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Examining Perceived Stigma, Disclosure, Self-Compassion, and Health-Related Quality of Life in College Students with Cystic Fibrosis

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Cystic Fibrosis (CF) is a life-limiting genetic disorder that affects the lungs, pancreas, and other organs. Recent advances in CF-related healthcare have improved the life expectancy of individuals with CF from childhood to approximately 50 years old (CFF, 2020). Therefore, more individuals with CF are attending college and facing challenges within this new stage of life. This study examined perceived stigma, disease disclosure, self-compassion, and health-related quality of life (HRQoL) in a sample of current and former college students with CF to understand their psychosocial experience of managing their illness while in college. Results indicated that perceived stigma and HRQoL were negatively related and perceived stigma and self-compassion predicted HRQoL. Disease disclosure was also examined to uncover the frequency and comfort of disclosure within this sample, which found that the participants most frequently disclosed to close friends (n=33/34), followed by casual friends/acquaintances (n=27/34), professors (n=24/34), then their romantic partner/spouse (n=17/19). Participants reported they felt most comfortable disclosing their disease to their romantic partner/spouse and close friends. These results can help inform CF-related care and support by shedding light on the significance of perceived stigma and self-compassion in predicting HRQoL, and disease disclosure as an important step in the process of adapting to life as a college student with CF.

Keywords: Chronic Illness, Cystic Fibrosis (CF), Perceived Stigma, Disease Disclosure, Self-Compassion, Health-Related Quality of Life (HRQoL)

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Chapter 1: Introduction

> *When we can let go of what other people think and own our story, we gain access to our worthiness – the feeling that we are enough just as we are and that we are worthy of love and belonging. When we spend a lifetime trying to distance ourselves from the parts of our lives that don't fit with who we think we're supposed to be, we stand outside of our story and hustle for our worthiness by constantly performing, perfecting, pleasing, and proving. Our sense of worthiness – that critically important piece that gives us access to love and belonging – lives inside of our story. (Brown, 2010, p.23)*

Chronic illness impacts approximately six out of every ten adults in the United States (Centers for Disease Control and Prevention [CDC], 2019). Common chronic illnesses include heart disease, cancer, chronic lung disease, stroke, Alzheimer's disease, diabetes, and chronic kidney diseases (CDC, 2019). A more uncommon chronic illness is Cystic Fibrosis (CF), a genetic disorder that affects the lungs, pancreas, and other organs (Cystic Fibrosis Foundation [CFF], 2020). CF was formerly considered a pediatric disease due to a limited life expectancy, but medical advances in specialized CF care have increased the life expectancy for people with CF to approximately 50 years old (CFF, 2020). With more people with CF transitioning to adulthood, the developmental milestones associated with adulthood are more commonplace. One of these rising milestones for people with CF is attending college. According to data published by the Cystic Fibrosis Foundation's Patient Registry (2018), the number of adults who had attained a Bachelor's/Advanced Degree increased steadily every 10 years from 1998-

2018. In 1998, the number of adults who had attained a Bachelor's/Advanced Degree was 1,429, which increased to 3,174 in 2008 and 5,675 in 2018.

In a similar vein, the American College Health Association seeks to understand experiences of college students through their survey, the National College Health Assessment, which includes data regarding chronic illness (American College Health, 2021). The Fall 2021 data reported the prevalence rates of various chronic illnesses in their 23,600-person undergraduate sample, as well as the experience of various health-related variables. Relevant to this study, these data reported that 5.1% of their sample endorsed having a chronic illness not listed, 4.2% of these individuals reported having a respiratory disorder, and of that percentage, 4 individuals disclosed they had CF. Furthermore, of the students who endorsed having an ongoing or chronic medical condition diagnosed or treated in the last 12 months, 31.2% reported their illness negatively affected their academic performance in a class and 6.0% reported their illness delayed their progress toward their degree.

Considering the findings from the National College Health Assessment that chronic illness can negatively affect academic performance, it is reasonable to assume that having a chronic condition may influence other areas of a college student's life as well. There is a significant research base on the psychological components of chronic illness in young adults, including college students. These studies include topics such as: psychological therapies; educational, vocational, and social outcomes; illness perceptions; psychological symptoms like anxiety and depression; self-management of

healthcare; and self-compassion (e.g., Bennett et al., 2015; Maslow et al., 2010; Mullins et al., 2017; Ravert et al., 2017; Sirois et al., 2015).

There are some strong areas of research on the psychosocial aspects of being a person with CF specifically involving health-related quality of life (HRQoL), qualitative understandings of the transition to adulthood as a person with CF, self-compassion, perceived stigma, and development of CF-specific measures for disease disclosure, coping, and treatment adherence (e.g., Abbott et al., 2001; Borschuk, 2015; George et al., 2010; Kauser et al., 2021; Oliver et al., 2014; Sawicki et al., 2011). However, very few studies include college students in their sample, and no studies were found that study only college students. It is becoming clear that mental health is an important predictor of physical health outcomes in people living with chronic illness (Bennett et al., 2015). Thus, to contribute to the field of behavioral health research in the CF population, research on the psychosocial components of being a college student with CF is warranted.

Purpose and Justification for the Current Study

The purpose of this study was to examine the psychosocial experiences of being a college student living with CF. The college experience was the major focus of this study due to the combining factors of navigating complex social and academic settings while managing one's medical care as a person with a chronic medical condition. CF requires unique and specific treatment regimens to achieve desired health outcomes which could be related to various psychological variables relevant to being a college student including perceived stigma, disease disclosure, self-compassion, and HRQoL. Furthermore, there is limited research available on the experiences of being a college student with CF due to

the recently increased life expectancy and therefore increased number of individuals with CF attending college.

Research on the transition to college as a person with a medical condition and the transition to adulthood as a person with CF has focused on loneliness, HRQoL, outlook on life, and overall functioning (e.g., Askew et al., 2017; Herts et al., 2014; Higman et al., 2013). Herts et al. (2014) compared 22 students with chronic physical illness to 118 of their healthy peers and found that college students with a chronic illness reported more impaired HRQoL and loneliness scores compared to their healthy peers. Askew et al. (2017) and Higman et al. (2013) studied the more general experiences of transitioning to adulthood as a person with CF, including themes of their hopes and fears for the future. Participants in both studies reported positive overall functioning while also acknowledging difficulties of having CF.

A common difficulty experienced by young adults with chronic illness, including CF, is the fear of others' opinions, judgment, or rejection, often referred to as perceived stigma. Perceived stigma is an important variable to investigate due to its known associations with isolation, depression, anxiety, treatment adherence, and HRQoL (Bakula et al., 2019; George et al., 2010; Kaushansky et al., 2017; Muther et al., 2018; Oliver et al., 2014; Pakhale et al., 2014). Bakula et al. (2019) studied young adults with chronic illness and reported that perceived stigma was associated with greater depression and anxiety with illness intrusiveness as a mediator. This means that the positive association between perceived stigma and psychological symptoms was influenced by the amount participants believed their illness influenced their lifestyle, activities, values, and

interests. Additionally, George et al. (2010) studied individuals with CF who experienced embarrassment/stigma regarding their condition which influenced their treatment adherence and Muther et al. (2018) reported themes of social isolation and ostracization in a review of psychosocial challenges facing young people with CF. Oliver et al. (2014) found that stigma was related to worse lung function, HRQoL, and optimism. Furthermore, Pakhale et al. (2014) studied the relationships between CF symptoms, HRQoL, and stigma. They found that stigma was a partial mediator in the significant negative relationship between CF symptoms and HRQoL, meaning that CF symptoms and stigma both partially explain lower HRQoL.

It also has been documented that fear of judgment/embarrassment (i.e., perceived stigma) is a barrier to disease disclosure, the process of revealing one's disease to others (George et al., 2010). Borschuk et al. (2016) and Modi et al. (2010) both studied disease disclosure in people with CF by relationship category (e.g., close friends, romantic partners, bosses, etc.) finding variations in frequency and comfort of disclosure based on relationship. Borschuk et al. (2016) also reported psychosocial associations with comfort disclosing CF status including social support, employment, and medication adherence self-efficacy. Werner et al. (2019) qualitatively examined disclosure in individuals with CF and found themes regarding disclosure styles and their psychosocial implications, as well as individual perceptions of past and current disclosure styles. They found that disclosure decisions were based on benefits and costs of disclosure, as well as one's taking ownership of the decision to disclose.

The use of self-compassion is one way for young adults with chronic illness to navigate emotional experiences and promote better functioning in various areas of life (Barnes et al., 2018; Edwards et al., 2019; Sirois et al., 2015). Sirois et al. (2015) studied self-compassion in young adults with chronic illness and found that self-compassion was associated with more use of adaptive coping and less use of maladaptive coping, which in turn was associated with coping efficacy and less stress. Some studies regarding self-compassion in the CF population have been conducted in recent years with mixed results (Kauser et al., 2021, 2022; Mitmansgruber et al., 2019, 2021). Kauser (2021) found that quality of life and self-compassion were correlated and self-compassion and/or self-criticism moderated ten relationships between various sub-domains of quality of life and negative emotions. Mitmansgruber et al. (2019, 2021) examined self-compassion in relation to psychological well-being and mental health symptomology but did not find significant results regarding self-compassion in their studies.

HRQoL is a topic of interest in many studies regarding psychosocial aspects of chronic illness, specifically as an outcome variable. Sawicki et al. (2011) found that participants who perceived their CF as having a large influence on functioning or overall quality of life showed associations with lower HRQoL in many psychosocial domains. However, perceptions of having more personal control over CF and more understanding of CF were associated with better HRQoL in psychosocial domains such as overall health perceptions and social and emotional well-being.

The aim of this study was to incorporate some of the well-established variables found in the literature that are related to chronic illness and CF and at the same time,

expand the literature by including a focus on these variables in a college population of students with CF. The primary purpose of the current study was to examine the links between perceived stigma and self-compassion with HRQoL in college students with CF. Since previous studies have linked perceived stigma and self-compassion with psychosocial outcomes such as HRQoL, HRQoL was chosen as the outcome variable for this study. Furthermore, disease disclosure was explored within this sample. This was the first study to investigate these variables in a population of individuals with CF focusing on their college experience.

Overall, no empirical evidence has examined how perceived stigma, disease disclosure, self-compassion, and HRQoL operate in conjunction with one another in a sample of college students with CF. Gaining additional understanding of which variables can impact HRQoL could help inform CF-related care and college/university support services to improve the functioning and wellbeing of college students with CF. Additionally, an understanding of disclosure and self-compassion in this study can help provide interventions for college students with CF who are struggling with perceived stigma, disclosure, and aspects of their HRQoL due to their disease.

Research Hypotheses and Research Questions

Table 1
Hypotheses, Variables, and Statistical Procedures

Hypothesis	Variables	Statistics
Hypothesis 1: There will be a negative correlation between perceived stigma and HRQoL.	Stigma Scale-Revised (SS-R) total score	Pearson's r correlation

	Cystic Fibrosis Questionnaire-Revised (CFQ-R) standard score	
Hypothesis 2: There will be a positive correlation between self-compassion and HRQoL.	Self-Compassion Scale (SCS) total score Cystic Fibrosis Questionnaire-Revised (CFQ-R) standard score	Pearson's r correlation
Hypothesis 3: There will be a negative correlation between perceived stigma and self-compassion.	Stigma Scale-Revised (SS-R) total score Self-Compassion Scale (SCS) total score	Pearson's r correlation
Hypothesis 4: Perceived stigma and self-compassion will be examined as independent variables in a regression model to determine the effect on the dependent variable, HRQoL.	Stigma Scale-Revised (SS-R) total score Self-Compassion Scale (SCS) total score Cystic Fibrosis Questionnaire-Revised (CFQ-R) standard score	Multiple Linear Regression

In addition to the research hypotheses outlined above, two research questions were proposed to explore the disease disclosure behavior of college students with CF. The research questions were a) Which relationship groups do individuals with CF disclose their disease to most and least frequently? and b) How comfortable do individuals with CF feel with disclosing their disease to individuals in these relationship groups?

Methodology and Design

This section includes a brief overview of the methodology that was used to address the research hypotheses outlined above. Chapter Three involves a more comprehensive description. Participants in this study included individuals with CF aged 18-35. To be eligible, participants needed to be currently in college or have attended college in the last 10 years as of May 2022. Participants were recruited from pediatric and adult CF Clinics throughout the United States, as well as through online methods such as social media, email listservs, and CF organizations, foundations, and research institutes. Due to CF being a low incident disease, there was difficulty in recruiting a large sample, which led to fewer participants in this study than were originally proposed. Therefore, this study can be considered a pilot study to uncover initial findings regarding the experiences of college students with CF.

This study used a nonexperimental, predictive research design and assessed participants only once. Participants were asked to complete an online survey, including a demographic and experiences questionnaire, then validated measures of perceived stigma, disease disclosure, self-compassion, and HRQoL. Perceived stigma was

measured using the Stigma Scale Revised (SS-R; Bakula et al., 2019). The SS-R is an adapted version of the Stigma Scale (SS) created by Austin et al. (2004) to assess perceived stigma related to living with epilepsy. Bakula et al. (2019) replaced the word "epilepsy" with "chronic illness" throughout the SS-R to fit their sample, and in a similar fashion, the measure for this study replaced "epilepsy" with "cystic fibrosis". The Cystic Fibrosis Disclosure Questionnaire (CFDS; Borschuk, 2015; Borschuk et al., 2016) was used to capture disease disclosure. The CFDS examines disclosure of one's CF in various relationship groups (i.e., Close Friends, Casual Friends, Significant Other, Professors, and Classmates) and subsequent comfort of discussing their CF or administering CF treatments in front of these various groups of people. For this study, "roommates" was added as a relationship group. Self-compassion was investigated using the Self-Compassion Scale (SCS; Neff, 2003). The SCS is a widely used measure of the components of self-compassion, including self-kindness vs. self-judgment, common humanity vs. isolation, and mindfulness vs. over-identification. Finally, the Cystic Fibrosis Questionnaire-Revised (CFQ-R; Quittner et al., 2005; Quittner et al., 2012) was used as a measure of HRQoL and health status. This is another widely used measure and comprises generic and disease-specific content areas to assess health-related wellbeing.

Definitions

Chronic Illness. A medical condition that lasts for longer than a year and requires ongoing medical care and/or causes changes in daily functioning (CDC, 2019).

Cystic Fibrosis (CF). A life-limiting genetic disorder that affects the lungs, pancreas, and other organs, requiring a treatment regimen with a high treatment burden (CFF, 2020).

Treatment Adherence. Commitment to the care plan (e.g., medications, treatments, etc.) recommended by one's healthcare providers (CFF, 2020).

Perceived Stigma. The anticipation or felt experience of negative judgment, disapproval, discrimination, or rejection associated with an attribute or characteristic that is different or viewed as undesirable (Bakula et al., 2019; Pakhale et al., 2014).

Disease Disclosure. The process of revealing one's disease status to others. This can include implicit (i.e., indirect) methods such as performing one's treatments in front of others and explicit (i.e., direct) methods such as directly discussing one's diagnosis with someone (Borschuk et al., 2016).

Self-Compassion.

> Being open to and moved by one's own suffering, experiencing feelings of caring and kindness toward oneself, taking an understanding, nonjudgmental attitude toward one's inadequacies and failures, and recognizing that one's own experience is part of the common human experience (Neff, 2003, p. 224)

Health-Related Quality of Life. A multidimensional self-report of well-being related to one's health including disease state and physical symptoms, functional status, psychological and emotional state, and social functioning (Quittner et al., 2005).

Summary

The present study used perceived stigma, disease disclosure, self-compassion, and HRQoL as variables to investigate the lives of college students with CF. These variables were important to investigate with this population, as no studies to date had examined

them within the college experience. Exploring these constructs contributes understanding of the experience of college students with CF as they navigate the phenomena of perceived stigma, disease disclosure, and self-compassion, which could ultimately be associated with their health-related quality of life (HRQoL). It is hoped that these findings can be used to improve CF-related care and college/university services for young people with CF.

