

PREGNANCY INTENTION AMONG WOMEN WITH CYSTIC FIBROSIS: A
THEORY OF PLANNED BEHAVIOR MODEL

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and hereby certify that, in their opinion, it is worthy of acceptance.

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Dedicated to the lives and in memory of those with Cystic Fibrosis, with special honors to the memory of J.D., S.V., and A.P., whose legacies are woven throughout this work.

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Chapter 1

Introduction

Cystic fibrosis (CF) is an autosomal genetically inherited disease; it is the most common genetic disorder among Caucasians. CF affects the respiratory system, gastrointestinal system and endocrine system. CF is a life-shortening disease that is often treated daily with an extensive and time-consuming regimen of oral and inhaled medications. CF patients often require inpatient hospitalizations and home antibiotic infusions, especially as the disease progresses. However, with the advent of new medications, survival of patients into adulthood has increased (Cystic Fibrosis Foundation [CFF], 2011). Recent advances have resulted in the first-ever medication that actually treats one of the genetic mutations that affects about four percent of the CF population (Food and Drug Administration [FDA], 2012). However, there is no definitive cure for all CF mutations.

As the median age of survival increases among individuals with CF, so do the needs of adults with CF. CF can longer be considered a “pediatric disease”. As the population of adults with CF continues to grow, new “adult” issues are becoming more prevalent. That is, these adult issues must be addressed by formal and informal care providers, such as those providing medical care for the unique physical needs of adults and those addressing the need for social and economic security in the form of relationships and careers. Among women with CF, the issue of family planning and sexual reproduction is becoming a more salient issue. According to the CFF (2012) the rate of pregnancies among women with CF continues to rise annually. In 2012, 249 women with CF reported pregnancies, compared to 137 in 1997 (CFF, 2012). Demographic information is limited and not available for this population. However, a recent epidemiological study of 119 women with CF, one of the largest to date of US women with CF, who were pregnant reported a mean age of 23.4 and 94.1% white/Caucasian (Schechter, Quittner, Konstan, Millar, Pasta, & McMullen, 2013). Another sample of 48 pregnant women with CF reported a mean age of 29.5 (Thorpe-Beeston,

Madge, Gyi, Hodson, & Bilton, 2013) and another study of 12 women reported a mean age of 28.9 at delivery (Burden, Ion, Chung, Henry, Downey, & Trinder, 2012).

Problem Statement

Pregnancy and motherhood can be a rewarding experience for women who are willing and able to provide physical, psychosocial and financial investments. Pregnancy among women with CF has many implications for the women's health, their social networks, and the children. Pregnancy among women with CF has been associated with more clinic visits, pulmonary exacerbations, and lower quality of life than compared to match health control subjects (Schechter et al., 2013). Nutritional needs increase during pregnancy and for women with CF and a preexisting malabsorption issue or cystic fibrosis related diabetes (CFRD) can jeopardize the health of the mother and fetus if not aggressively managed (Whitty, 2010).

The physical effects of pregnancy have a reciprocal and interrelated relationship with the psychosocial domain of women with CF. Furthermore, general statements about pregnancy's impact on women with CF may be difficult to apply since the genotype may affect the degree of disease severity and different genotypes have been linked to different pregnancy outcomes (Giacobbe et al., 2012). However, within the limited literature, some information has emerged regarding pregnancy among women with CF.

Healthcare costs increase for women with CF when they become pregnant. McMullen et al. (2006) reported that women with CF who were pregnant had more inpatient stays during pregnancy, required more disease management and CFRD treatment doubled compared to their baseline functioning. A decline in physical functioning during pregnancy may increase women's reliance on their social network for emotional, physical, and financial support. In fact, respiratory, physical functioning, vitality and health perception quality of life measures in women with CF who have had children are lower than healthy women (Schechter et al., 2013). Women with CF who have other children may also have to sacrifice caring for those children during pregnancy and depend on other resources and support (Cambridge,

2013). For women with CF who do not have access to adequate social resources, pregnancy can be an even greater challenge.

Despite the continual increase in pregnancies, the research surrounding sexual and reproductive health knowledge among women with CF has been greatly focused on biophysical aspects (Gage, 2012). Psychosocial research and knowledge is oftentimes limited to children and adolescents and factors associated with medication compliance. In order for a CF center to be accredited by the CF foundation, the center is required to provide psychosocial services from a social worker or psychologist. Despite this endorsement for the importance of a psychosocial perspective, there is a lack of research focusing on the psychosocial perspective on adults with CF, particularly from the social work perspective. In fact, this literature review did not yield a single publication from a social worker as first author on the topic of pregnancy among women with CF except for a systematic literature review written by this author (Gage, 2012). No other publications in social worker journals were located on the topic, either. To date, there is a single publication focused exclusively on the psychosocial effects of pregnancy and motherhood; this is a qualitative dissertation with a small sample size ($N=11$) not yet published in a peer-reviewed journal from a doctoral candidate in psychology (Cammidge, 2013).

Pregnancy and motherhood are not necessarily “problems” for women with CF. This research does not assume that pregnancy among women with CF is problematic nor does it aim to place any affective connotation on pregnancy among women with CF. However, the lack of research, particularly from a psychosocial perspective, limits the ability of professionals to work from an evidence base and little empirical evidence is known about this population.

