian or Other Pacific Islander
_____ White
_____ Other, Please
specify:_______________________________________________

Highest Education level:
_____ Middle or High school attendance
_____ High school diploma/GED
_____ Some college
_____ Associates degree
_____ Bachelor’s degree
_____ Some graduate school
_____ Master’s degree
_____ Specialists degree
_____ Doctoral degree
_____ Post-graduate

Currently employed? _____ Yes _____ No

If yes: _____ Full-time _____ Part-time

If no: How long ago were you last employed? _________________________

_____ Full-time _____ Part-time
LIST OF REFERENCES


Stucki, G., & Rauch, A. (2010). The international classification of functioning, disability and health (ICF), a unifying model for physical and rehabilitation medicine (PRM). In J.-P. Didier, & E. Bigand, Rethinking physical and rehabilitation medicine (pp. 19-52).


BIOGRAPHICAL SKETCH

Pablo Saldana, CRC, LCSW is a doctoral candidate in the Rehabilitation Science Doctoral Program at the University of Florida College of Public Health and Health Professions. Mr. Saldana received master’s degrees in counseling from the William Paterson University of New Jersey in 1994, in social work from Rutgers University in 1999, and in rehabilitation counseling from the University of North Florida in 2005. He earned his bachelor’s degree in social science from the William Paterson University of New Jersey in 1990. Accomplishments during Mr. Saldana’s doctoral student career include being a recipient of a four-year alumni fellowship, which allowed him to conduct his dissertation studies. Additionally, during his doctoral training, Mr. Saldana was selected to present at two national conferences (NCRE and CFF) and at University of Florida’s PHHP Research Day conferences. While completing the requirements for his doctoral degree, Mr. Saldana worked as a research assistant for Dr. Jamie Pomeranz in the Department of Behavioral Science and Community Health at the University of Florida.

Mr. Saldana is a Licensed Clinical Social Worker and a Certified Rehabilitation Counselor. Throughout his doctoral studies, Mr. Saldana has been the social worker for the Cystic Fibrosis center at Nemours Children’s Clinic since 2005. Prior to joining Nemours he worked for the Florida Department of Children and Families for four years providing social work technical assistance to contracted providers of mental health and substance abuse services.