Chapter Two: Review of the Literature

Introduction

Chronic illness is defined as a medical condition that lasts for longer than a year and requires ongoing medical care and/or causes changes in daily functioning (CDC, 2019). Approximately six out of every ten adults in the United States have a chronic illness, with four out of ten adults having more than one (CDC, 2019). Common chronic illnesses include heart disease, cancer, chronic lung disease, stroke, Alzheimer's disease, diabetes, and chronic kidney disease (CDC, 2019). One less common chronic illness is Cystic Fibrosis (CF), a genetic disorder that affects the lungs, pancreas, and other organs (CFF, 2020). CF is a life-limiting disease with a high treatment burden for individuals impacted by the disease. Until very recently, CF was considered a pediatric disorder, as many people with the disease did not survive beyond childhood. Due to medical advances in specialized CF care, the median life expectancy for people with CF is currently 50 years old. Though an uncommon illness, it is the most common of the uncommon chronic illnesses, affecting approximately 30,000 people in the United States, with about half of those people being 18 years and older (CFF, 2020). This increase in life expectancy and quality of life indicates that more adolescents with CF will transition to young adulthood. The developmental tasks involved in this transition to young adulthood might include moving out of their family's home, going to college, getting a job, getting married, and/or starting a family. These transitions hold challenges for typically healthy young adults,

and persons with CF will likely experience added stressors and difficulties due to their medical condition. Few studies exist studying the transition to young adulthood with CF and this author found none that investigate the experiences in college as a person with CF. The lack of attention to the college experience within the CF was an important motivator in conducting this study.

This chapter begins with a brief overview of psychosocial research in relation to chronic illness. Research on chronic illness more broadly is included because it is expected that research focusing on chronic illness is relevant for the CF population as well. This section provides an overview of research regarding college students with a chronic illness, stigma and disease disclosure, and self-compassion. The focus of this chapter will then turn to CF, to provide a deeper explanation of the condition, along with research on the interaction between having CF and the transition to adulthood, health-related quality of life and coping, stigma and disease disclosure, and self-compassion. This chapter will conclude with a summary of the strengths and limitations of the extant research on CF.

Chronic Illness

Previous research has made it very clear that mental health is related to the management and physical consequences of chronic illness, creating a focus of research and treatment of chronic illness that includes psychological components (Bennett et al., 2015). Studies investigating the psychosocial elements of these chronic illnesses are prevalent. In pediatric and young adult populations, some of the most researched disease populations include diabetes, asthma, inflammatory bowel disease, epilepsy, rheumatoid

arthritis, and chronic pain (e.g., Bennett et al., 2015; Maslow et al., 2010; Mullins et al., 2017; Ravert et al., 2017; Sirois et al., 2015).

Data also exist that show the importance of examining chronic illness in a college student population. The American College Health Association invests in studying the health of college students with their bi-annual survey, the National College Health Assessment (American College Health, 2021). This research survey collects data on students' habits and behaviors regarding the most common health topics. Survey data from Fall 2021 reported the prevalence rates of various chronic illnesses in their 23,600 person undergraduate sample, including asthma (16.2%), chronic pain (5.5%), diabetes or pre-diabetes/insulin resistance (1.9%), heart and vascular disorders (2.0%), irritable bowel syndrome (4.0%), and migraine headaches (9.6%). Relevant to this study, this data reported that 5.1% of their sample endorsed having a chronic illness not listed, 4.2% of these individuals reported having a respiratory disorder, and of that percentage, 4 individuals disclosed they had CF. Furthermore, of the students who endorsed having an ongoing or chronic medical condition diagnosed or treated in the last 12 months, 31.2% reported their illness negatively affected their academic performance in a class and 6.0% reported their illness delayed their progress toward their degree.

The College Experience and Chronic Illness

Young adults with chronic illness who attend college report negative effects on their academic performance due to their condition (American College Health, 2021). Beyond that, having a chronic condition affects other areas of a college student's life, including their social life, relationships with professors and bosses, and living situation.

Herts et al. (2014) conducted a study examining the experience of being chronically ill and transitioning to college. They compared first-year college students with chronic illness to their first-year healthy peers on measures of health-related quality of life (HRQoL) and loneliness. The sample of students with chronic illness included individuals with chronic physical illness, mental illness, and learning disabilities. For the 22 students who reported having a chronic physical illness, their illnesses ranged widely including asthma and heart conditions. The healthy peers group included 118 participants. Herts et al. (2014) found that college students with a chronic physical illness reported significantly more impaired HRQoL and loneliness scores compared to their healthy peers. This study shows a disparity in psychosocial variables between individuals with chronic illness and their healthy peers in a college sample.

Chronic Illness, Stigma, and Disease Disclosure

Stigma or embarrassment regarding one's disease can be a stressful experience for those who have a chronic disease. Therefore, it is important to consider the potential impact of perceived stigma on young adults with chronic illnesses. Bakula et al. (2019) investigated illness-related stigma in adolescents/young adults (AYAs) with a chronic illness using the Stigma Scale-Revised (SS-R), adapted from the Stigma Scale (SS) created by Austin et al. (2004). They examined illness intrusiveness in relation to illness-related stigma and psychosocial outcomes, with illness intrusiveness defined as "the extent to which one's illness is believed to induce disruptions in lifestyle, activities, values, and interests" (p. 612). They found that illness-related stigma was positively associated with depression and anxiety with illness intrusiveness as a mediator. In other

words, higher levels of illness-related stigma were correlated with higher levels of depression and anxiety, and illness intrusiveness helped explain this relationship. These findings align with previous studies that showed that illness-related stigma and illness intrusiveness are predictors of negative psychosocial outcomes (e.g., Dancey et al., 2002).

The experience of stigma can relate to disease disclosure, the navigation of if, when, how, and to whom one discloses their disease. Many studies regarding disease disclosure are qualitative and focus on specific disease populations such as HIV/AIDS (e.g., Lam et al., 2007). Kaushansky et al. (2017) qualitatively examined disease disclosure in 25 adolescents and young adults with various illnesses, including spina bifida, rheumatology, cardiology, cystic fibrosis, and renal transplant/dialysis. Five participants from each disease population were interviewed. The authors aimed to learn to whom participants chose to disclose their disease, why they chose these people, the extent of their disclosure, and any consequences of nondisclosure. Many participants across disease groups described not disclosing their disease due to fears related to judgment, rejection, or being misunderstood or pitied. The authors note that nondisclosure can contribute to fear of stigma, psychological distress, and social discomfort. However, few participants described actual experiences of rejection, pity, or isolation due to their condition once they disclosed. Since these fears often do not become a reality, it is possible that the fear of judgment ultimately creates worse outcomes than sharing one's disease with others (Kaushansky et al., 2017). In fact, some

participants discussed that when they were encouraged to disclose their disease, they felt normalization of their condition and increased emotional support.

Chronic Illness and Self-Compassion

The use of self-compassion can be a helpful strategy for young people with a chronic illness, especially those who experience perceived stigma or struggle with disclosure, due to its emphasis on self-acceptance and adaptively responding to stress (Sirois et al., 2015). Self-compassion typically is defined as having three main components: Self-kindness, Mindfulness, and Common Humanity (Neff & McGehee, 2010). Sirois et al. (2015) found that self-compassion was associated with more use of adaptive coping and less use of maladaptive coping in individuals with IBD and arthritis. This relative use of an adaptive coping pattern compared to a maladaptive coping pattern was associated with coping efficacy and less stress. Similarly, there is research that shows self-compassion to be helpful for chronic pain populations, specifically with navigating emotional experiences and promoting better functioning in many life domains (Barnes et al., 2018; Edwards et al., 2019). Barnes et al. (2018) found that self-compassion was a valuable tool for helping young women navigate challenging emotional experiences associated with their chronic pain. Barnes et al. (2018) specifically highlighted that self-compassion was useful for their participants by encouraging them to accept their pain and respond to their pain with kindness, understanding, and connectedness. Edwards et al. (2019) found that self-compassion was significantly positively associated with pain acceptance, use of pain coping strategies, and success in

valued activities, while negatively associated with depression severity, pain anxiety, and physical and psychosocial disability.

This section included a description of chronic illness and the research involving psychosocial variables in populations of individuals with chronic illness. This research highlighted that being a college student with a chronic illness yields worse outcomes than being a college student who is typically healthy. This research also highlights that individuals with chronic illness struggle with worries of what others may think of them due to their condition, which can impact their openness with the people in their lives regarding their condition. Other research indicates that self-compassion can be an antidote to some of the distress of having a chronic illness, as self-compassion encourages one to accept oneself as they are and treat oneself with kindness. The next section will describe CF and how psychosocial variables have been studied within this disease population.

Cystic Fibrosis

CF is a progressive, genetic disease (CFF, 2020). For people with CF, the cystic fibrosis transmembrane conductance regulator (CFTR) gene has mutations, which causes dysfunctions in the CFTR protein. As a result of the protein not working correctly, mucus in various organs becomes thick and sticky (CFF, 2020). In the lungs, the sticky mucus causes complications such as infection, inflammation, and respiratory failure due to the mucus clogging the airways and trapping germs. In the pancreas, there is a buildup of mucus, which then prevents the appropriate release of digestive enzymes. These enzymes are necessary for the body to absorb the key nutrients in food, and without them the body

can become malnourished. Mucus also can block the bile duct which can cause liver damage. Furthermore, male infertility is a common result of CF (CFF, 2020).

Common symptoms experienced by individuals with CF include persistent coughing, sometimes producing phlegm; frequent lung infections; wheezing or shortness of breath; poor growth or low weight despite a good appetite; frequent greasy, bulky stools or difficulty with bowel movements; and differences in physical appearance such as digit clubbing, which is inflammation of the fingers and toes due to lack of oxygen (CFF, 2020). Typically measured health outcomes in individuals with CF include FEV_1% (mean forced expiratory volume in 1 second) – a primary measure of lung function; BMI (body mass index) – which helps asses for nutritional level; the presence or absence of bacteria in the lungs that are commonly known to cause lung infection in people with CF, such as *Pseudomonas aeruginosa*, *Burkholderia cepacia* complex, and nontuberculous mycobacteria; and transplant history (Askew et al., 2017). Due to these symptoms and targeted health outcomes, individuals with CF are required to adhere to a multi-component treatment regimen to maintain optimal health. This involves airway clearance to loosen mucus in the lungs, routine courses of oral or nebulized antibiotics to eliminate and/or prevent lung infection, pancreatic enzyme supplements taken with every meal and most snacks to improve the body's ability to absorb nutrients, nutritional supplements (e.g., Boost, Kate Farms, Ensure, etc.) and/or gastrostomy tube (G-tube) feedings in the case of insufficient nutrition, insulin in the case of CF-related diabetes, and a specialized fitness plan to improve lung function (Bucks et al., 2009). Furthermore, individuals with CF are highly advised to avoid situations that could increase their risk for infection, such

as people who are sick and other individuals with CF. People with CF are asked not to come within six feet of each other, due to the unique bacteria each person has and the risk of sharing dangerous bacteria with each other (CFF, 2020).

It is important to note that the health outcomes measured in people with CF are not typically day-to-day measurements of symptoms, but rather outcomes over time. The treatment regimens for CF are effective when done correctly and they are highly recommended for the prevention of CF-related complications. However, many people with CF consider these treatments burdensome. Some of the treatments require a lot of time and energy, some require a disruption in typical routine, and some result in temporarily unpleasant side effects, such as coughing. With this treatment burden, little symptomatic benefit in the moment, and lost sight of the long-term benefit of adhering to treatments, non-adherence to CF treatment regimens during adolescence is commonplace, particularly as adolescents transition to managing their own care (Bucks et al., 2009).

Using a qualitative approach, George at al. (2010) examined the barriers and facilitators of self-management of CF treatment among older adolescents and young adults. The amount of social support and the amount of perceived treatment burden emerged as important themes regarding adherence to a treatment regimen for adolescents and adults with CF. Participants discussed increased independence from their parents as well as increased reliance on peers and romantic partners for social support, an expected result based on developmental stage. However, while some participants found social relationships that encouraged their treatment adherence, some participants found it difficult to integrate their treatments into their daily lives, including school, work,

relationships, and other areas of their life. Nine of these participants identified stigma/embarrassment as the reason for not completing treatment protocols, specifically describing the stigma of performing treatments in front of others (George et al., 2010).

Cystic Fibrosis and Young Adulthood

While no study was found specifically investigating the transition to college or the experiences in college for those with CF, studies have examined the transition to adulthood more generally (Higman et al., 2013; Askew et al., 2017). Both Higman et al. (2013) and Askew et al. (2017) used qualitative methods to explore this experience. Higman et al. (2013) highlighted hopes and fears of adults with CF and the following themes emerged: (a) Living with unpredictable health and the fear of death and dying; (b) Hopes for normality; (c) Hopes for a normal relationship and/or marriage; (d) Hopes to become a parent; and (e) Hopes for a normal work life. Participants also wondered how CF might affect the outcomes of these hopes and plans. Some participants acknowledged difficulties that CF introduced in their close relationships, as they struggled with disclosure of their disease, treatment burden, and hospitalizations. Other participants reported their condition interfering with the jobs they could choose and limited their ability to attend their job consistently, causing job loss.

Askew et al.'s (2017) study yielded more positive results, with their participants reporting good functioning, a positive attitude about gaining independence in life, and their work toward pursuing further education and employment, relationships, and parenthood. The participants also reported satisfaction with transitioning from pediatric to adult care. However, in line with findings from Higman et al. (2013), 52% of

participants did feel that their CF negatively altered their experiences in education, employment, and certain life situations.

Health-Related Quality of Life (HRQoL) and Coping with Cystic Fibrosis

HRQoL has increasingly become a valuable measure of well-being. In a study of healthy college students, Sharkey et al. (2017) posited the need to examine the factors associated with physical and psychological functioning and the predictors of health care behaviors in college students. They used HRQoL as a primary outcome variable in their study, which they stated, "encompasses individual functioning and perception of both mental and physical domains of well-being (e.g., emotional well-being and role limitations owing to physical health)" (p. 953). Their argument that HRQoL is an essential component of adaptive functioning for college students can be extended to research with young adults with CF as well.

Several studies addressed HRQoL and coping in the young adult CF population (Abbott et al., 2008; Sawicki et al., 2011). Abbott et al. (2008) examined coping as it relates to HRQoL in individuals with CF. The authors found that optimism was consistently associated with better quality of life, while distraction was associated with poorer quality of life. These findings were especially evident for the HRQoL domains of emotional and social functioning and interpersonal relationships. Optimism was the most common coping strategy. Abbott et al. (2008) asserted that coping with CF is a complex process. While the authors did not make a connection to self-compassion in their article, one could see how the methods of coping could relate to the components of self-

compassion (i.e., self-kindness vs. self-judgment, common humanity vs. isolation, and mindfulness vs. over-identification; Neff, 2003).

Sawicki et al. (2011) discussed that illness perceptions, defined as "the manner in which an individual identifies with and understands one's disease", are considered an influence on overall HRQoL in individuals with CF (p. 162). Participants who perceived that CF has a large impact of the illness on functioning or overall quality of life displayed associations with lower HRQoL in six of the seven psychosocial domains measured. Perceptions of having more personal control over CF and more understanding of CF were associated with better HRQoL in psychosocial domains such as overall health perceptions and social and emotional well-being (Sawicki et al., 2011).

Cystic Fibrosis and Self-Compassion

In addition to the research focusing on self-compassion in chronic illness populations more broadly, mixed results have been found in studies that examine self-compassion within the CF population (Kauser et al., 2021, 2022; Mitmansgruber et al., 2019, 2021). Kauser et al. (2022) and Kauser et al. (2021) found significant results regarding self-compassion in samples of adults with CF. In a qualitative study, Kauser et al. (2022) found that participants endorsed self-compassion and mindfulness as useful tools that enhanced health and psychological wellbeing. Kauser et al. (2021) found that self-compassion and HRQoL were positively associated, and self-compassion and HRQoL were each negatively associated with negative emotional states and self-criticism. Self-compassion also moderated relationships between anxiety and body image and anxiety and treatment issues.

In contrast to the findings of Kauser et al. (2022) and Kauser et al. (2021), Mitmansgruber et al. (2019, 2021) presented posters at the European Cystic Fibrosis Conference regarding self-compassion and psychological resilience and how they predict anxiety and depression. Self-compassion was not significant in either of their studies. Psychological resilience appeared more impactful in their studies, as psychological resilience differentiated patients with low anxiety and depression from patients with high anxiety and depression. Psychological resilience also displayed predictive power for psychological symptoms and wellbeing.

Cystic Fibrosis, Stigma, and Disease Disclosure

Research has shown that perceived stigma and issues of disclosure can have negative impacts on individuals with chronic illness, and embarrassment and stigma seem to extend to the CF population, which can be difficult for adolescents. In addition to the findings by George et al. (2010), Muther et al. (2018) and Pakhale et al. (2014) discussed themes of social isolation and ostracization experienced by young people with CF. In a review of psychosocial challenges facing adolescents with CF, Muther et al. (2018) described adolescents that felt that their peers avoided them due to their increased coughing and differences in physical appearance related to their CF, as well as feeling that they do not fit in with their peers because of frequently missing school due to their illness and having to avoid situations that could increase their risk of infection. Pakhale et al. (2014) reported that participants in their study believed that their symptoms change others' reactions to them and that many people have misunderstandings and lack of awareness about their illness. These experiences of social isolation and ostracization

reported by Muther et al. (2018) and Pakhale et al. (2014) likely contribute to the amount of stigma one feels about their condition and the amount of detail they choose to disclose to those around them.