Conceptual Framework

Gehlert and Bollinger (2012) argue that in comparison to orienting theories, health theories are more inclusive of all types of behaviors. They not only consider problematic behaviors; they consider all behaviors within the context of health (p. 125). Due to the

multiple dimensions of health within the issue of pregnancy intention among women with CF, this research may best be explored by using a theory of health behavior.

The Theory of Reasoned Action (TRA) has been one of the foremost health theories to inform the understanding of health behaviors. The TRA is an expectancy value model that considers how individuals' beliefs and values contribute to attitude development (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975). An extension of the TRA is the Theory of Planned Behavior (TPB); the TPB is different in that there is an additional concept in the TPB model. The TPB posits that human behavior, specifically intention of behavior, can be predicted by three different determinants based on beliefs: attitudes, subjective norms, and perceived behavioral control (Ajzen, 1991). The TPB has been a common theoretical framework used to study health behaviors. Pregnancy intention, as measured as an intention of behavior in the TPB model, may predict and provide an understanding of pregnancy and pregnancy intention among women with CF.

Significance

As treatments advance and more CF patients live longer lives, “adult” issues will become relevant to a growing numbers of patients. Recent pharmaceutical discoveries are lending hope for a cure, as well, as a new medication to treat the gene dysfunction is showing great promise with several types of mutations (Federal Drug Administration [FDA], 2012). With this rapid increase in the adult CF patient population comes a greater demand for knowledge to inform adult care. As the adult population increases, so do the abilities to sample subpopulations and their particular needs. Therefore, there is a need for research and there are increasing research opportunities, but still a significant gap remains in the literature.

Approaching pregnancy and motherhood can be a professional challenge for formal care providers of women with CF if there is not a significant knowledge base to inform practice. A base of knowledge is also valuable for the support network for women with CF. Any decline in the health of a woman with CF, as well as the effects of having a new child, has implications for women's social networks.

This study will contribute to the limited body of social work research in the area of CF. Working from the TPB model, this study will examine a variety of behavioral influences to identify what factors influence pregnancy intention among women with CF. A better understanding of the salient factors can inform and enhance interventions and approaches that clinical care teams provide for women with CF. This and future work can influence CF centers' policies and procedures in regards to pregnancy among women with CF.

Statement of purpose

This study examines the extent to which attitudes, subjective norms, and perceived behavioral control predict the pregnancy intention of women with CF. The purpose of this study is to answer the following research questions:

- 1) What are the contributions of attitudes, social norms, and perceived behavioral control for women with CF in predicting pregnancy intention and do external variables significantly contribute to the prediction of pregnancy intention?
- 2) What are the pertinent influential behavioral beliefs, specific referents, and perceived power factors that influence these attitudes, social norms, and perceived behavioral control?

The dependent variable is pregnancy intention (likely/unlikely); the independent variables are attitude (level of favorable attitude), behavioral beliefs, subjective norms (level of perceived normalcy of pregnancy), normative beliefs, perceived behavioral control (level of perceived control), and control beliefs. This inquiry will also evaluate related external variables, including demographics and CF health related quality of life.

Directionality

1. Attitudes, social norms, and perceived behavioral control for women with CF will predict pregnancy intention among women with CF.
2. There will be pertinent influential behavioral beliefs, specific referents, and perceived power factors that influence attitudes, social norms, and perceived behavioral control.

3. External variables, such as demographic factors, importance of religion and CF-related health status, will not significantly contribute to the prediction of pregnancy intention beyond attitudes, social norms, and perceived behavioral control.

Limitations and Delimitations

Women with CF may be influenced by social desirability when they report answers to questions regarding such a personal topic. Pregnancy intention may be no different in women with CF compared to the general population of women. Perceived health may also be a confounding factor since current health status may impact one's plans for the future, especially for those with more advanced disease and symptoms that impede everyday living activities.

Assumptions

The Theory of Planned Behavior makes several assumptions. As an expectancy-value model, the TPB assumes that people have the capacity to use rational thought to use their beliefs to form attitudes (Fishbein & Ajzen, 1975). First, the model assumes that attitudes, norms, and perceived behavioral control can predict behavioral intention and behavioral intention can predict the behavior (Fishbein & Ajzen, 2010; Ajzen, 1991). Salient beliefs are assumed to underlie and influence attitudes, subjective norms, and perceived behavioral control (Fishbein & Ajzen, 2010). A motivation to comply with social referents is assumed to mediate subjective norms (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975). Perceived power over obstacles is assumed to influence one's perception that she can overcome obstacles to accomplish or not accomplish a behavior (Fishbein & Ajzen, 2010). Finally, Perceived behavioral control will be influenced by an individual's perception of her historical performance of overcoming health related problems (Gehlert and Bollinger, 2012, p.128-130).

The research project assumes certain issues about the target population. First, the research project is based on the assumption that women with CF have thought about

pregnancy and parenthood. Additionally, the assumption is made that some women with CF desire to pursue pregnancy and parenthood.