Another commonly found theme was the impact of perceived stigma on quality of life. Pakhale et al. (2014) found a significant negative relationship between stigma and quality of life and Oliver et al. (2014) found that greater stigma was associated with more distress and worse lung function, HRQoL, and optimism. However, Oliver et al. (2014) found that higher levels of optimism could be helpful in these relationships, as it acted as moderator between stigma and anxiety, and between stigma and emotional functioning.

Related to disease stigma is disease disclosure. Borschuk et al. (2016), Modi et al. (2010), and Werner et al. (2019) examined disease disclosure in individuals with CF. Werner et al. (2019) conducted in-depth qualitative interviews to understand individuals' disclosure of their disease, then examined the responses for disclosure styles posited by Corrigan and Lundin (2001). These styles include: 1) social avoidance; 2) secrecy; 3) selective disclosure; 4) indiscriminate disclosure; and 5) broadcasting. Werner et al. (2019) found that most of their participants fell into secrecy, selective disclosure, and indiscriminate disclosure, and disclosure varied by stages of life and illness, due to the weighing of benefits and costs.

Modi et al. (2010) and Borschuk et al. (2016) studied disclosure to specific relationship groups and found that individuals with CF are most likely to reveal their diagnosis to individuals in the following order: relatives, close friends, dating partners, bosses/supervisors/ teachers, co-workers, and casual friends. Regarding the outcomes of

disclosure, Modi et al. (2010) found that participants reported mostly neutral or positive consequences of their disclosure with infrequent reports of negative consequences. When negative consequences were reported, they were most likely to be associated with dating partners and bosses/supervisors/teachers (Modi et al., 2010). Borschuk et al. (2016) found that disease disclosure was associated with better social support, social functioning, and medication adherence and self-efficacy. The results from these studies suggest that greater disclosure can yield positive outcomes depending on the situation, and therefore it may be helpful to support individuals in moving toward greater disclosure.

Summary

Chronic illness broadly, and CF specifically, extensively impacts one's social-emotional functioning, including HRQoL, disease disclosure, disease-related stigma, and self-compassion. These psychosocial variables then influence treatment adherence and attitudes toward treatment. The aim of this study was to build upon previous research within the CF population by addressing gaps in the literature. Strengths of the previous research include an in-depth understanding of HRQoL, qualitative understandings of the transition to adulthood as a person with CF, explorations into self-compassion, and development of CF-specific measures for disease disclosure, coping, and treatment adherence. However, no studies have been conducted regarding disease disclosure, perceived stigma, self-compassion, and HRQoL within the college experience exclusively. This study is a unique contribution to the literature due to its focus on college students with CF and the combination of the psychosocial variables of perceived stigma, disease disclosure, self-compassion, and HRQoL.

The following chapter describes the methodology used to respond to some gaps in the literature. The study examined associations between perceived stigma, self-compassion, and HRQoL. Perceived stigma and self-compassion also were examined in a regression model to determine the amount of variance in HRQoL that was explained by these variables. Disease disclosure was examined to uncover participants' patterns of sharing their disease with others. The next chapter outlines the participant eligibility criteria, participant characteristics, study procedures, and descriptions of the measures used to examine disease stigma, disease disclosure, self-compassion, and HRQoL. Finally, the chapter outlines the statistical procedures used to analyze the data and answer the research questions.

Chapter 3: Methodology

This chapter provides a description of the methodology used for this dissertation. Described in this chapter are the study design, eligibility criteria and participant characteristics, measures, and procedures. While other studies have examined the social-emotional experience of transitioning to college with a chronic illness, being a college student with a chronic illness, or the general transition to adulthood as a person with CF, this study focused on the social-emotional experience of being a college student with CF. The study examined correlations between perceived stigma, self-compassion, and HRQoL. The study also examined the amount of variance explained in HRQoL by perceived stigma and self-compassion and patterns of disease disclosure within the sample. The methodology will detail how the research hypotheses and research questions identified in Chapter One were examined.

Design

A non-experimental research design using correlation and regression was utilized to investigate associations between perceived stigma, self-compassion, and HRQoL, and to determine the amount of variance of HRQoL was explained by perceived stigma and self-compassion. Descriptive statistics were used to answer the research questions regarding disclosure within the sample. The participants in this study included 34 adults with CF, including current undergraduate students and adults who had attended college in the past 10 years as of May 2022. CF is a low incident disease that made it difficult to

recruit a large sample and therefore, this study can be considered a pilot study with the goal of uncovering the experiences of college students with CF.

Participants

Study participants included young adults aged 18-35, both male and female, diagnosed with CF who were currently attending a 2- or 4-year college or university or had attended a 2- or 4-year college or university in the past 10 years as of May 2022. Transfer students and students who previously began an undergraduate degree and took a break before continuing were included if they were still in their first undergraduate program. Participants who had attended college in the last 10 years were asked to complete the survey from their perspective when they were in college. Given that CF is more common in the White population than in other ethnic groups, it was expected that a higher number of participants would be White (National Institute of Health [NIH], 2020). The Cystic Fibrosis Foundation Patient Registry (2018) reported 93.5% of CF patients in the United States were White, 4.7% were African American, 3.7% were another race, and 9.4% were Hispanic. This registry also indicated an almost even split by sex, with 48.2% of patients identifying as female.

Thirty-four individuals aged 18 to 34 participated in this study. The mean BMI of the sample was 22.72 (SD = 3.022) and the mean FEV1% was 76.03 (SD = 32.92). The race/ethnicity composition of the sample was, 85.3% White, 8.8% African American or Black, 2.9% Asian American or Asian, and 2.9% Hispanic or Latinx. Regarding gender, 64.7% of the sample identified as women, 32.4% identified as men, and 2.9% did not report. For student status, 61.8% of the sample stated they were currently in college, and

38.2% were past college students (i.e., completed some college or graduated from college in the last 10 years).

Table 2

Overview of Participant Demographic Characteristics

Total Sample	34			
Demographics	**Mean**	**Min**	**Max**	**SD**
Age	22.71	18.0	34.0	4.094
BMI	22.72	17.5	32.1	3.022
FEV1%	76.03	2.80	123	32.92

Total Sample	34	
Demographics	**Frequency**	**Percentage**
Racial/Ethnic Group		
White	29	85.3%
African American or Black	3	8.8%
Asian American or Asian	1	2.9%
Hispanic or Latinx	1	2.9%
Gender		
Woman	22	64.7%
Man	11	32.4%
Did Not Report	1	2.9%
Age of CF Diagnosis		
In utero/before birth	4	11.8%
0-4 weeks old	5	14.7%
1-5 months old	4	11.8%
1-4 years old	8	23.5%
5 years or older	11	32.4%
I don't know when I was diagnosed	1	2.9%
Did Not Report	1	2.9%
Student Status		
First-year (Freshman)	8	23.5%
Second-year (Sophomore)	6	17.6%
Third-year (Junior)	4	11.8%

Fourth-year (Senior)	2	5.9%
Fifth-year or beyond	1	2.9%
I attended some college	3	8.8%
I am a college graduate	10	29.4%
Current College Student	21	61.8%
Past College Student	13	38.2%
Transfer Status		
Yes	8	23.5%
No	26	76.5%
Miles From Home		
<10 miles	5	14.7%
10-30 miles	6	17.6%
30-60 miles	4	11.8%
60-90 miles	2	5.9%
>120 miles	10	29.4%
I live at home	6	17.6%
Did Not Say	1	2.9%
Type of College – Public vs. Private		
Public	20	58.8%
Private	6	17.6%
Did Not Say	8	23.5%
Number of Students		
< 2,500 students	5	14.7%
2,500 - 4,999 students	10	29.4%
5,000 - 9,999 students	6	17.6%
10,000 - 19,999 students	4	11.8%
20,000 students or more	9	26.5%

Measures

Introduction Video

At the start of the survey was a video created by this researcher which explained the study. The video included slides with writing and a voiceover, as well as this researcher on camera explaining aspects of the study, including the purpose of the study,

eligibility criteria, benefits of participating (including incentive), and how to receive the results of the study. This video was approximately two minutes long and preceded the consent form and all measures detailed below as an introduction to the study.

Participant Demographics and Experiences Form

Participants provided their demographic information and experiences with CF and college via a self-report measure (See Appendix A). The participants were asked to complete the 22-item questionnaire prior to filling out the other measures. The first two questions acted as screening questions: age and whether they were currently in college or had attended college in the last 10 years. If participants did not meet study criteria based on either of these questions, they were prompted to discontinue taking the survey. If they met eligibility criteria after answering these questions, they could continue with the survey. The demographic questionnaire included questions about participants' gender, race/ethnicity, and whether they had a major medical condition unrelated to their CF, and then included items about their CF including age of diagnosis, their treatment regimen, their perceived level of adherence to their treatment regimen, their transplant and surgery history, and their history of pulmonary exacerbations. Following this were questions about the college experience, namely whether they were a transfer student, accommodations they received that were related to their CF, their living situation, their proximity to home, the type of college/university they attended (e.g., private or public), and the size of their campus. This information was used to describe the sample. Participants were asked to report objective health data, including FEV_1% and their height and weight to calculate BMI. This information was used to understand aspects of

participants' health other than the subjective health-related quality of life measure. Participants who previously attended college were asked to provide their best estimates of these values from when they were in college.

Stigma Scale-Revised (SS-R)

Perceived illness-related stigma was measured using the 8-item Stigma Scale-Revised, (SS-R; Bakula et al., 2019; See Appendix B). This measure was adapted from the Stigma Scale (SS) created by Austin et al. (2004), which was originally created to assess perceived stigma related to living with epilepsy. In the revised version by Bakula et al. (2019), the word "epilepsy" was replaced with the term "chronic illness" throughout the measure. In a similar fashion, the term "epilepsy" was replaced with the term "cystic fibrosis" throughout the measure for this study with permission from the author (See Appendix F). A 5-point Likert scale is used, ranging from 1 (*never*) to 5 (*very often*). The measure is scored by calculating an average score across the eight items, with higher scores indicating higher perceived stigma. An example item from the SS-R is, "How often do you feel people may not like you if they know you have cystic fibrosis?" With psychometric data, Austin et al. (2004) demonstrated good content validity, predictive validity, and internal consistency reliability (α = .81) in a sample of children with epilepsy. Bakula et al. (2019) demonstrated good internal consistency in their sample using the SS-R with adolescents and young adults with chronic illnesses (α = .94).

Cystic Fibrosis Disclosure Questionnaire (CFDS)

Disease disclosure was measured using the Cystic Fibrosis Disclosure Questionnaire (CFDS; Borschuk, 2015; Borschuk et al., 2016; See Appendix C). Very

few validated questionnaires regarding disease disclosure currently exist and many studies regarding disease disclosure are qualitative. If the studies are quantitative, they rely on single items to measure disease disclosure, such as "How many people have you made aware of your HIV status?" (Heggeness et al., 2017). Instead, the CFDS measures disease disclosure in a more detailed and systematic way. It was created in a dissertation study by Borschuk (2015) who used qualitative research on disease disclosure and existing disclosure literature (George et al., 2010; Rand-Giovannetti et al., 2010) to develop the measure. The 2015 dissertation study was conducted to validate the CFDS and was found to have strong convergent and discriminant validity (based on effect sizes, .18-.65 and .23-.26 respectively) and internal consistency (α = .71-.83). Other studies have not yet provided additional validation for this measure; however, the questionnaire has been used in subsequent studies with good internal consistency (α = .78-.83; Borschuk et al., 2016; Borschuk et al., 2019).

The CFDS includes different sections of questions, based on relationship groups (i.e., Close Friends, Casual Friends, Significant Others, Professors, and Classmates). The first question in each relationship group asked participants to report whether they had disclosed to all, some, or none of the people in each relationship group (e.g., "Do your close friends know that you have CF?"). If participants had disclosed, they were asked three subsequent questions within that relationship group, rated on a scale from 1 (*not at all comfortable*) to 10 (*completely comfortable*). They were asked to rate their comfort discussing their CF with those individuals (e.g., "Rate your overall comfort in discussing your CF experience with your close friends."). They also were asked about their comfort

using nebulized medications in front of those individuals (e.g., “Rate your overall comfort using your nebulized medications [including antibiotics] in front of your close friends.”), and their comfort taking enzymes in front of those individuals (e.g., “Rate your overall comfort taking your enzymes [for example Creon, Zenpep, etc.] in front of your close friends.”). The questionnaire includes 32 items but can be shorter if a relationship category did not apply to a participant. For the purpose of this study “Roommates” was added as a relationship category with the permission of the author (See Appendix F). For this study, the number of participants that endorsed reporting to each relationship category was calculated along with each participant’s level of comfort reported for disclosing in each relationship category. The comfort level was reported as a mean for each category. Higher scores indicate greater reported comfort in disclosure behaviors.

Self-Compassion Scale (SCS)

Self-compassion was measured using the 26-item Self-Compassion Scale (SCS; Neff, 2003; See Appendix D). This measure includes items capturing the main components of self-compassion and includes six subscales: self-kindness (5 items), self-judgment (5 items), common humanity (4 items), isolation (4 items), mindfulness (4 items), and over-identification (4 items). The items are answered on a scale from 1 (*almost never*) to 5 (*almost always*) and reversed scored when negatively worded, which is the case on the self-judgment, isolation, and over-identification subscales. The total score on this measure was calculated by averaging items on each of the six subscales then averaging the means of the six subscales, with higher scores reflecting higher self-compassion. In this study, only the total score was used. Factor analysis has shown that

one higher order factor of self-compassion is a good explanation of the intercorrelation between the subscales on the SCS (NNFI = .88; CFI = .90). Examples of questions on the SCS include: “I’m kind to myself when I’m experiencing suffering” (self-kindness); “I try to see my failings as part of the human condition” (common humanity); and “When something upsets me I get carried away with my feelings” (over-identification).

The SCS has been shown to have sound psychometric properties. The SCS shows promising test-retest reliability across three weeks (r = .80-.93 depending on the subscale), construct validity (e.g., showing a moderate positive correlation with a measure of self-esteem, r = .59), and discriminant validity (e.g., showing a strong negative correlation with a measure of self-criticism, r = .65; Neff, 2003).

Cystic Fibrosis Questionnaire-Revised (CFQ-R)

Participants’ HRQoL was captured using the Cystic Fibrosis Questionnaire-Revised (CFQ-R; Quittner et al., 2005; Quittner et al., 2012; See Appendix E). This measure was explained by Quittner et al. (2012) as assessing how an individual “survives, functions, or feels in relation to his or her health condition” (p. 1280). This measure is comprised of 50 items that capture 12 generic and disease-specific scales: physical functioning, emotional functioning, social functioning/school functioning, body image, eating problems, treatment burden, respiratory symptoms, digestive symptoms, vitality, health perceptions, weight, and role functioning. The items are asked in various ways. Some questions involve frequency of specific experiences and use a four-point scale from 1 (*always*) to 4 (*never*) (e.g., “How often does CF get in the way of meeting your school, work, or personal goals?”). Other questions require responding to the level

of difficulty required to conduct certain activities ranging from 1 (*a lot of difficulty*) to 4 (*no difficulty*) (e.g., "walking as fast as others"), and other questions ask how true a specific question is ranging from 1 (*very true*) to 4 (*very false*) (e.g., I have to stay home more than I want to."). Other sets of questions ask participants to choose from a list of responses that best fit them (e.g., "Question: How do you feel about eating? Responses: Just thinking about food makes you feel sick; You never enjoy eating; You are sometimes able to enjoy eating; You are always able to enjoy eating"). An overall standard score was calculated, and scores range from 0 to 100, with higher scores indicating better quality of life. The CFQ-R is a widely used measure of HRQoL with the CF population and displays construct validity, convergent validity, and discriminant validity (Quittner et al., 2012; Simon et al., 2011).

Procedure

Approval to conduct this research study was first granted by the IRB at the University of Denver on May 19, 2021. Several amendments to this IRB package were later submitted and approved by the University of Denver IRB, due to changes to the originally proposed recruitment methods and eligibility criteria. The recruitment for this study was conducted via various outlets. CF Clinics and online channels were identified as sites for recruitment and data collection for the study. Sites and organizations with a CF population aged 18-35 were used.