Conclusion

The sparse research in the area of pregnancy among women with CF is significantly lacking and does not provide an adequate knowledge base for practice and the establishment of clinical care policies. However, despite this lack of knowledge, the adult population is rapidly increasing and such issues are becoming more prominent and important. In order to better understand the process of pregnancy decision-making, the TPB model is proposed as a framework for understanding any behavioral determinants. The TPB components are hypothesized to predict whether a woman with CF intends to become pregnant in the future and the results will inform care and support practice.

Chapter 2

Literature Review

The purpose of this study was to explore the pregnancy intention of women with CF using the theoretical constructs of the Theory of Planned Behavior (TPB). Herein, the description of CF is provided followed by literature exploring the physiological and psychosocial aspects of pregnancy and women with CF. Pregnancy intention among women with CF is compared to women with human immunodeficiency virus (HIV). Possible theoretical models are discussed and TPB is justified as the framework for the study and the constructs of TPB are applied to the behavioral intention of pregnancy.

Most literature was retrieved through a variety of databases, including Medline/Pubmed, CINAHL, and PsycINFO with PsycArticles, between October 2010 and April 2012. Further exploration included Google Scholar, hand searches of pertinent peer-reviewed journals (e.g. *Journal of Cystic Fibrosis*), and resources provided by the Cystic Fibrosis Foundation (CFF). The literature was periodically updated and then systematically searched again in April 2014.

Cystic Fibrosis

CF is a genetic disorder characterized by multiple body system dysfunctions (Strausbaugh & Davis, 2007). CF occurs due to mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) protein (Orenstein, 2003, p. 3). Even though advances in CF care have extended and improved the lives of CF patients over the last couple of decades, the median age for survival is still only 41.1 years of age (CFF, 2012). Due to this abnormality in the CFTR protein in patients with CF, chloride does not properly exit the cells and abnormal levels of sodium are absorbed by the cell (Orenstein, 2003, p. 3). These cellular abnormalities result in a thicker, stickier mucus in individuals with CF, which then obstructs the bronchial tubes, parts of the pancreatic and hepatic systems, and impacts digestive functions (Orenstein, 2003, p. 1). There are over 1,000 different CFTR mutations

that result in different CF phenotypes (Orenstein, 2003, p. 7). Therefore, disease symptoms may vary among CF patients depending upon their particular mutation.

Respiratory System. Although there does seem to be disease variability between mutations, overall the different gene mutations do not appear to correlate with variances in lung disease; this variability seems to be related to other genetic and environmental factors (Orenstein, 2003, p. 222). The respiratory system is a central focus of CF care since respiratory failure is the primary cause of death for patients with CF (Orenstein, 2003, p. 19). The upper respiratory tract may be abnormal in patients with CF, in that the sinuses may be atypical and patients with CF have a slightly higher incidence of nasal polyps (Orenstein, 2003, p. 27). However, respiratory problems are largely a result of mucus in the pulmonary system.

The respiratory system encounters a variety of harmful substances and the mucociliary escalator attempts to expel these pollutants by trapping them in mucus, then expelling them out the trachea and into the digestive track (Orenstein, 2003, p. 25). In patients with CF the mucociliary escalator cannot properly expel the mucus because the mucus in patients with CF is thicker and stickier (Orenstein, 2003, p. 26). Bacteria, viruses, and fungi have a greater chance to colonize and remain in the airway due to the abnormal mucus, reduced efficiency of the mucociliary escalator, and abnormalities in the respiratory tract (Orenstein, 2003, p. 27). Finally, the collection of mucus can obstruct airways, resulting in labored breathing and inflammation (Orenstein, 2003, p. 25). As a result of infection and inflammation, lung function progressively decreases as damage is incurred over time.

Gastrointestinal system. Many researchers have well documented the inextricable relationship between lung function and nutrition in patients with CF (e.g. Corey, McLaughlin, Williams, & Levison, 1988; Steinkamp & Wiedemann, 2002). Malnutrition is significantly related to poorer lung function and weight loss can have a concomitant decrease in lung function (Steinkamp & Wiedemann, 2002). Malnutrition can occur in a variety of

ways in a patient with CF, since malabsorption of fats and nutrients is diminished as a result of progressive damage and obstruction from abnormal mucus.

Just as the mucus obstructs and damages airways in the lungs, the same process occurs throughout other bodily systems. For example, the pancreas may lose some insulin producing abilities over time due to the obstruction of the pancreatic islets, resulting in cystic fibrosis related diabetes (CFRD) (Orenstein, 2003, p. 85). Patients with CF who have CFRD are usually insulin or medication dependent to manage their blood glucose. Pancreatic insufficiency is another possible result in patients with CF, although not all patients with CF will be pancreatic insufficient (Orenstein, 2003, p. 80).

Pancreatic insufficiency occurs when the pancreas is unable to excrete enzymes necessary for digestion; patients with CF are usually born pancreatic sufficient, but progressive damage from obstructed ducts tends to eventually create insufficiency (Orenstein, 2003, p. 81). Although there are intestinal cells that also excrete enzymes, digestion and absorption cannot usually be completed by the intestinal cells alone (Orenstein, 2003, p. 81). In particular, intestinal cells can only partially digest starches and protein and they cannot digest fats at all, resulting in malabsorption (Orenstein, 2003, p. 81). Fat malabsorption leads to difficulty gaining weight, a lack of essential fat-soluble vitamins and fatty acids, and abnormal bowel habits (Orenstein, 2003, p. 81).

Fat digestion may also be reduced if bile ducts are blocked by the abnormal CF mucus (Orenstein, 2003, p. 93). Prolonged obstruction to the bile ducts can result in the formation of scar tissue, which if severe, develops into liver cirrhosis (Orenstein, 2003, p. 93). Further complications can result if the patient with CF has an abnormal gallbladder and bile duct connecting the gallbladder and liver; this abnormality is less common and occurs in about one-third of the CF population (Orenstein, 2003, p. 95).

Although rare, some intestinal issues related to CF may require invasive interventions such as surgery. When supplemental enzymes are not taken with meals, digestion is difficult and bowel movements become large and sticky (Orenstein, 2003, p. 87). As a result,

constipation and bowel obstructions can occur or in extreme cases, and rectal prolapse and intussusception, which are instances where the bowel turns inside out, can result from passing the sticky and bulky stool (Orenstein, 2003, p. 88-89).

Compliance with medications can decrease the risk of developing extreme gastrointestinal problems; however the side effects of some medications can also create new issues. For example, some medications used in the treatment of CF relax part of the esophagus, which increases the chance of acid reflux (Orenstein, 2003, p. 91).

Gastroesophageal reflux is common in patients with CF and can be attributed to side effects of medications and the frequency of coughing (Orenstein, 2004, p. 91). Although the process is less understood, patients with CF may also produce more stomach acid than individuals who do not have CF, which may contribute to the greater incidence of reflux in the CF population (Orenstein, 2003, p. 92).

Treatment

Patients must adhere to regular medical care and treatment regimens in order to delay progression of CF. Johnson, Butler, Konstan, Morgan, and Wohl (2003) reported that CF centers that report some of the better cumulative lung function scores tend to see patients more often and prescribe oral and intravenous (IV) antibiotics more than do comparison sites. Rigorous daily treatments aim to thin and expel mucus, dilate airways, aid in nutrient absorption and manage symptoms. Daily regimens are time consuming; Sawicki, Sellers, and Robinson (2009) reported the average length of CF treatment regimens took 108 minutes a day. Treatment may also include inpatient hospitalizations, which are required for intensive management of infections and some patients with CF may be eligible for lung transplants. Time-consuming treatments are also financially costly; the average cost for care of a CF patient is \$48,000 a year (Ouyang, Grosse, Amendah, & Schechter, 2009). Even with the numerous medical interventions available, progression cannot be stopped and there is no cure for CF.

Routine care. Routine and daily treatment plans will vary among patients with CF and are dependent upon several variables, particularly the progression of lung disease, presence of CFRD, and status of pancreatic sufficiency. Several medications are recommended for daily use in order to maintain pulmonary function. Some medications, such as inhaled antibiotics, hypertonic saline, and dornase alfa, a medication used to thin mucus, are delivered through nebulizers (Flume et al., 2007). Bronchodilators, which open airways, are also administered via a nebulizer and are recommended for chronic use in the CF populations (Flume et al., 2007). Although support for efficacy is fair, inhaled and oral corticosteroids are also used in CF care (Flume et al., 2007). Despite common use of corticosteroids in CF care, it has many adverse effects and long-term use of such medications is discouraged (O’Sullivan & Freedman, 2009).

Non-pharmacological interventions are also utilized to maintain pulmonary health. Airway clearance techniques are used to “break-up” mucus in order for the patient to expel the mucus (O’Sullivan & Freedman, 2009). There are a variety of options, including chest percussion, which involves another individual beating on the back and chest of the patient; high frequency chest wall oscillation, which involves wearing an inflatable vest that compresses and releases the patient’s chest several times per second and positive expiratory pressure devices, which involve a sequence of breathing exercises (O’Sullivan & Freedman, 2009). However, there are a variety of airway clearance techniques and patients usually choose the best option for their needs. Regardless of the technique, they all require treatment times and they are usually required twice a day or more (O’Sullivan & Freedman, 2009).

A patient with CF is usually trying to meet nutritional needs several times a day; this is especially true for patients with CF who are pancreatic insufficient (Orenstein, 2003, p. 119). Nutrition is important for pediatric patients with CF, who are still developing, and is also important for adult patients with CF, as nutritional status often progressively declines concurrently with lung function (Marshall & Samuelson, 1998). Orenstein (2004) explains that there are three central aspects for CF nutrition: a diet high in calories, the use of

supplemental enzymes and frequent snacking, and vitamin supplements (p. 107). Enzymes must be taken with every meal, including snacks (Orenstein, 2003, p. 110). Along with supplemental enzymes and vitamins, supplemental salt intake may also be necessary, especially for patients who are very active. Since patients with CF excrete more salt in their sweat, they may be at risk for hyponatremia, a deficiency in the sodium and chloride electrolytes (Orenstein, 2003, p. 117).