In the case of recruiting within CF Clinics, research psychologists were contacted via email requesting permission to conduct the study in their clinic. Once the research psychologists gave permission, this researcher worked with the respective IRBs for each

institution to receive their permission to conduct the study at their site. One of the IRBs agreed to cede to the IRB at University of Denver. The other IRB granted this researcher permission to conduct research at their site if potential participants were solely given information about the study and clinic staff were not involved in consenting participants, if this researcher did not access the Electronic Medical Record at the clinic, and if this researcher and clinic staff did not collect names of participants to track level of participation. After the appropriate permissions were granted, the research psychologists at each clinic assisted this researcher with connecting with their clinic teams and other colleagues for study recruitment. This researcher requested that the primary method for recruitment include approaching individuals during their clinic visits and request participation. Clinic teams were provided a script to read to potential participants to introduce the study. The script reads: *"A study you might be interested in is being conducted by a PhD student who wants to learn more about your experiences with CF. You are being considered for the study due to your age and the fact that you are in college right now or you graduated from college in the last 10 years. The researcher would like to know more about your experiences as a college student while being a person with CF. If you are interested in learning more about this study, I have a short video that the researcher created, which can help give you a better idea of the details of the study. The video will also describe how you can participate in the study if you are interested. Would you be willing to watch the video right now?"*

The attempts at recruitment within CF Clinics were multifaceted. Clinic teams posted the study flyer in clinic rooms, introduced the study to potential participants

during their clinic visits, emailed the study information to their patient listserv, posted the study information on their hospital website and Facebook page, and emailed the study information to relevant collegial networks. Approximately four participants in the final sample were recruited through this method.

Another avenue for recruitment in this study was via online recruiting methods. This researcher identified outlets via social media and email that could target potential participants. These outlets included: a Reddit page focused on CF, the CF Foundation Facebook page, a Facebook group called "Cystic Fibrosis", this researcher's alumni Facebook networks, the Cystic Fibrosis Research Institute (email newsletter and social media), the University of Utah Adult CF Clinic email newsletter, the Johns Hopkins CF Center patient listserv, the Mayo Clinic CF Center, the College Student Personnel listserv, this researcher's personal social media pages (including Facebook, Instagram, and LinkedIn), connections of this researcher in higher education (i.e., colleagues who work in higher education who could distribute the information to their students, departments, etc.), and social media influencers with CF who agreed to share the study with their followers. Most participants in the current study were recruited via these methods.

Study data were collected and managed using REDCap electronic data capture tools hosted at the University of Denver (Harris et al., 2009; Harris et al., 2019). REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3)

automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. REDCap was used as the data collection platform for this study since it is a HIPAA Compliant software.

Potential participants clicked on the link and began by viewing the video that described the study. The video explained that if participants were interested in participating after watching the video, they could continue to the next page to participate. The consent form came next and stated that participation in the study was wholly voluntary and included completing online questionnaires which were expected to take approximately 15-20 minutes to complete. Participants were informed that their information would be anonymous, meaning their identifying information would be kept separate from their data, and that the only identifying information gathered included an email address for the purposes of an incentive drawing and dissemination of study results, should they choose to provide this information. Participants were assured that their email addresses would be kept separate from their data and deleted once the incentive drawing and/or dissemination of survey results was completed.

After completing the consent form, the participants then completed the measures, including the Demographics and Experiences Questionnaire, SS-R, CFDS, SCS, and CFQ-R. Once the participant completed the last question of the CFQ-R (the last measure), they were directed to another page of the REDCap survey. This page prompted participants to enter their email address to be entered into a drawing to receive one of twenty $20 Visa gift cards for their participation. After inputting their email address for

the gift card drawing, participants were then directed to another page of the survey. This page prompted participants to enter their email address to receive generalized, sample-level results of the study once they were available. After participants completed this page, they arrived at the last page, which thanked them for their participation.

Since this researcher was not available during survey completion for questions regarding the survey, every attempt was made to ensure the survey questions were clear to avoid participant confusion. This survey's items were tested with volunteer colleagues that fit the study age group to resolve any issues with the survey questions. These volunteers also tracked how long it took to complete the surveys to provide potential participants with an accurate estimate.

This researcher maintained consistent contact with the research psychologists at each participating CF Clinic to adjust the study methods as needed. Repeated attempts at recruitment were made via the online recruitment strategies to capture the largest sample possible.

Summary

This chapter provided an overview of the research design, participant eligibility and characteristics, instruments, and procedures used to examine the study's research hypotheses and research questions. The naturalistic design of this research study examined the experiences of being a college student with CF. The study specifically measured how perceived stigma and self-compassion were related to health-related quality of life (HRQoL). It was expected that there would be correlations between these relationships and that perceived stigma and self-compassion would help explain the

variance in HRQoL. This study also examined disease disclosure behavior of individuals with CF. The following chapter describes the data analysis and provides the results of the hypotheses that were tested and research questions examined.

Chapter Four: Results

This chapter provides an outline of the statistical analyses and results of the study hypotheses and research questions. Preliminary data analyses are discussed, including missing data, power analyses, descriptive statistics of the measures, and regression assumptions. The main analyses were performed using correlation and multiple linear regression. Statistical analyses for this study were conducted using the program Statistical Package for the Social Sciences (SPSS, version 27 [IBM Corporation, 2022]). The alpha level was set at 0.05. This researcher used a statistical guide called Laerd Statistics to assist with data analysis and interpretation.

For this study, HRQoL, as measured by the total standard score on the Cystic Fibrosis Questionnaire-Revised (CFQ-R; Quittner et al., 2005; Quittner et al., 2012), is the dependent variable in the regression models. The independent variables are perceived stigma, measured using the Stigma Scale-Revised, (SS-R; Bakula et al., 2019) and self-compassion, measured using the Self-Compassion Scale (SCS; Neff, 2003).

Preliminary Data Analysis

Data Cleaning

A total of 517 surveys were started in REDCap during the data collection period that occurred from June 2021 to May 2022. Of the generated surveys, 331 surveys were completed. The first step in data analysis was to check for missing data and fraudulent data. Participants who did not complete significant portions of the measures were

removed from the study. Participants who did not appear to take the survey seriously (i.e., took fewer than five minutes to complete, gave nonsense responses to open-ended questions, and/or provided an email address that appeared to be a fake email address based on visual inspection) or did not seem to fit the eligibility criteria based on their responses (i.e., did not appear to genuinely have CF based on responses to open-ended questions) were removed from the study. The researcher excluded 297 respondents based on these criteria. It is likely that these respondents were only interested in the incentive lottery, rather than being genuine respondents. The final number of participants included in the study was 34. Given this sample size, a post-hoc power analysis was conducted via G*Power (Faul et al., 2007). A post-hoc power analysis based on multiple linear regression was conducted based on the acquired sample of 34 people with a medium effect size (f^2) of .15, an alpha of .05, and a total of 2 predictors (i.e., perceived stigma and self-compassion). The results of this power analysis indicated the power level of the analysis was .71, which indicates a 71% chance of detecting a true effect and 29% chance of a Type II error. In the cases where participants had a small amount of missing data (i.e., less than 5% missing responses), person mean substitution (PMS) was used for the missing values (Downey & King, 1998). PMS includes averaging the responses given by a person on each scale, then using that average as a substitute for missing data. While this method can be used for up to 20% of missing data, there was only 5% missing in this study, and the pattern of missing data appeared random, making this method acceptable (Downey & King, 1998). The PMS method was used to input missing data to calculate the total scores on the SS-R, the CFDS, the SCS, and the CFQ-R. Participants'

demographic information was analyzed via descriptive statistics to help describe the identities and experiences of the study sample. Data from the SS-R, CFDS, SCS, and CFQ-R were also analyzed using descriptive statistics to investigate how the sample generally responded in terms of perceived stigma, disease disclosure, self-compassion, and HRQoL.

Descriptive Statistics for Instruments

Stigma Scale-Revised (SS-R)

The total possible range on the SS-R is from 1 to 5 and scores for this study ranged from 1.25 to 5 (n = 34). Higher scores indicate higher perceived stigma. The descriptive statistics for the total sample on the SS-R were: M = 2.67, SD = .896, Median = 2.56. Reliability for all 8 items on the SS-R in this study was $\alpha = .889$.

Cystic Fibrosis Disclosure Questionnaire (CFDS)

The CFDS was scored by calculating frequencies for each relationship group reported by the 34 participants and a mean score of their comfort with disclosure for each of these endorsed relationship categories. For each relationship category, the mean score for comfort was reported. The total possible scores on the CFDS ranged from 1 to 10 and the entire range was utilized in this sample. Higher scores indicated greater reported comfort in disclosure behaviors.

Table 3 shows the results from the descriptive analyses of the CFDS, including the number of participants who disclosed to each relationship group, and a mean score of comfort with disclosure within relationship group. All but one participant disclosed to their close friends. While most participants disclosed to their close friends, the average

comfort with disclosure was highest for the romantic partner/spouse relationship group. The lowest frequency of disclosure and comfort with disclosure was for bosses and coworkers. Well over half of the participants (70.6%) reported disclosing to their professors.

Table 3

Cystic Fibrosis Disclosure Questionnaire (CFDS) Descriptive Statistics

Total Participants	34			
	Count	Percentage	Comfort M	Comfort SD
Disclosed to:				
Close Friends	33	97.1%	6.78	2.37
Casual Friends/ Acquaintances	27	79.4%	5.81	2.36
Romantic Partner/ Spouse	17	50.0%	7.84	2.53
Boss	9	26.5%	6.18	2.68
Coworkers	13	38.2%	4.08	2.88
Professors	24	70.6%	4.79	2.75
Classmates	18	52.9%	4.13	2.60
Roommates	14	41.2%	6.19	2.83

Self-Compassion Scale (SCS)

The total possible scores on the SCS ranged from 1 to 5 and scores for this study ranged from 2.11 to 3.77 (n = 34). Higher scores indicate higher levels of self-compassion. The descriptive statistics for the total sample on the SCS were: M = 2.92, SD = .345, Median = 2.93. Reliability for all 26 items on the SCS was $\alpha = .774$.

Cystic Fibrosis Questionnaire-Revised (CFQ-R)

The total score for the CFQ-R is a standardized score, making the total possible score a range from 0 to 100. Scores for this study ranged from 26.71 to 95.09 (n = 34). Higher scores indicate higher levels of health-related quality of life. The descriptive statistics for the total sample were: M = 63.31, SD = 17.603, Median = 61.27. Reliability for the 49 numerically scored items on the CFQ-R was $\alpha = .963$.

Assumptions Testing

The eight assumptions of a multiple regression model were examined prior to running statistical analyses (Laerd Statistics, 2022). These assumptions include: 1) A continuous dependent variable; 2) Two or more independent variables; 3) Independence of observations (i.e., independence of residuals); 4) A linear relationship between (a) the dependent variable and each of the independent variables, and (b) the dependent variable and the independent variables collectively; 5) Homoscedasticity of residuals (i.e., equal error variances); 6) Lack of multicollinearity; 7) No significant outliers, high leverage points, or highly influential points; and 8) The residuals (i.e., errors) being approximately normally distributed.

Most assumptions of the multiple linear regression were met. There was a continuous dependent variable and multiple independent variables (Assumption #1 and #2). There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.924 (Assumption #3). There was a linear relationship between (a) the dependent variable and each of the independent variables, and (b) the dependent variable and the independent variables collectively (Assumption #4; See Appendix G). There was

homoscedasticity based on a visual inspection of a plot of studentized residuals versus unstandardized predicted values (Assumption #5; See Appendix G). There was not multicollinearity, as the independent variables were not highly correlated with each other, and all of the Tolerance values were greater than 0.1 (Assumption #6; See Appendix G). There were no significant outliers, as there were no studentized deleted residuals greater than 3 and there were no highly influential points, as there were no Cook's Distance values greater than 1 (Assumption #7). It should be noted that there were some leverage values that are considered risky (i.e., ranging from 0.2 to 0.5), which requires some caution when interpreting the results of this analysis (Assumption #7). Lastly, the residuals (i.e., errors) were approximately normally distributed (Assumption #8; See Appendix G).

Main Statistical Analyses

The main analyses for this study were performed in SPSS using correlation and multiple linear regression. The research questions were answered using descriptive statistics in SPSS. The alpha level was set at .05 for all analyses.

Hypotheses

Hypothesis 1. Hypothesis One stated that there would be a statistically significant negative relationship between perceived stigma and HRQoL. There was a statistically significant, strong negative correlation between perceived stigma and HRQoL, $r(32) = -.70$, $p < 0.01$. The data for this correlation can be found in Appendix H. This hypothesis was supported and suggests that as perceived stigma increases, HRQoL decreases.

Hypothesis 2. Hypothesis Two stated there would be a statistically significant positive relationship between overall self-compassion and HRQoL. This relationship was not found, $r(32) = .23$, $p = .19$. The results for Hypothesis 2 are displayed in Appendix H. This hypothesis was not supported and indicated that in this sample, self-compassion and HRQoL were not related.

Hypothesis 3. Hypothesis Three stated that there would be a statistically significant negative relationship between perceived stigma and self-compassion. A statistically significant correlation between perceived stigma and self-compassion was not found, $r(32) = .03$, $p = .866$. See Appendix H for the data table for Hypothesis 3. This hypothesis was not supported and suggests that there was not an association between perceived stigma and self-compassion in this sample.

Hypothesis 4. A multiple linear regression was conducted to understand the amount of variance in HRQoL that was explained by perceived stigma and self-compassion. The multiple regression model significantly predicted HRQoL, $F(2, 31) = 18.624$, $p < .001$, adj. $R2 = .55$. Perceived stigma and self-compassion added significantly to the prediction, $p < .05$. Regression coefficients and standard errors can be found in the tables in Appendix H. These results suggest that perceived stigma and self-compassion significantly predicted HRQoL. In this regression model, higher perceived stigma resulted in lower HRQoL, and higher self-compassion resulted in higher HRQoL. This suggests that it is possible to predict HRQoL based on reports of perceived stigma and self-compassion.

Research Questions

Research Question One. The first research question asked, which relationship groups do individuals with CF disclose their disease to most and least frequently? The results of descriptive statistics showed that in this sample, most participants disclosed to their close friends (n=33). The second most common relationship group participants disclosed to was casual friends/acquaintances (n=27), followed by professors (n=24), then their romantic partner/spouse (n=17). Notably, there were fifteen participants who did not have a romantic partner/spouse at the time of completing the survey, therefore prompting them to mark "Does not apply." The relationship groups participants disclosed to the least were their boss (n=9) and coworkers (n=13). Fourteen participants out of 34 disclosed to their roommates, but similarly to the romantic partner/spouse question, fifteen participants did not have roommates and therefore marked "Does not apply."

Research Question Two. The second research question asked, how comfortable do individuals with CF feel with disclosing their disease to individuals in these relationship groups? The relationship group participants felt most comfortable in disclosing their disease were romantic partner/spouses (M = 7.84, SD = 2.53). This was followed by close friends (M = 6.78, SD = 2.37) and roommates (M = 6.19, SD = 2.83). Interestingly, while bosses were the least likely to be disclosed to, the participants who did respond (n = 9), had high comfort scores (M = 6.18, SD = 2.68). The relationship group participants felt least comfortable in disclosing their disease to were coworkers (M = 4.08, SD = 2.88) and classmates (M = 4.13, SD = 2.60).

Summary

This chapter included an explanation of the preliminary and main data analyses used to examine the hypotheses in this study. Pearson's r correlational analyses were conducted to assess the relationships between perceived stigma, self-compassion, and HRQoL. Multiple regression analysis was then used to assess the amount of variance explained in HRQoL by perceived stigma and self-compassion. Descriptive statistics were used to answer the research questions regarding disease disclosure. The research design, measures, procedures, and data analyses in this study were used to investigate which variables are related to and help explain HRQoL in a sample of college students with CF.

Chapter Five: Discussion

This study was the first to focus on college students with CF. Given the low incidence of CF, the sample is small with 34 participants, yet this pilot study provides some important results that potentially can guide mental health treatment and educational interventions for individuals with CF. One variable included in this study is a common indicator of well-being, HRQoL. HRQoL is a self-report measure that includes disease state and physical symptoms, functional status, psychological and emotional state, and social functioning (Quittner et al., 2005). This is a well-researched outcome variable in the CF population, due to the impact CF has on all areas of an individual's life (Sawicki et al., 2011). Like other studies (Kauser et al., 2021; Oliver et al., 2014; Pakhale et al., 2014), the current study found that perceived stigma was related to lower HRQoL and that perceived stigma and self-compassion can predict HRQoL. It seems clear that psychosocial variables can have an impact on an individual's overall HRQoL. One positive finding was that the HRQoL levels were relatively high suggesting that in this sample the participants appear to be functioning relatively well. Furthermore, this is the first study to examine these variables with college students, making this a new contribution to the literature.