In some patients, enzymes and dietary habits may not be enough to obtain sufficient nutrition. For these patients, interventions with appetite stimulants or tube feedings may be necessary (Orenstein, 2003, p. 126). Appetite stimulants are medications that increase a patient's desire to eat and are a less invasive option than tube feeds. Tube feedings can be administered through a nasogastric tube (NG tube), which is inserted through the nose and into the stomach or intestine; this option is oftentimes used temporarily due to the discomfort (Orenstein, 2003, p. 126). Tube feeds may also be administered via a surgically placed access point in the abdomen and are more of a long-term option for nutritional supplement (Orenstein, 2003, p. 127).

Intensive care. The majority of inpatient admissions for patients with CF are due to a pulmonary exacerbation, which is characterized by declining lung function tests and positive microbiology cultures (Orenstein, 2003, p. 131). Inpatient admission generally lasts about 14 days, the length of time it takes to administer a full course of IV antibiotics (Orenstein, 2003, p. 131). Patients who have the support and knowledge to receive their course of IV antibiotics at home may only be admitted for a day or only come in for a clinic visit. However, not all patients have the support, financial situations, or knowledge to administer home IV antibiotics. Although the cost of home IV antibiotics is significantly less than an inpatient stay, Thornton, Elliott, Tully, Dodd, and Webb (2004) reported that long-term health was better maintained in their sample of patients who received IV antibiotics in a hospital.

Transplant. End-stage lung disease can only be treated with lung transplant. However, not all patients are candidates for transplant and variables such as age, sex, lung function and infection, health of other bodily systems, history of treatment compliance and social support all impact candidacy for transplant (O’Sullivan & Freedman, 2009). Even though patients may be eligible for transplant, some patients may pass away before receiving new lungs (CFF, 2011). Although living-donor transplants are possible, most are cadaveric transplants (CFF, 2011). According to CFF (2011), about 90% of CF lung transplant recipients are alive one year after transplant, and about 50% are alive after five years.

Emerging treatments and the potential for a cure. In January of 2012, the U.S. Federal Drug Administration (FDA) approved the first ever medication to treat one of the CF gene mutations (FDA, 2012). However, it may impact other mutations, and clinical trials began in 2012 (CFF, 2012). Kalydeco® (ivacaftor) only treats a mutation that affects about four percent of the CF population and it is unknown if the medication will actually “cure” the genetic mutation or if the medication will have to be taken one’s entire life (FDA, 2012). Kalydeco® is a Class B drug based on initial animal studies; this classification indicates that the medication is not likely teratogenic (Vertex Pharmaceuticals, 2012).

Gender Differences in CF

The progression of CF differs by gender, both psychosocially and physiologically. Women with CF report lower quality of life scores than males with CF (Arrington-Sanders et al., 2006; Gee, Abbott, Conway, Etherington, & Webb, 2003). Researchers have suggested that normative gender roles affect how patients with CF approach self-care (Willis, Miller, & Wyn, 2001). For example, noncompliance with nutritional treatments, which in turn supports the feminine social expectation of a thin physical appearance, will result in malabsorption of food and eventual weight loss.

Women with CF have shorter life spans than that of men with CF (Rosenfeld, Davis, Fitzsimmons, Pepe, & Ramsey, 1997). Compared to their male counterparts, women with CF tend to have more rapid reduction in lung function (Demko, Byard, & Davis, 1995; Kaza,

Katz, Cumming, Frost, & Safdar, 2007). Additionally, they contract *Pseudomonas aeruginosa*, a low antibiotic susceptible bacteria (Demko et al., 1995), and have more acute pulmonary exacerbations (Block et al., 2006). Researchers have provided preliminary data supporting a hypothesis that women's increased estrogen levels during menstruation may increase viscosity of the mucus, resulting in more difficulty expelling mucus and increasing susceptibility to infection and disease exacerbation (Coakley et al., 2008).

Women with CF have a better chance at natural reproduction than men with CF. Approximately 98% of men with CF are infertile due to an incomplete vas deferens (Orenstein, 2003, p. 104). However, the ability for women with CF to reproduce more easily than men with CF presents different ethical dilemmas in the event of a pregnancy, especially an unplanned pregnancy. In the event of a pregnancy, women with CF must be concerned with the dual care of CF and pregnancy and the possible short and long-term physiological impacts (Edenborough et al., 2008).

Women with CF and Pregnancy

When women with CF become pregnant there are numerous complications and long-term implications to consider. As the lifespan of people with CF continues to improve, adult-centered care is becoming more important and as treatment and gene therapy advances, the population of adults with CF will continue to increase. Adult-centered care and knowledge of adult patients with CF will only grow in importance and demand. The consideration of certain adulthood developmental milestones such as family planning are becoming salient for more adult patients with CF and their care providers.

The gains in lifespan and longer quality of health have resulted in an increase in the prevalence of pregnancy and birth for women with CF (Odegaard et al., 2002). Two hundred and forty-nine women with CF were pregnant in 2012 (CFF, 2012); in comparison, women with CF were cautioned against having children as late as the 1980s (CFF, 2011). Despite the increase in pregnancy among women with CF, there is a deficit in sexual and reproductive health knowledge among women with CF (Gage, 2012).

Pregnancy and motherhood can be a rewarding experience for adults who are able to assume the responsibilities associated with parenthood. However, pregnancy and motherhood present a variety of short and long-term effects on the patient as well as the patient's family. Women with CF experience a variety of physiological effects during pregnancy (Whitty, 2010). Although pregnancy outcomes have improved, especially for women who have relatively good lung function prior to pregnancy, risks and implications for the patient and family remain (Odegaard et al., 2002; Gillet, De Braekeller, Bellis, & Durieu, 2002).

Managing CF requires a rigorous daily treatment regimen. As patients age and lung function eventually degrades, treatment needs increase. Furthermore, if pregnancy results in a decline in a patient's baseline lung function, treatment needs will further increase. During pregnancy, the teratogenic effects of some CF treatments will necessitate the cessation or substitution of some necessary medications.

Physiological outcomes. Many complications can accompany pregnancy, several of which are of particular concern to women with CF. Changes during pregnancy tend to be manageable for women without CF, but for women with CF the changes may result in varying and more severe complications. Caution must be taken in the presentation of generalized statements about the impact of pregnancy on women with CF, as genotype may affect the severity of disease and tolerance to pregnancy. Giacobbe et al. (2012) report that women with two copies of the Delta F508 mutation have an increased risk of pregnancy complicated by diabetes compared to women with only one copy.

Pregnancy among women with CF is related to a greater incidence of preterm labor and caesarean section (Thorpe-Beeston et al., 2013). Women with CF who have a lung function less than 60% FEV¹ should be counselled about pregnancy due to the increased likelihood of death before the child reaches her teenage years (Thorpe-Beeston et al., 2013). Furthermore, pregnancies after the first child tend to be much more difficult and risks of preterm delivery and poorer lung function increase (Ciavattini, Ciattaglia, Cecchi, Gagliardini & Tranquilli, 2012).

The usual adjustments in pulmonary function during pregnancy pose a risk for women with CF who already have suppressed respiratory systems (Whitty, 2010). In comparison to women with CF who do not become pregnant, women with CF have lower BMI values and a greater decrease in lung function (Gillet et al., 2002). This is especially true for women who have moderate and severe pulmonary disease, which is associated with more pregnancy complications than in women with mild pulmonary disease (Gilljam et al., 2000; Lau et al., 2011; Thorpe-Beeston et al., 2013). Nutritional needs increase in pregnancy and the maldigestion and malabsorption issues associated with CF can decrease the ability to reach those nutritional needs. In particular cystic fibrosis related diabetes (CFRD) can cause a serious complication during pregnancy (Whitty, 2010). Complications arise with lung transplantation, which is a potential treatment for CF patients (Whitty, 2010).

Women with CF who become pregnant need more health care which can be demanding as well as costly. For example, women with CF attend more outpatient appointments, have more frequent exacerbations requiring inpatient care and require more pharmacological interventions (McMullen et al., 2006). The treatment needs of women with CF who have CFRD increase during pregnancy, and women without CFRD may develop pancreatic insufficiency during pregnancy (Giacobbe et al., 2012; McMullen et al., 2006). Guidelines recommend women with CF who are pregnant are followed by a high-risk obstetrician in collaboration with the CF team.

Psychosocial outcomes. Ethical issues arise when a female patient with CF becomes pregnant. Some women with CF are aware of the ethical dilemma associated with having children despite their shortened lifespan (Johannesson, Carlson, Brucefors, & Hjelte, 1998). However, mothers with CF report they are encouraged to take care of their health and prepare as much as possible prior to pregnancy to achieve better health and longer lifespan (Cambridge, 2013). Despite these efforts, mothers with CF report feeling guilty over a shortened lifespan and the impact of their health on their ability to parent (Cambridge, 2013).

Ethical issues also center on the possibility of passing on the CF gene, and despite the option to have paternal genetic testing, the mother still has a chance to pass on the recessive CF gene (Edenborough et al., 2001). A number of parents of children with CF also have CF, in fact some parents are diagnosed with CF after their children are identified in newborn screening, illustrating the vast difference in disease severity among genotypes (Lomas & Fowler, 2010).

As the CF population ages, new needs will emerge. Depressive symptoms are more prevalent in the adult CF population compared to adults without CF (Riekert, Bartlett, Boyle, Krishnan, & Ran, 2007). Studies have reported a significant, but weak negative correlation between lower lung function and more depressive symptoms (Riekert et al., 2007). Mothers with CF also report an increased need for emotional support and discussions focused on lifestyle changes in care planning with their CF team (Cambridge, 2013).

Social support is important for the quality of life of CF patients. Women with CF are more likely to have a partner, a situation which has implications for planned and unplanned pregnancies (Besier, Schmitz, & Goldbeck, 2009). Spouses have been found to be important in the prevention of deterioration in health for CF patients (Edenborough et al., 2008; Tuchman & Gisone, 2010).

The effects of CF and CF treatments may challenge interpersonal relations, and the additional physical and emotional stress of pregnancy may impact the quality of these relationships. Mothers with CF have reported that family dynamics change after the birth of a child, bringing families closer together, though they also report feelings of guilt associated with a greater burden on their partners (Cambridge, 2013). Mothers with CF explain that their social support network, including family and friends, is important to maintaining their physical health and adhering to their treatment regimens and they draw on this support, as necessary (Cambridge, 2013).