This study also included other variables studied in the extant research on CF. Disease disclosure and self-compassion were variables involved in the research base of individuals with CF to further understand their psychosocial experience while living with

a chronic illness (Borschuk et al., 2016; Kauser et al., 2021, 2022; Modi et al., 2010; Oliver et al., 2014; Pakhale et al., 2014; Sirois et al., 2015). There are no known studies that combine all these variables into one study. Furthermore, there are no studies that examine these variables within the college experience of individuals with CF. This study addresses gaps in the literature regarding psychosocial experiences of college students with CF by exploring disease disclosure, examining the relationships between perceived stigma, self-compassion, and health-related quality of life (HRQoL), and investigating how much of HRQoL was explained by perceived stigma and self-compassion. The findings from this study are important to inform interventions to support college students with CF.

Interpretation of Findings

Disease Disclosure

Results of this study described how this sample navigated disease disclosure. This included who the participants chose to disclose to and how much comfort they had when revealing their CF to those specific people. It was encouraging to see that participants were willing to divulge their diagnosis to several different categories of people. An earlier study suggested that individuals with CF varied in their disclosure, specifically that most of the participants fell into secrecy, selective disclosure, and indiscriminate disclosure (Werner et al., 2019). It is possible that the stigma of having CF has decreased in the past few years and that more people are aware of CF, allowing the participants to feel more comfortable communicating their diagnosis to others.

Looking more closely at the categories of persons that the participants disclosed to, 33 out of 34 participants disclosed to their close friends. Frequency of disclosure to other relationship groups followed in this order: casual friends, professors, classmates, romantic partner/spouse, roommates, coworkers, and boss. This is partially consistent with previous research that discovered frequency of disclosure in this descending order: relatives, close friends, dating partners, bosses/supervisors/ teachers, co-workers, neighbors, and acquaintances in one study (Modi et al., 2010) and close friends, romantic partners, bosses, and coworkers in another study (Borschuk et al., 2016). It should be noted that while it would be expected that more individuals in this sample would disclose to their romantic partner/spouse, there were fifteen participants who did not have a romantic partner/spouse at the time of completing the survey, therefore prompting them to mark "Does not apply." Furthermore, it is promising that so many participants in this study disclosed to their professors, as this is likely a helpful strategy for success as a college student with a chronic condition.

It was positive to see that all students had relationships within which they could reveal their disease. It was also positive that individuals felt comfortable revealing their disease within these relationships. This is consistent with previous research by Borschuk et al. (2016) who found that participants felt more comfortable discussing CF with and doing treatments in front of romantic partners and close friends than other groups. The frequency of disclosure to professors in this sample is reassuring given that the participants reported less comfort with the disclosure. This could be potentially related to the findings from Werner et al. (2019) who discussed that individuals often weigh

benefits and costs when making disclosure decisions. Perhaps the benefits of disclosing their disease to their professors, such as improved accommodations and support, could outweigh the discomfort of needing to discuss it with them. Indeed, disease disclosure has been found to be positively correlated with several benefits such as social support, social functioning, and medication adherence and self-efficacy (Borschuk et al., 2016).

Perceived Stigma, Self-Compassion, and HRQoL

A finding that was consistent with earlier studies was that perceived stigma was found to be significantly and negatively correlated with HRQoL. Pakhale et al. (2014) and Oliver et al. (2014) both found a significant negative relationship between perceived stigma and HRQoL in samples of adults with CF. This study's results corroborate the results of earlier studies regarding stigma and HRQoL but expand them to a sample of college students and within the experience of being in college. It is hoped that as the stigma related to CF is decreased, more students will experience higher HRQoL levels.

Another interesting finding was that perceived stigma and self-compassion explained a portion of the variance in HRQoL. This suggests that HRQoL was partly impacted by the level of perceived stigma and self-compassion, and that as perceived stigma increases, HRQoL decreases, and as self-compassion increases, HRQoL increases. This points to the potential protective nature of self-compassion and reflects recent findings from studies with CF participants. Specifically, Kauser et al. (2022) and Kauser et al. (2021) highlighted the benefit of self-compassion and found self-compassion positively associated with HRQoL and negatively associated with negative emotionality and self-criticism. Therefore, individuals who are more likely to use self-compassion

appear to have a better chance of higher quality of life and a lower chance of psychological difficulties.

For Hypotheses 2 and 3, it was expected that there would be correlations between self-compassion and perceived stigma and self-compassion and HRQoL, but these hypotheses were not supported. It is possible that a restricted range of scores resulted in a nonsignificant finding. Participants ranged from 2.11 to 3.77 in their total self-compassion scores [M = 2.92, SD = .345, Median = 2.93]. This is a relatively limited range of scores, with few participants scoring low on self-compassion and no participants scoring on the very high end. It is possible that this restricted range influenced the possibility of finding correlations with other variables, particularly with a small sample size. Another way to consider this finding, and one that is hopeful for CF, is that most participants show a moderate amount of self-compassion, suggesting that in general participants are using self-compassion methods to address their symptoms.

Limitations and Strengths of the Study

Limitations

A limitation of this study is the sample size of 34 participants. Initially it was expected that a sample of approximately 70 participants would be possible. Due to the small sample size, there was less power for the statistical analyses than desired. Therefore, the results need to be considered with caution. This study was considered a pilot given the reduced number of participants even after many different methods of obtaining participants were employed. CF is a low incident diagnosis with a prevalence of only 30,000 children and adults in the United States and 70,000 individuals worldwide,

helping explain this difficulty with recruitment. In future research, mixed methods could be a useful tool to capture more in depth information when using small samples.

Also pertaining to the sample, there was an unequal distribution of gender of the participants. Sixty-four percent of the sample identified as women, which could make the results of this study less generalizable than desired since CF impacts all genders equally. It could be possible that the experiences of women with CF differ from the experiences of men with CF due to internalized norms regarding masculinity/femininity, social support, and one's feelings towards themselves.

Additionally, several unanticipated obstacles occurred during data collection, and there was a reliance on self-report measures to collect data. The original intent of this study was to collect participant data exclusively through CF clinics in Colorado. However, a limited number of individuals participated in this way, necessitating alternative recruitment strategies. Recruitment was adjusted to include online methods, including social media and email listservs/newsletters. These recruitment methods, combined with the use of self-report data, introduced several difficulties in gaining actual CF individuals as many persons entered the survey who were not appropriate for the study and were ultimately excluded. Furthermore, past research has shown that self-report of objective health data, such as treatment adherence and FEV1% values, proves less reliable than gathering the health data directly (Oates et al., 2019). Future studies would benefit from less reliance on self-report data regarding objective health outcomes for a more accurate understanding of participants' health. Instead, objective health data could be collected from participants' health records.

Strengths

There are several strengths of this study. This is the first study to explore perceived stigma, disease disclosure, self-compassion, and HRQoL in a sample of college students with CF. This is an important contribution to the literature base, as little is known about the specific experiences of college students with CF. The results of this study offer ideas for interventions to support individuals with CF while they navigate their disease and the college experience.

Additionally, it is encouraging that even with a small sample size, there were significant findings that were consistent with previous research within the CF population. These findings were intuitive based on what is known about the CF experience, and they offered additional support for the need to decrease felt stigma to improve the lives of individuals with CF. Furthermore, the findings on disclosure were also similar to previous research, which suggests that the participants in this sample respond similarly to other individuals with CF.

While the findings were expected, the finding of perceived stigma and self-compassion explaining the variance in HRQoL is a unique contribution to the literature. This finding highlights that while perceived stigma can impact HRQoL in a negative direction, self-compassion can impact HRQoL in a positive direction and serve as a protective element. The previous finding by Kauser et al. (2021) that self-compassion was negatively correlated with self-criticism is relevant, but this study adds to the understanding of how perceived stigma and self-compassion might influence HRQoL.

Another strength of this study was that in general, the participants in this sample are functioning well. Participants reported a moderate level of self-compassion overall (M = 2.92, SD = .345) and the average reported HRQoL fell in the moderate range (M = 63.31), with most participants (75.4%) reporting a score of 50 or above. Again, this may be an intuitive result given that attending college and progressing into adulthood does imply an increased level of functioning, but it is beneficial to see, nonetheless.

Implications for Clinical Practice

Perceived stigma was negatively correlated with HRQoL, but perceived stigma and self-compassion significantly explained variance in HRQoL. This shows that perceived stigma is likely accompanied by lower self-reported HRQoL, but self-compassion is likely a protective factor, as higher levels of self-compassion are associated with higher self-reported HRQoL. Past research indicated that the use of self-compassion results in favorable outcomes for individuals with a chronic illness (Kauser et al., 2021; Sirois et al., 2015). The results of this study provide additional support for the positive impact of self-compassion in the lives of individuals with CF. Self-compassion is a skill that can be learned through self-study, in group settings, and with the help of a mental health professional. Because individuals with CF are advised not to be near others with the disease, self-compassion groups could be adapted for an online format. Online self-compassion trainings are also being developed which could provide additional resources to individuals with CF (Finlay-Jones et al., 2020). With practice, one can learn to be more self-compassionate over time, which can influence one's quality of life. This knowledge can be beneficial for individuals with CF to seek out self-compassion

resources, as well as for mental health professionals working with individuals with CF to incorporate it into their work.

Studies have shown that knowing someone with a chronic illness tends to decrease stigmatizing beliefs regarding chronic illness and an individual with a chronic illness is more likely to disclose their disease to someone who has familiarity with chronic illness (Kaushansky et al., 2017; Rohde et al., 2018). This study, in combination with previous findings, highlights the importance of additional education and awareness regarding chronic illness, specifically CF, to potentially decrease incidence of perceived stigma and increase disease disclosure, social support, and positive emotional functioning. This can include teaching individuals with CF how to appropriately discuss their disease with others and advocate for themselves. This could also include providing education to family members so they can serve as a resource and advocate. Another idea would be for CF foundations and institutes to offer educational resources and events to allow the general public to learn about CF, its impact on individuals affected by the disease, and how someone in the community could provide support to someone with CF.

Recommendations for Future Research

Previous research has found self-compassion to be significant in navigating emotional experiences and promoting better functioning in many life domains within chronic illness populations (Barnes et al., 2018; Edwards et al., 2019). Self-compassion was also found to be positively correlated with HRQoL, and self-compassion and HRQoL were each negatively associated with negative emotional states and self-criticism in a sample of individuals with CF (Kauser et al., 2021). Given there was only one

significant finding for self-compassion in this study, despite it being found to have positive outcomes with more general chronic diseases and in one study including individuals with CF, it seems reasonable that including it with CF participants in a larger sample may produce different results. Another possibility for further research could be to create a CF-specific self-compassion scale, similar to efforts of creating CF-specific disease disclosure and HRQoL measures (Borschuk, 2015; 2016; Quittner et al., 2005; 2012). While the SCS has been found to be relevant for chronic illness populations, it is possible that some aspects of the SCS may not be as pertinent to individuals with CF. In particular, the common humanity scale reinforces the universality of personal difficulties. For example, one question on the common humanity scale reads, "When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am." Given the low incidence of CF, it is unclear whether individuals with CF can see themselves as part of a universal experience, or if stigma causes them to feel substantially different from their peers. This could make measures of common humanity differ for this population.

Beyond the scope of the current study was an examination of correlations between each HRQoL subscales and each self-compassion domain. Initial analyses found that there were some relationships between these variables, including a) self-kindness and vitality, $r(32) = .401$; b) common humanity and physical functioning $r(32) = .369$; c) common humanity and vitality $r(32) = .374$; d) isolation and school functioning $r(32) = .378$; e) isolation and eating problems $r(32) = .398$; and f) over-identification and weight

$r(32) = -.344$. Perhaps individual tenets of self-compassion such as self-kindness and common humanity could be related to specific areas of HRQoL.

Unlike the national figures which show equal distribution of the disease by gender, this sample included 64% women. Future studies that look at gender more closely by including gender as a variable, or by conducting qualitative interviews to assess differences in persons of varying genders, could provide additional information about CF. For example, women are often thought to seek more emotional support from their friends and family due to norms regarding the socialization of girls and women. Examinations of how gender interacts with these variables could further inform CF-related care and support. However, with the low incidence of CF in the population, recruitment for these kinds of studies would be difficult.

Given the fact that the participants in this sample are functioning relatively well, one idea for further study would be to incorporate features of positive psychology into research with the CF population. Linley et al.'s (2006) article on positive psychology suggests that posttraumatic growth, promoting resilience, strengths-based interventions, and meaning-making about what makes life worth living are important features of positive psychology and these could be intriguing elements to introduce into the research of individuals with CF. These investigations could further promote ideas for intervention within the CF population and build additional avenues for flourishing as a person with CF.

Conclusions

This study predicted that there would be statistically significant relationships between perceived stigma, self-compassion, and HRQoL. Furthermore, this study examined if stigma and self-compassion would explain the variance in HRQoL. This study also explored disease disclosure within this sample. Results of these hypotheses indicated that perceived stigma and HRQoL were significantly negatively correlated and perceived stigma and self-compassion helped explain the variance in HRQoL. It was discovered that participants felt most comfortable disclosing their disease to their romantic partner/spouse and close friends, and most likely to disclose to close friends.

This study is the only known study to examine psychosocial variables in a sample of college students with CF. This study highlighted that perceived stigma and self-compassion were both involved in explaining overall HRQoL in college students with CF. This sample functioned well, which points to the possibility of future research within the CF population focusing on themes found within positive psychology such as resilience and finding meaning. This study offers ideas for future research and intervention regarding self-compassion to support individuals with CF.

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Appendix A: Demographic and Experiences Questionnaire

Instructions: Please respond to each of the following questions regarding information about yourself, your CF, and your college experience. Select the option(s) that best fits your experience. If none of the options apply, specify under "other". Thank you for your participation.

Please keep in mind that in order to participate in this study you must have Cystic Fibrosis, be between 18 and 35 years old, and you must be an undergraduate college student OR have attended college within the last 10 years. If you do not fit these criteria, you will be prompted to discontinue participation in the study.

If you are a college graduate or attended some college, please answer these questions from the perspective of yourself when you were in college.

1. **Age:** _____
If you are under 18 or over 35, please discontinue taking this survey.

2. **Student Status:**
   First-year (Freshman)
   Second-year (Sophomore)
   Third-year (Junior)
   Fourth-year (Senior)
   Fifth-year or beyond
   Graduate student
   I attended some college
   I am a college graduate

   If you are not an undergraduate college student or have not attended college, please discontinue taking this survey.

3. If you are a college graduate, what year did you graduate? _____

4. If you attended some college, approximately how many terms did you attend and what year was your last year of attendance? _____ _____

5. **Gender:**
   Female
   Male
   Transgender
   Genderqueer or gender non-conforming
   Other (Please specify): _____

6. **Race/Ethnicity:**
   African American or Black
   American Indian or Alaska Native
   Asian American or Asian
   Hispanic or Latinx
   Middle Eastern
   Multiracial
   Native Hawaiian or Other Pacific Islander
   Pacific Islander
   White
   Other (Please specify): _____

7. **How tall are you?** (If you are a college graduate or attended some college, please estimate how tall you were while you were in college) _____

8. **How much do you weigh?** If you are a college graduate or attended some college, please estimate how much you weighed while you were in college) _____

9. **What was your FEV1% value at your most recent CF clinic visit?** (If you are a college graduate or attended some college, please estimate your average FEV1% value while you were in college) _____

10. **Do you have any major medical condition(s) unrelated to your CF (For example, a heart condition or cancer)?**
    Yes (Please specify):
    No

11. **Cystic Fibrosis – Age of Diagnosis:**
    In utero/before birth
    0-4 weeks old
    1-5 months old
    6 months-1 year old
    1-4 years old
    5 years or older
    I don't know when I was diagnosed

12. **Cystic Fibrosis – Please select which of the following treatments are prescribed or recommended for you by your CF care team.**
    Airway clearance (vest treatments)
    Nebulized medications (including antibiotics)
    Enzymes (For example, Creon, Zenpep, etc.)
    Nutritional supplements (For example, Boost, Kate Farms, Ensure, etc.)

Gastrostomy tube (G-tube) feedings
Insulin
Exercise program
Other(s) (Please specify): _____

13. **Cystic Fibrosis – On average, how successful have you felt in completing your treatment regimen on a day-to-day basis in the last month?** Please rank each on a scale from 1-5, using the following scale:

Not at all Successful	**Often Not Successful**	**Sometimes Successful**	**Often Successful**	**Very Successful**
1	**2**	**3**	**4**	**5**

_____ Airway clearance (vest treatments)
_____ Nebulized medications (including antibiotics)
_____ Enzymes (For example, Creon, Zenpep, etc.)
_____ Nutritional supplements (For example, Boost, Kate Farms, Ensure, etc.)
_____ Gastrostomy tube (G-tube) feedings
_____ Insulin
_____ Exercise program
_____ Other(s) (Please specify): _____

14. **Cystic Fibrosis – Transplant and Surgery History:**
Please list (and explain if necessary) your transplant and/or surgical history related to your CF.
_____

15. **Cystic Fibrosis – Approximately how many times has your CF care team prescribed antibiotics for you to take at home to treat a pulmonary exacerbation? _____**

16. **Cystic Fibrosis – Approximately how many times have you been hospitalized for a pulmonary exacerbation? _____**

17. **College – Have you transferred to your current college/university from another school?**
Yes
No

18. **College – Are you currently receiving any special services, support, or circumstances as a result of your CF?**
Academic (Please specify):
_____

Living (Please specify):
_____
Health (Please specify):
_____
Other (Please specify):
_____

19. **College – Please select your living arrangements while you are attending school.**
    Living on-campus with a roommate/roommate(s)
    Living on-campus alone
    Living off-campus with a roommate/roommate(s)
    Living off-campus alone
    Living off-campus with caregivers/family
    Other (Please specify): _____

20. **College – Approximately how many miles do you live from home (in other words, the home where your caregivers reside or the home where you grew up)?**
    <10 miles
    10-30 miles
    30-60 miles
    60-90 miles
    90-120 miles
    >120 miles

21. **College – What type of college/university are you currently attending?**
    Public
    Private
    2-year
    4-year or above

22. **College – How many students attend your college/university?**
    < 2,500 students
    2,500 – 4,999 students
    5,000 – 9,999 students
    10,000 – 19,999 students
    20,000 students or more

Appendix B: Stigma Scale-Revised (SS-R)

Please read each statement carefully before answering. If you are a college graduate or attended some college, please answer these questions from the perspective of yourself when you were in college. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Never	Not Often	Sometimes	Often	Very Often
1	2	3	4	5

___ 1. How often do you feel different from other people because you have cystic fibrosis?

___ 2. How often do you feel people may not like you if they know you have cystic fibrosis?

___ 3. How often do you feel other people are uncomfortable with you because of your cystic fibrosis?

___ 4. How often do you feel people may not want to be friends with you if they know you have cystic fibrosis?

___ 5. How often do you feel people would not want to go out with you or ask you to parties if they know you have cystic fibrosis?

___ 6. How often do you feel embarrassed about your cystic fibrosis?

___ 7. How often do you keep your cystic fibrosis a secret from others?

___ 8. How often do you try to avoid talking to other people about your cystic fibrosis?

Appendix C: Cystic Fibrosis Disclosure Questionnaire (CFDS)

People with CF have different groups of people that they may feel comfortable informing about their diagnosis. We want to know which people in your life know about your CF. For the questions below, please indicate whether all, some, or none of each of these groups know that you have CF.

For those groups of people who know about your CF, we would like to know how comfortable you are discussing your CF with them and doing your treatments in front of them. On a scale of 1 to 10, where 1 is not at all comfortable, 10 is completely comfortable, and 5 is somewhere in between (somewhat comfortable), please indicate how comfortable you are engaging in the following CF-related activities with the specified audience.

If you have never been in a position where you needed to do your treatments in front of a particular group, please choose your answer by thinking about how you might feel in this situation. Remember, there are no right or wrong answers to these questions. If you are a college graduate or attended some college, please answer these questions from the perspective of yourself when you were in college.

FRIENDS

1. **Do your close friends know that you have CF?**
   Yes, all of them.
   Yes, some of them.
   No, none of them. (Skip to question #2)

Rate your overall comfort in…	1 Not at all comfortable	2	3	4	5 Somewhat comfortable	6	7	8	9	10 Completely comfortable
…discussing your CF experience with your close friends.										
…using your nebulized medications (including antibiotics) in front of your close friends.										
…taking your enzymes (for example Creon, Zenpep, etc.) in front of your close friends.										

2. **Do your casual friends/acquaintances know that you have CF?**
   Yes, all of them.
   Yes, some of them.
   No, none of them. (Skip to question #3)

Rate your overall comfort in…	1 Not at all comfortable	2	3	4	5 Somewhat comfortable	6	7	8	9	10 Completely comfortable

…discussing your CF experience with your casual friends or acquaintances.										
…using your nebulized medications (including antibiotics) in front of your casual friends or acquaintances.										
…taking your enzymes (for example Creon, Zenpep, etc.) in front of your casual friends or acquaintances.										

SPOUSE/ROMANTIC PARTNER

3. **Does your current spouse/romantic partner know that you have CF?**
   Yes.
   No. (Skip to question #4)
   I do not have a spouse/romantic partner. (Skip to question #4)

Rate your overall comfort in…	1	2	3	4	5	6	7	8	9	10
	Not at all comfortable				Somewhat comfortable				Completely comfortable	
…discussing your CF experience with your current spouse/romantic partner.										
…using your nebulized medications (including antibiotics) in front of your current spouse/romantic partner.										
…taking your enzymes (for example Creon, Zenpep, etc.) in front of your current spouse/romantic partner.										

WORKPLACE

4. **Does your current boss know that you have CF?**
   Yes.
   No. (Skip to question #5)
   I am not currently working. (Skip to question #6)

Rate your overall comfort in…	1	2	3	4	5	6	7	8	9	10
	Not at all comfortable				Somewhat comfortable				Completely comfortable	
…discussing your CF experience with your current boss.										
…using your nebulized medications (including antibiotics) in front of your current boss.										

…taking your enzymes (for example Creon, Zenpep, etc.) in front of your current boss.										

5. **Do your current coworkers know that you have CF?**
   Yes, all of them.
   Yes, some of them.
   No, none of them. (Skip to question #6)

Rate your overall comfort in…	1	2	3	4	5	6	7	8	9	10
	Not at all comfortable				Somewhat comfortable				Completely comfortable	
…discussing your CF experience with your current coworkers.										
…using your nebulized medications (including antibiotics) in front of your current coworkers.										
…taking your enzymes (for example Creon, Zenpep, etc.) in front of your current coworkers.										

SCHOOL

6. **Do your current professors know that you have CF?**
   Yes, all of them.
   Yes, some of them.
   No, none of them. (Skip to question #7)

Rate your overall comfort in…	1	2	3	4	5	6	7	8	9	10
	Not at all comfortable				Somewhat comfortable				Completely comfortable	
…discussing your CF experience with your current professors.										
…using your nebulized medications (including antibiotics) in front of your current professors.										
…taking your enzymes (for example Creon, Zenpep, etc.) in front of your current professors.										

7. **Do your current classmates know that you have CF?**
   Yes, all of them.
   Yes, some of them.
   No, none of them. (Skip to question #8)

Rate your overall comfort in…	1	2	3	4	5	6	7	8	9	10
	Not at all comfortable				Somewhat comfortable				Completely comfortable	
…discussing your CF experience with your current classmates.										

…using your nebulized medications (including antibiotics) in front of your current classmates.										
…taking your enzymes (for example Creon, Zenpep, etc.) in front of your current classmates.										

LIVING

8. **Do your current roommates know that you have CF?**
   Yes, all of them.
   Yes, some of them.
   No, none of them. (Go on to the next questionnaire)
   I live with family and/or I do not currently have roommates (Go on to the next questionnaire)

Rate your overall comfort in…	1	2	3	4	5	6	7	8	9	10
	Not at all comfortable				Somewhat comfortable				Completely comfortable	
…discussing your CF experience with your current roommates.										
…using your nebulized medications (including antibiotics) in front of your current roommates.										
…taking your enzymes (for example Creon, Zenpep, etc.) in front of your current roommates.										

Appendix D: Self-Compassion Scale (SCS)

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. If you are a college graduate or attended some college, please answer these questions from the perspective of yourself when you were in college. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost Never				**Almost Always**
1	**2**	**3**	**4**	**5**

_____ 1. I'm disapproving and judgmental about my own flaws and inadequacies.

__ ___ 2. When I'm feeling down I tend to obsess and fixate on everything that's wrong.

_____ 3. When things are going badly for me, I see the difficulties as part of life that everyone goes through.

_____ 4. When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.

_____ 5. I try to be loving towards myself when I'm feeling emotional pain.

_____ 6. When I fail at something important to me I become consumed by feelings of inadequacy.

_____ 7. When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am.

_____ 8. When times are really difficult, I tend to be tough on myself.

_____ 9. When something upsets me I try to keep my emotions in balance.

_____ 10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.

_____ 11. I'm intolerant and impatient towards those aspects of my personality I don't like.

_____ 12. When I'm going through a very hard time, I give myself the caring and tenderness I need.

_____ 13. When I'm feeling down, I tend to feel like most other people are probably happier than I am.

_____ 14. When something painful happens I try to take a balanced view of the situation.

_____ 15. I try to see my failings as part of the human condition.

_____ 16. When I see aspects of myself that I don't like, I get down on myself.

_____ 17. When I fail at something important to me I try to keep things in perspective.

_____ 18. When I'm really struggling, I tend to feel like other people must be having an easier time of it.

_____ 19. I'm kind to myself when I'm experiencing suffering.

_____ 20. When something upsets me I get carried away with my feelings.

_____ 21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.

_____ 22. When I'm feeling down I try to approach my feelings with curiosity and openness.

_____ 23. I'm tolerant of my own flaws and inadequacies.

_____ 24. When something painful happens I tend to blow the incident out of proportion.

_____ 25. When I fail at something that's important to me, I tend to feel alone in my failure.

_____ 26. I try to be understanding and patient towards those aspects of my personality I don't like.

Appendix E: Cystic Fibrosis Questionnaire-Revised (CFQ-R)

Please note this is a copyrighted instrument and the first page is included here only to provide a sample of the questions asked (per the author's request). The instrument should not be published based on the copyright information.

Understanding the impact of your illness and treatments on your everyday life can help your healthcare team keep track of your health and adjust your treatments. For this reason, this questionnaire was specifically developed for people who have cystic fibrosis. Thank you for your willingness to complete this form.

Instructions: The following questions are about the current state of your health, as you perceive it. This information will allow us to better understand how you feel in your everyday life. Please answer all the questions. There are **no** right or wrong answers! If you are not sure how to answer, choose the response that seems closest to your situation. If you are a college graduate or attended some college, please answer these questions from the perspective of yourself when you were in college.

QUALITY OF LIFE. Please check the box indicating your answer.
During the past two weeks, to what extent have you had difficulty…?

	A lot	Some	A little	No
1. …performing vigorous activities such as running or playing sports.				
2. …walking as fast as others.				
3. …carrying or lifting heavy things such as books, groceries, or school bags.				
4. …climbing one flight of stairs.				
5. …climbing stairs as fast as others.				

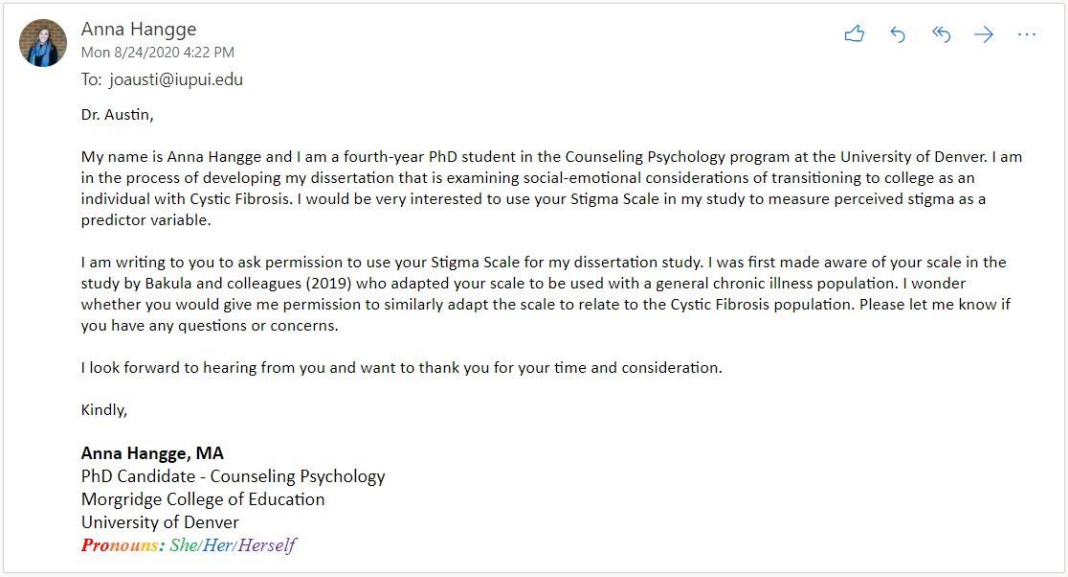
During the past two weeks, indicate how often…	Always	Often	Sometimes	Never
6. …you felt well.				
7. …you felt worried.				
8. …you felt useless.				
9. …you felt tired.				
10. …you felt energetic.				
11. …you felt exhausted.				
12. …you felt sad.				

Please select the box indicating your answer. Please choose only one answer for each question. Thinking about the state of your health over the last two weeks…

13. To what extent do you have difficulty walking?
    - You can walk a long time without getting tired.
    - You can walk a long time but you get tired.
    - You cannot walk a long time because you get tired quickly.
    - You avoid walking whenever possible because it is too tiring for you.

Appendix F: Consent to Use Instruments

Stigma Scale-Revised (SS-R)



Anna Hangge
Mon 8/24/2020 4:22 PM
To: joausti@iupui.edu

Dr. Austin,

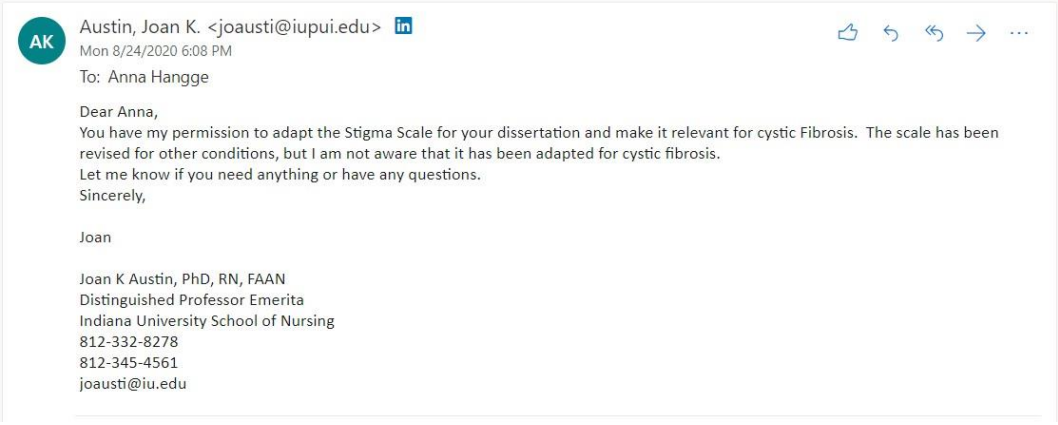
My name is Anna Hangge and I am a fourth-year PhD student in the Counseling Psychology program at the University of Denver. I am in the process of developing my dissertation that is examining social-emotional considerations of transitioning to college as an individual with Cystic Fibrosis. I would be very interested to use your Stigma Scale in my study to measure perceived stigma as a predictor variable.

I am writing to you to ask permission to use your Stigma Scale for my dissertation study. I was first made aware of your scale in the study by Bakula and colleagues (2019) who adapted your scale to be used with a general chronic illness population. I wonder whether you would give me permission to similarly adapt the scale to relate to the Cystic Fibrosis population. Please let me know if you have any questions or concerns.

I look forward to hearing from you and want to thank you for your time and consideration.