Pregnancy Intention

Pregnancy intention is a concept widely used to measure women's access to sexual and reproductive health information and health services and has been utilized in health studies (e.g. Loutfy et al., 2009). In the United States, the National Survey of Family Growth (NSFG) collects retrospective, longitudinal trends of pregnancies; the terminology and definitions used for measurement of pregnancy intention are detailed in the NSFG methodology (Brown & Eisenberg, 1995, p. 22). The term *pregnancy intention* is oftentimes used in the context of unplanned or unintended pregnancies, but also includes planned pregnancies (Brown & Eisenberg, 1995, p. 22). *Planned pregnancy* is one that is wanted by the mother or a pregnancy that occurs later than the mother intended, whereas *unintended pregnancy* refers to those pregnancies that are mistimed or unwanted (Brown & Eisenberg, 1995, p. 22). *Mistimed pregnancies* are those that occur before the mother intends; that is, the mother plans to become pregnant in the future but the actual time of conception is earlier than the mother expected (Brown & Eisenberg, 1995, p. 22). *Unwanted pregnancies* include elective abortions and conceptions that were not wanted at any time (Brown & Eisenberg, 1995, p. 22). These definitions are based upon feelings at the time of conception, not at the time of birth.

This framework for measuring pregnancy intention has been criticized by a number of researchers (e.g. Sable, 1999; Santelli et al., 2003; Santelli, Duberstein Lindberg, Orr, Finer & Speizer, 2009). Klerman (2000) explains that the "time" aspect is ambiguous in the NSFG concept of *mistimed pregnancies*; that is they can include pregnancies that were inconvenient at the time of conception as well as pregnancies that caused significant changes in life course. As Sable explains (1999), mistiming of a pregnancy and wantedness of pregnancy can be misaligned in the NSFG model, in that mistiming is not necessarily equal to unwantedness of a pregnancy.

The wantedness of a pregnancy is also independent from pregnancy intendedness (Miller, Sable, & Csizmadia, 2008). Intendedness is related to deliberate and rational planning based on the desire to become pregnant (Miller et al., 2008). However, wantedness

is an affective component; it can be characterized by excitement at the prospect of having a baby (Fischer, Stanford, Jameson, & DeWitt, 1999).

The strict categories of pregnancy intention also fail to incorporate complex psychosocial factors. For example, the NSFG model ignores the importance of a woman's partner in the decision-making process (Sable, 1999). A significant other may contribute to a woman's attitude towards pregnancy or even a lack of defined attitude as in the case of pregnancy ambivalence. Pregnancy ambivalence has been correlated with poorer contraceptive use (Schwarz, Lohr, Gold, & Gerbert, 2007; Higgins, Hirsch, & Trussell, 2008), which may increase the risk for an unintended pregnancy.

Comparison to Pregnancy Intention among Women with HIV

There are a number of retrospective studies exploring predictors of pregnancy, and prospective studies exploring variables that are associated with future pregnancy, for women with HIV. A literature review of these studies was conducted, excluding samples outside of Western, industrialized nations, such as the United Kingdom, Canada, and the United States. Samples that were taken from these areas, but were composed mostly of HIV positive immigrant populations from Africa were also excluded.

CF and HIV have many similarities and differences in the context of pregnancy. Both can be passed to a child, though transmission differs and women with CF have more control through partner genetic-screening. However, advances in HIV treatment no longer guarantee vertical transmission of the disease from mother to child and if HIV is known prior to pregnancy or early in pregnancy, transmission can fall to a risk of less than 2% (Department of Health and Human Services [DHHS], 2014). Similar to women with CF, upward trends have been reported of women with HIV becoming pregnant (Rahangdahl et al., 2014).

Pregnancy desire among women with HIV appears to be similar to that of the general population, in that, past research has suggested that HIV status does not seem to affect the desire for childbearing among young women with HIV (Finocchario-Kessler, Sweat, et al., 2012; MacCarthy, Rasanathan, Fergusin, & Gruskin, 2012) and matched African-American

women with HIV and those uninfected reported no difference in the desire to have children (Wesley, 2003).

The most frequently reported, and often ranked the most important, indicator of pregnancy intention and/or desire was the influence of a woman's partner (Craft et al, 2007; De La Cruz, Davies, & Stewart, 2011; Kirshenbaum et al., 2004; Ogilvie et al., 2007; Siegel & Schrimshaw, 2000; Sowell, Murdaugh, Addy, Moneyham, & Tavokoli, 2002).

Furthermore, some studies suggested that the health care team may influence pregnancy decision-making among women with HIV (Craft, Delany, Bautista, & Serovich, 2007; Kirshenbaum et al., 2004). Despite the relative importance of their health care team's influence, women with HIV report that they have not discussed future pregnancy and motherhood with their health care providers (Finnocchario-Kessler, Bastos, et al., 2012) and they would like to have these discussions with their health care providers (Finnocchario-Kessler, Dariotis, et al., 2010). The partner's influence remained most frequently reported above all others despite some mentions of the health care team's impact.