Kindly,

Anna Hangge, MA
PhD Candidate - Counseling Psychology
Morgridge College of Education
University of Denver
Pronouns: *She/Her/Herself*



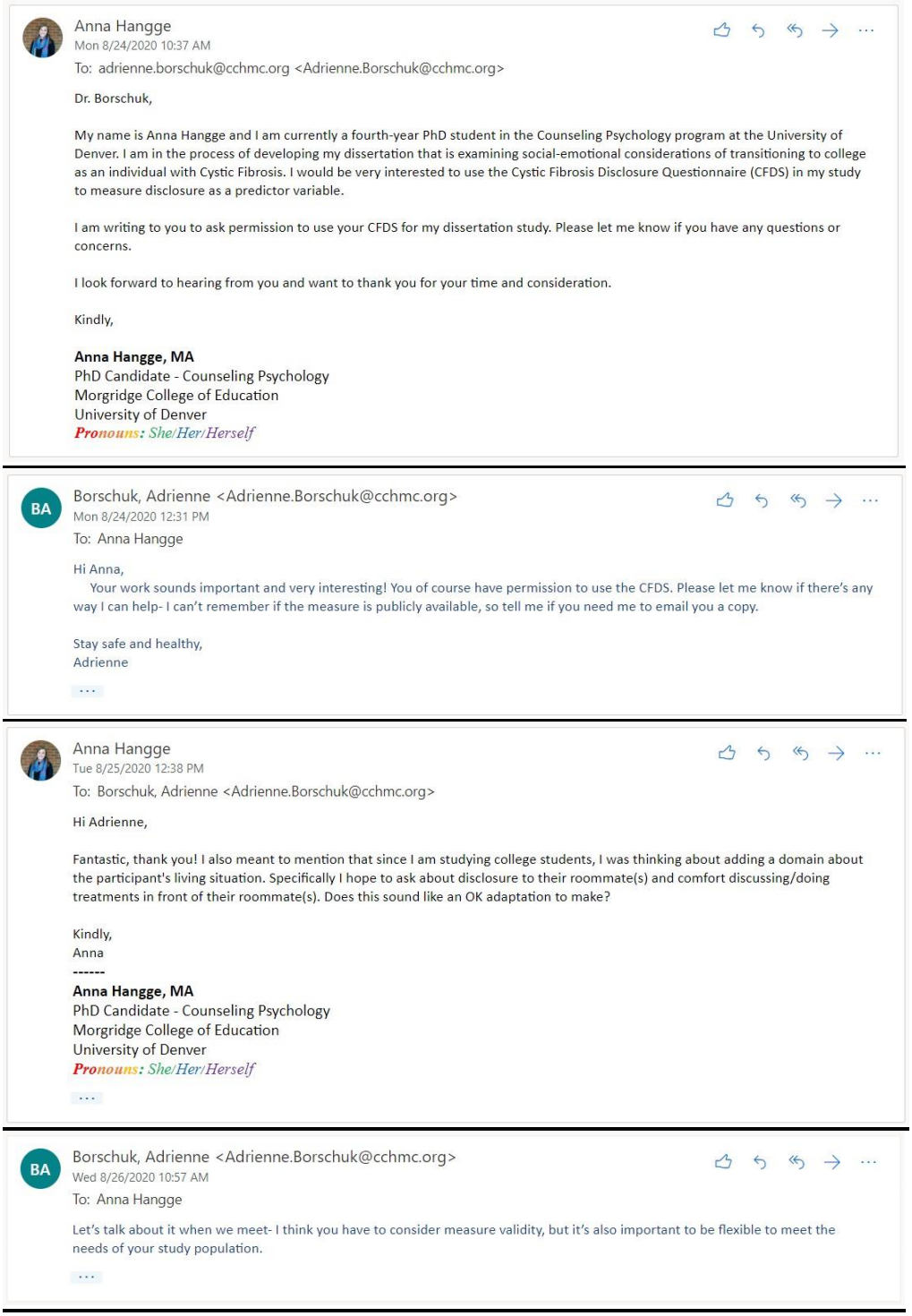
AK
Austin, Joan K. <joausti@iupui.edu>
Mon 8/24/2020 6:08 PM
To: Anna Hangge

Dear Anna,
You have my permission to adapt the Stigma Scale for your dissertation and make it relevant for cystic Fibrosis. The scale has been revised for other conditions, but I am not aware that it has been adapted for cystic fibrosis.
Let me know if you need anything or have any questions.
Sincerely,

Joan

Joan K Austin, PhD, RN, FAAN
Distinguished Professor Emerita
Indiana University School of Nursing
812-332-8278
812-345-4561
joausti@iu.edu

Cystic Fibrosis Disclosure Questionnaire (CFDS)



Anna Hangge
Mon 8/24/2020 10:37 AM
To: adrienne.borschuk@cchmc.org <Adrienne.Borschuk@cchmc.org>

Dr. Borschuk,

My name is Anna Hangge and I am currently a fourth-year PhD student in the Counseling Psychology program at the University of Denver. I am in the process of developing my dissertation that is examining social-emotional considerations of transitioning to college as an individual with Cystic Fibrosis. I would be very interested to use the Cystic Fibrosis Disclosure Questionnaire (CFDS) in my study to measure disclosure as a predictor variable.

I am writing to you to ask permission to use your CFDS for my dissertation study. Please let me know if you have any questions or concerns.

I look forward to hearing from you and want to thank you for your time and consideration.

Kindly,

Anna Hangge, MA
PhD Candidate - Counseling Psychology
Morgridge College of Education
University of Denver
Pronouns: *She/Her/Herself*

BA
Borschuk, Adrienne <Adrienne.Borschuk@cchmc.org>
Mon 8/24/2020 12:31 PM
To: Anna Hangge

Hi Anna,
Your work sounds important and very interesting! You of course have permission to use the CFDS. Please let me know if there's any way I can help- I can't remember if the measure is publicly available, so tell me if you need me to email you a copy.

Stay safe and healthy,
Adrienne

...

Anna Hangge
Tue 8/25/2020 12:38 PM
To: Borschuk, Adrienne <Adrienne.Borschuk@cchmc.org>

Hi Adrienne,

Fantastic, thank you! I also meant to mention that since I am studying college students, I was thinking about adding a domain about the participant's living situation. Specifically I hope to ask about disclosure to their roommate(s) and comfort discussing/doing treatments in front of their roommate(s). Does this sound like an OK adaptation to make?

Kindly,
Anna

Anna Hangge, MA
PhD Candidate - Counseling Psychology
Morgridge College of Education
University of Denver
Pronouns: *She/Her/Herself*

...

BA
Borschuk, Adrienne <Adrienne.Borschuk@cchmc.org>
Wed 8/26/2020 10:57 AM
To: Anna Hangge

Let's talk about it when we meet- I think you have to consider measure validity, but it's also important to be flexible to meet the needs of your study population.

...

*Permission was ultimately granted verbally during a meeting via Zoom.

Self-Compassion Scale (SCS)

To Whom it May Concern:

Please feel free to use the Self-Compassion Scale in your research. Masters and dissertation students also have my permission to use and publish the Self-Compassion Scale in their theses.

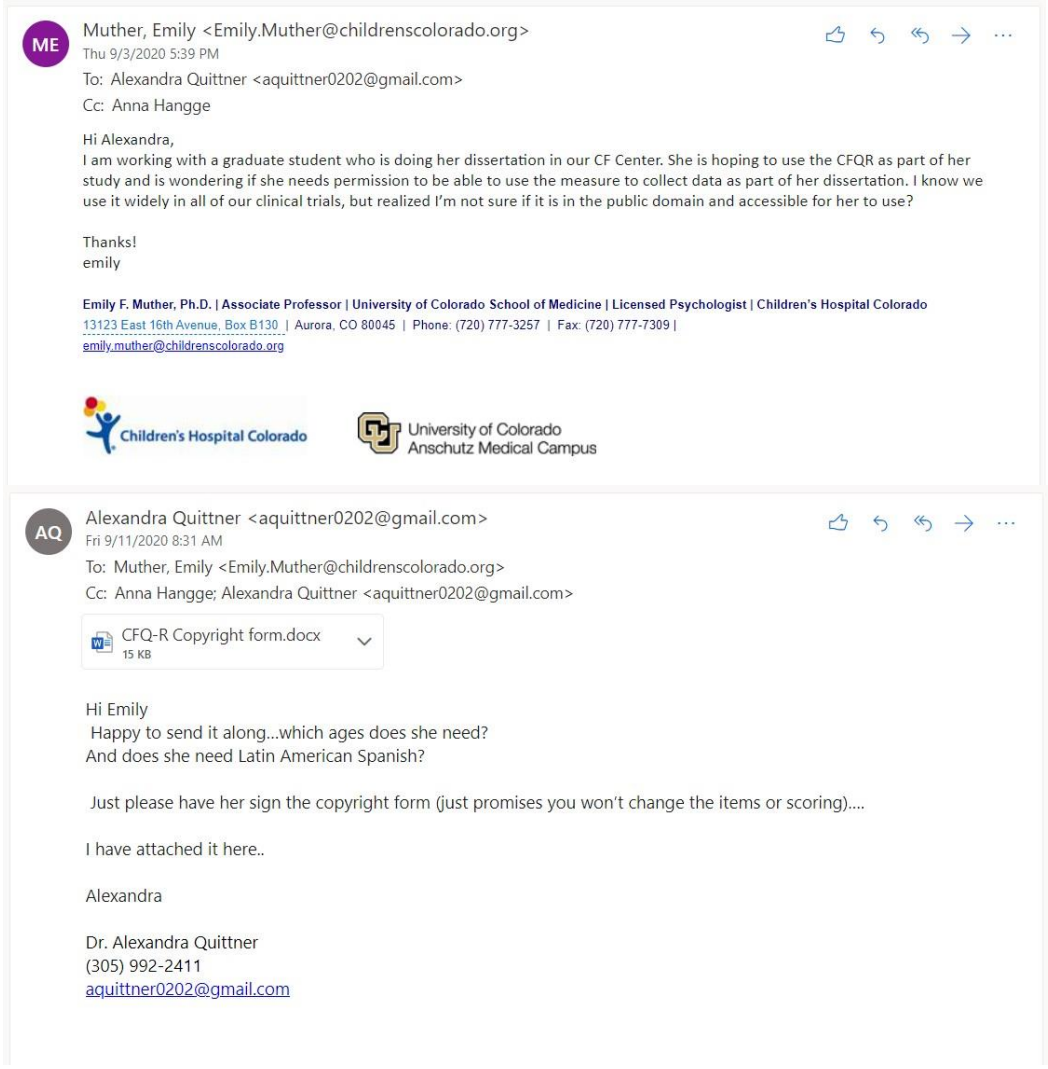
The appropriate reference is listed below.

Best,
Kristin Neff, Ph. D.
Associate Professor
Educational Psychology Dept.
University of Texas at Austin
e-mail: kneff@austin.utexas.edu

Reference:

Neff, K. D. (2003). Development and validation of a scale to measure self-compassion. *Self and Identity, 2, 223-250.*

Cystic Fibrosis Questionnaire-Revised (CFQ-R)



ME

Muther, Emily <Emily.Muther@childrenscolorado.org>
Thu 9/3/2020 5:39 PM
To: Alexandra Quittner <aquittner0202@gmail.com>
Cc: Anna Hangge

Hi Alexandra,
I am working with a graduate student who is doing her dissertation in our CF Center. She is hoping to use the CFQR as part of her study and is wondering if she needs permission to be able to use the measure to collect data as part of her dissertation. I know we use it widely in all of our clinical trials, but realized I'm not sure if it is in the public domain and accessible for her to use?

Thanks!
emily

Emily F. Muther, Ph.D. | Associate Professor | University of Colorado School of Medicine | Licensed Psychologist | Children's Hospital Colorado
13123 East 16th Avenue, Box B130 | Aurora, CO 80045 | Phone: (720) 777-3257 | Fax: (720) 777-7309 |
emily.muther@childrenscolorado.org

Children's Hospital Colorado

University of Colorado
Anschutz Medical Campus

AQ

Alexandra Quittner <aquittner0202@gmail.com>
Fri 9/11/2020 8:31 AM
To: Muther, Emily <Emily.Muther@childrenscolorado.org>
Cc: Anna Hangge; Alexandra Quittner <aquittner0202@gmail.com>

CFQ-R Copyright form.docx
15 KB

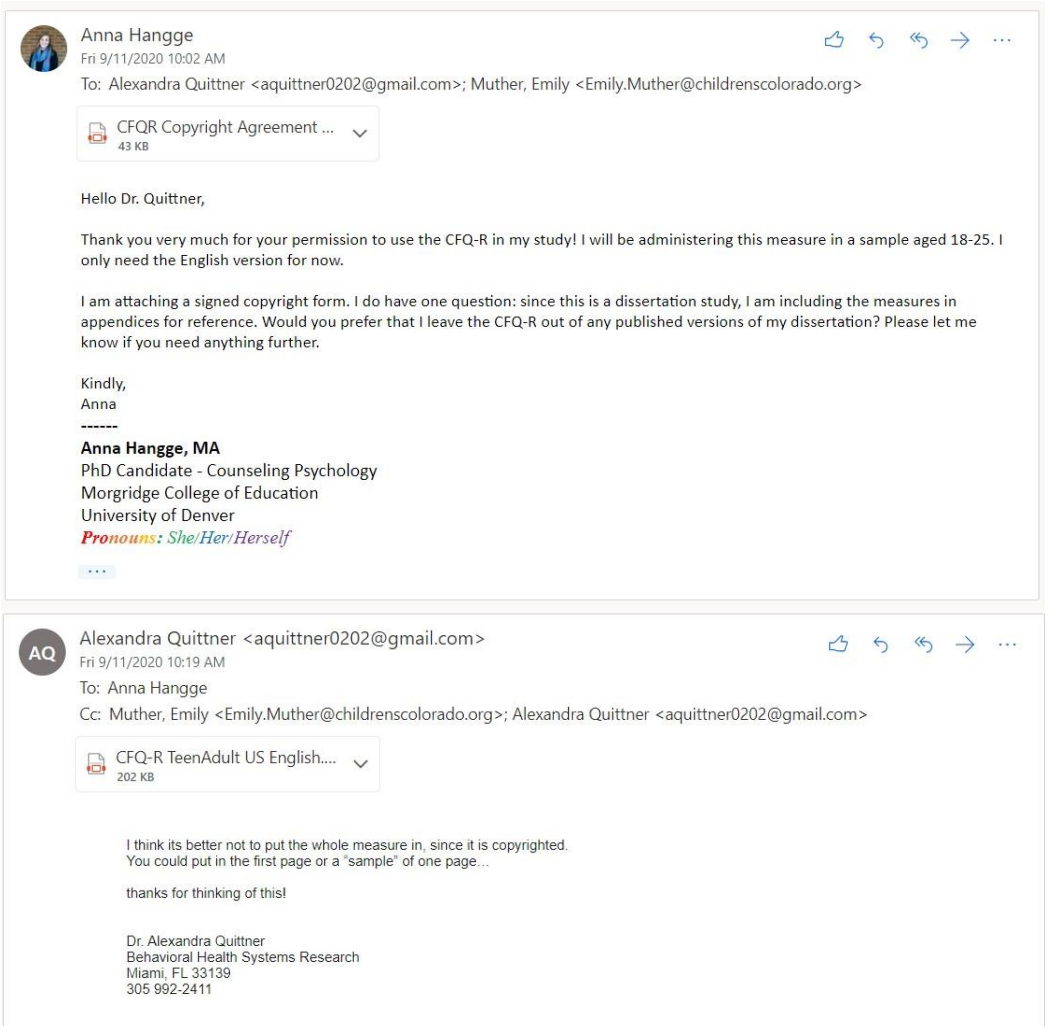
Hi Emily
Happy to send it along...which ages does she need?
And does she need Latin American Spanish?

Just please have her sign the copyright form (just promises you won't change the items or scoring)....

I have attached it here..

Alexandra

Dr. Alexandra Quittner
(305) 992-2411
aquittner0202@gmail.com



Anna Hangge
Fri 9/11/2020 10:02 AM

To: Alexandra Quittner <aquittner0202@gmail.com>; Muther, Emily <Emily.Muther@childrenscolorado.org>

CFQR Copyright Agreement ...
43 KB

Hello Dr. Quittner,

Thank you very much for your permission to use the CFQ-R in my study! I will be administering this measure in a sample aged 18-25. I only need the English version for now.

I am attaching a signed copyright form. I do have one question: since this is a dissertation study, I am including the measures in appendices for reference. Would you prefer that I leave the CFQ-R out of any published versions of my dissertation? Please let me know if you need anything further.

Kindly,
Anna

Anna Hangge, MA
PhD Candidate - Counseling Psychology
Morgridge College of Education
University of Denver
Pronouns: *She/Her/Herself*

...

Alexandra Quittner <aquittner0202@gmail.com>
Fri 9/11/2020 10:19 AM

To: Anna Hangge
Cc: Muther, Emily <Emily.Muther@childrenscolorado.org>; Alexandra Quittner <aquittner0202@gmail.com>

CFQ-R TeenAdult US English....
202 KB

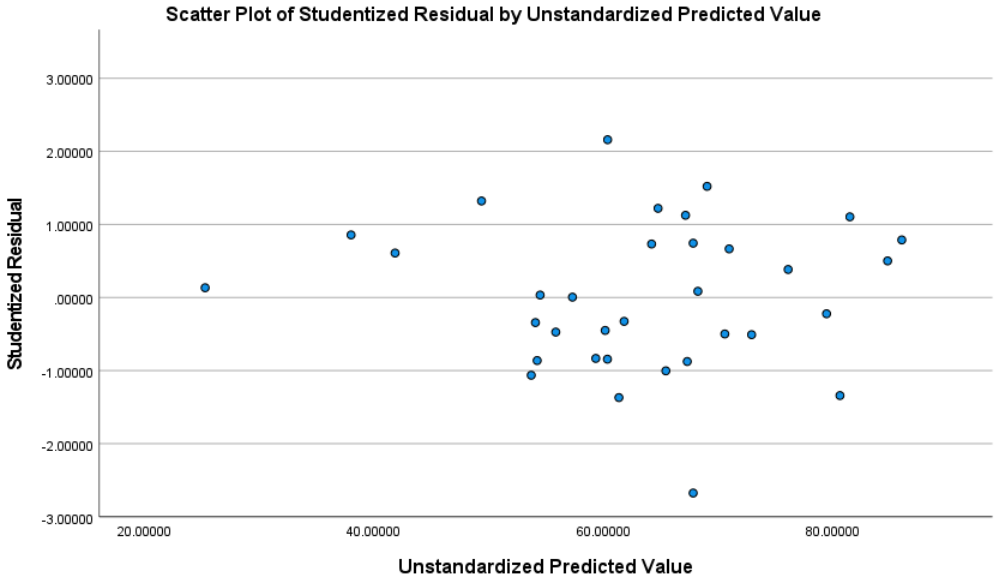
I think its better not to put the whole measure in, since it is copyrighted.
You could put in the first page or a "sample" of one page…

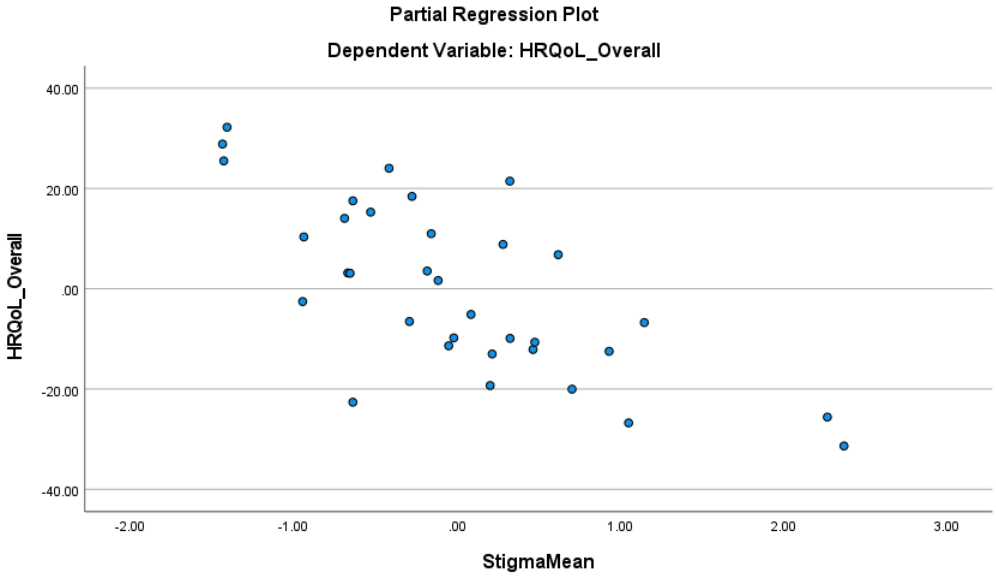
thanks for thinking of this!

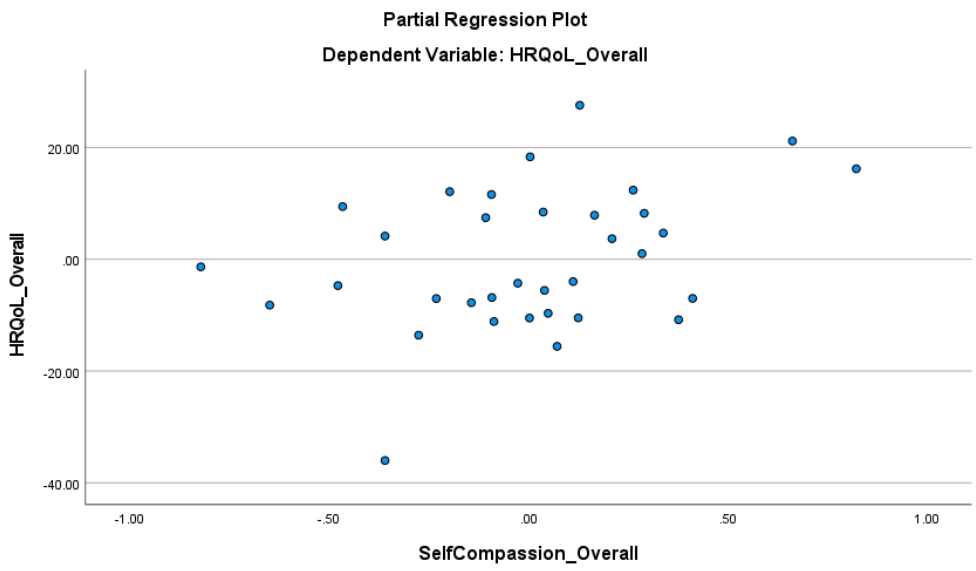
Dr. Alexandra Quittner
Behavioral Health Systems Research
Miami, FL 33139
305 992-2411

Appendix G: Assumptions Testing for Multiple Linear Regression

Assumption #4 and #5







Assumption #6

Correlations

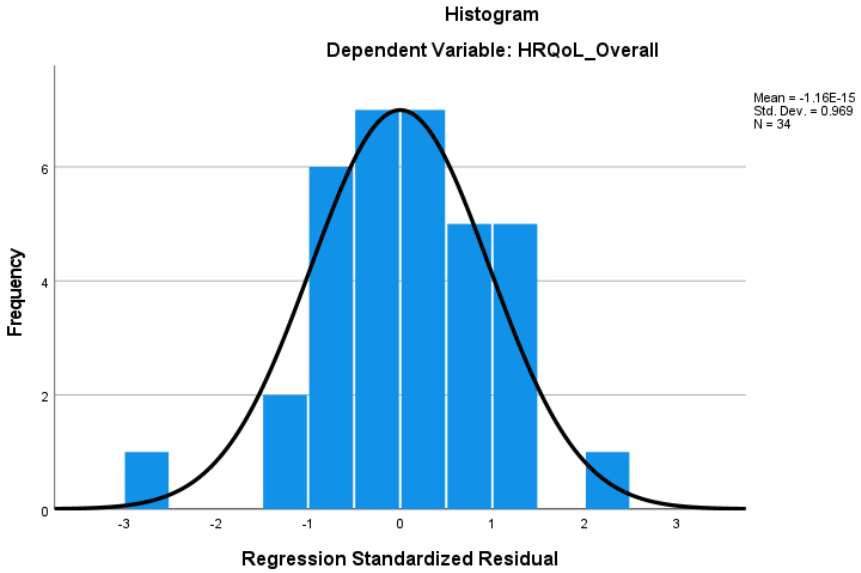
		HRQoL_Overall	StigmaMean	SelfCompassion_Overall
Pearson Correlation	HRQoL_Overall	1.000	-.695	.228
	StigmaMean	-.695	1.000	.030
	SelfCompassion_Overall	.228	.030	1.000
Sig. (1-tailed)	HRQoL_Overall	.	<.001	.097
	StigmaMean	.000	.	.433
	SelfCompassion_Overall	.097	.433	.
N	HRQoL_Overall	34	34	34
	StigmaMean	34	34	34
	SelfCompassion_Overall	34	34	34

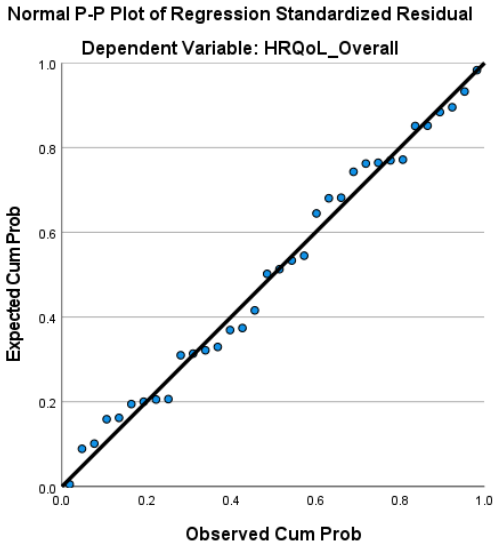
Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	63.014	19.042		3.309	.002	24.177	101.851					
	StigmaMean	-13.814	2.380	-.703	-5.804	<.001	-18.668	-8.960	-.695	-.722	-.703	.999	1.001
	SelfCompassion_Overall	12.724	6.177	.249	2.060	.048	.126	25.323	.228	.347	.249	.999	1.001

a. Dependent Variable: HRQoL_Overall

Assumption #8





Appendix H: Tables for Correlation and Regression Findings

Pearson Correlation

Correlations

		StigmaMean	SelfCompassion_Overall	HRQoL_Overall
StigmaMean	Pearson Correlation	1	.030	-.695**
	Sig. (2-tailed)		.866	<.001
	N	34	34	34
SelfCompassion_Overall	Pearson Correlation	.030	1	.228
	Sig. (2-tailed)	.866		.194
	N	34	34	34
HRQoL_Overall	Pearson Correlation	-.695**	.228	1
	Sig. (2-tailed)	<.001	.194	
	N	34	34	34

**. Correlation is significant at the 0.01 level (2-tailed).

Model Summary for Multiple Linear Regression

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.739[a]	.546	.516	12.24014	1.924

a. Predictors: (Constant), SelfCompassion_Overall, StigmaMean

b. Dependent Variable: HRQoL_Overall

ANOVA for Multiple Linear Regression

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	5580.536	2	2790.268	18.624	<.001[b]
	Residual	4644.454	31	149.821		
	Total	10224.991	33			

a. Dependent Variable: HRQoL_Overall

b. Predictors: (Constant), SelfCompassion_Overall, StigmaMean

Coefficients for Multiple Linear Regression

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	63.014	19.042		3.309	.002	24.177	101.851					
	StigmaMean	-13.814	2.380	-.703	-5.804	<.001	-18.668	-8.960	-.695	-.722	-.703	.999	1.001
	SelfCompassion_Overall	12.724	6.177	.249	2.060	.048	.126	25.323	.228	.347	.249	.999	1.001

a. Dependent Variable: HRQoL_Overall

Appendix I: Institutional Review Board (IRB) Approval Documents

UNIVERSITY of DENVER
OFFICE OF RESEARCH & SPONSORED PROGRAMS
Research Integrity & Education

DATE:	May 19, 2021
TO:	Anna Hangge, MA [Faculty Sponsor]
FROM:	University of Denver (DU) IRB
PROJECT TITLE:	[1733446-1] Stigma, Disclosure, and Self-Compassion as Predictors of Health-Related Quality of Life in New College Students with Cystic Fibrosis
SUBMISSION TYPE:	NEW **STUDENT PROJECT**
APPROVAL DATE:	May 19, 2021
NEXT REPORT DUE:	May 19, 2022
RISK LEVEL:	Minimal Risk
CHILD RISK ASSESSMENT:	45 CFR 46.404
REVIEW TYPE:	Expedited Review
ACTION:	**APPROVED**
REVIEW CATEGORY:	Expedited Category # 7
	Category 7: *Research on group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.*

Thank you for your submission of the New Project materials for this project. The University of Denver Institutional Review Board (IRB) has granted Full Approval for your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission. The IRB determined that the criteria for IRB approval of research, per 45 CFR 46.111, has been met.

UNIVERSITY of DENVER

OFFICE OF RESEARCH & SPONSORED PROGRAMS
Research Integrity & Education

DATE:	August 27, 2021
TO:	Anna Hangge, MA
FROM:	University of Denver (DU) IRB
PROJECT TITLE:	[1733446-2] Stigma, Disclosure, and Self-Compassion as Predictors of Health-Related Quality of Life in New College Students with Cystic Fibrosis
SUBMISSION TYPE:	**AMENDMENT**
APPROVAL DATE:	May 19, 2021
NEXT REPORT DUE:	May 19, 2022
RISK LEVEL:	Minimal
REVIEW TYPE:	Expedited
ACTION:	**Approved**

Thank you for your submission of Amendment/Modification materials for this project. The University of Denver (DU) IRB has granted FULL APPROVAL of your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received an expedited review based on applicable federal regulations.

UNIVERSITY of DENVER
OFFICE OF RESEARCH & SPONSORED PROGRAMS
Research Integrity & Education

DATE:	November 12, 2021
TO:	Anna Hangge, MA
FROM:	University of Denver (DU) IRB
PROJECT TITLE:	[1733446-3] Stigma, Disclosure, and Self-Compassion as Predictors of Health-Related Quality of Life in New College Students with Cystic Fibrosis
SUBMISSION TYPE:	**AMENDMENT**
APPROVAL DATE:	November 12, 2021
NEXT REPORT DUE:	May 19, 2022
RISK LEVEL:	Minimal Risk
REVIEW TYPE:	Expedited Review
ACTION:	**APPROVED**

Thank you for your submission of Amendment/Modification materials for this project. The University of Denver (DU) IRB has granted FULL APPROVAL of your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received an Expedited Review based on applicable federal regulations.

UNIVERSITY of DENVER
OFFICE OF RESEARCH & SPONSORED PROGRAMS
Research Integrity & Education

DATE:	January 7, 2022
TO:	Anna Hangge, MA
FROM:	University of Denver (DU) IRB
PROJECT TITLE:	[1733446-4] Stigma, Disclosure, and Self-Compassion as Predictors of Health-Related Quality of Life in New College Students with Cystic Fibrosis
SUBMISSION TYPE:	**AMENDMENT**
APPROVAL DATE:	January 7, 2022
NEXT REPORT DUE:	May 19, 2022
RISK LEVEL:	Minimal Risk
REVIEW TYPE:	Expedited Review
ACTION:	**APPROVED**

Thank you for your submission of Amendment/Modification materials for this project. The University of Denver (DU) IRB has granted FULL APPROVAL of your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received an Expedited Review based on applicable federal regulations.

UNIVERSITY of DENVER

OFFICE OF RESEARCH & SPONSORED PROGRAMS
Research Integrity & Education

DATE:	January 25, 2022
TO:	Anna Hangge, MA
FROM:	University of Denver (DU) IRB
PROJECT TITLE:	[1733446-5] Stigma, Disclosure, and Self-Compassion as Predictors of Health-Related Quality of Life in New College Students with Cystic Fibrosis
SUBMISSION TYPE:	**AMENDMENT**
APPROVAL DATE:	January 25, 2022
NEXT REPORT DUE:	May 19, 2022
RISK LEVEL:	Minimal Risk
REVIEW TYPE:	Expedited Review
ACTION:	**APPROVED**

Thank you for your submission of Amendment/Modification materials for this project. The University of Denver (DU) IRB has granted FULL APPROVAL of your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received an Expedited Review based on applicable federal regulations.

UNIVERSITY of DENVER

OFFICE OF RESEARCH & SPONSORED PROGRAMS
Research Integrity & Education

DATE:	May 19, 2022
TO:	Anna Hangge, MA
FROM:	University of Denver (DU) IRB
PROJECT TITLE:	[1733446-6] Stigma, Disclosure, and Self-Compassion as Predictors of Health-Related Quality of Life in New College Students with Cystic Fibrosis
SUBMISSION TYPE:	Other
ACTION:	ACKNOWLEDGED
EFFECTIVE DATE:	May 19, 2021
NEXT REPORT DUE:	May 19, 2023

Thank you for contacting the DU IRB regarding this project. The University of Denver Institutional Review Board (IRB) has ACKNOWLEDGED your submission. No further action on submission 1733446-6 is required at this time.

The following items are acknowledged in this submission: the date for the Next Report Due has been extended.

We will retain a copy of this documentation and this correspondence for our records.

If you have any questions, please contact the University of Denver Human Research Protection Program (HRPP)/Institutional Review Board (IRB) at (303) 871-2121 or at IRBAdmin@du.edu. Please include your project title and IRBNet number in all correspondence with the IRB.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Denver (DU) IRB's records.