The importance of a partner's influence on pregnancy is not a surprising finding, since conception will require the partner's consent and is generally the primary support person to a mother. In some studies, this was related or included with a variable measuring a woman's adherence to traditional gender-roles (Craft et al., 2007; Sowell et al., 2002). These studies suggested that women who held more traditional ideas about gender roles were more likely to intend or have had a pregnancy.

After the influence of a partner, several studies reported that the desire for motherhood influenced many women with HIV (Craft et al., 2007; D'Auria, Christian, & Miles, 2006; Kirshenbaum et al., 2004; Siegel & Schrimshaw, 2000). Women reported positive beliefs about motherhood and the rewards that came from becoming a mother. For example, Siegel and Schrimshaw (2001) explained that women with HIV reported that they expected becoming a mother would result in feelings of being "complete" and had positive

attitudes towards motherhood, that combined with a partnership and not having children, resulted in the main reasons for considering pregnancy.

From the same study by Siegel and Schrimshaw (2001), women believed they should not delay having a child, as they reported that they thought having a child earlier would lend to being better able to care for a child. Although it is unknown whether this is the reason that younger age is related to pregnancy among women with HIV, it was a common variable among studies (Bedimo-Rung, Clark, Dumestre, Rice, & Kissinger, 2005; Craft et al., 2007; Ogilvie et al., 2007; Stanwood, Cohn, Heiser, & Pugliese, 2007; Siegel & Schrimshaw, 2000). Age may impact many issues in relation to pregnancy, including prime childbearing age, social norms, poor use of contraception, etc. Therefore, as a variable for pregnancy intention is may be difficult to extrapolate its role and the studies rarely discussed reasons for younger age.

Two remaining themes from the literature were less frequently cited, but present in a few studies each. Religious and spiritual influences were influential in some studies of women with HIV. Kirshenbaum et al. (2004) identified childbearing in the context of religious values, while De La Cruz et al. (2011) and Wesley identified religious beliefs and practices as a correlate to the desire for motherhood. Siegel and Schrimshaw (2001) explained that women with HIV in their study justified pregnancy with religious beliefs, suggesting that faith in god would protect their child.

There are consistent variables among studies which have found to be associated with pregnancy intention: the presence of a partner, desire for motherhood, younger age, beliefs in traditional gender roles, and the influence of religious values. While comparing women with CF to women with HIV may lend to the knowledge base, there are a great number of differences in the populations and findings from women with HIV are not generalizable to women with CF.

Though the physiological research regarding women with CF and pregnancy is growing, there is still some unknown information. Women with CF who have mild lung

disease appear to fare the best during pregnancy (Thorpe-Beeston et al., 2013), however the effects on maternal mortality are still unclear and the weight of evidence is contradictory at this point for all women with CF (Ahluwalia, Hoag, Hadeh, Ferrin, & Hadjiliadis, 2014; Edenborough, Stableforth, Webb, Mackenzie, & Smith, 1995; Edenborough, Mackenzie, & Stableforth, 2000; Lau et al., 2011; Thorpe-Beeston et al., 2013). In order to ensure the best outcomes for each patient, early planning and interventions must occur. Ajzen and Fishbein (1975) suggest that intention is the best predictor of behavior, therefore understanding pregnancy intention among women with CF is important for providing support and necessary interventions to help patients achieve their best quality of life.

Theoretical Frameworks

The aim of this study is to examine intrinsic factors influencing pregnancy intention in women with CF. Cognitive aspects are the most proximal intrinsic behavioral determinants; therefore a model of understanding the cognitive factors that impact social behavior is most appropriate for the purpose of this study. Of the social cognitive models, the Social Cognitive Theory (SCT), Health Belief Model (HBM), and Theory of Reasoned Action (TRA)/Theory of Planned Behavior (TPB) are some of the most widely applied in health behavior research (Painter, Borba, Hynes, Mays, & Glanz, 2008).

Social Cognitive Theory. Social Cognitive Theory (SCT) posits that the *triadic reciprocity* (p. 18) model can explain human functioning, viewing it as an interaction between behavior, cognitions, and environment (Bandura, 1986). SCT outlines several basic capabilities of these factors that people use to navigate the world (Bandura, 1986). People utilize symbols to infer information, they are equipped with the ability to use forethought to be purposeful in action, people use vicarious learning to gain knowledge, they are able to self-regulate with personal standards, and they are capable of self-reflection to analyze and develop judgments about the world (Bandura, 1986). In turn, these capabilities are used to understand how people receive information regarding their health and to choose appropriate courses of action (Bandura, 1986).

Individuals interact with their world through mechanisms such as self-efficacy, which can be both a hindrance and a facilitative mechanism in goal attainment or personal change (Bandura, 1986). SCT explains that cognitions employed in the process of determining self-efficacy are anticipatory, meaning cognitions determining the perception of one's ability are created prior to action (Bandura, 1997). Anticipatory processes are developed through a variety of means; persons develop expectations from history, including the learned effects of certain behaviors, outcomes observed from others' behaviors and reactions to self-evaluation (Bandura, 1986). The culmination of these processes and the attitudes formed as a result are identified as perceived self-efficacy.

One's self-efficacious attitude toward a certain behavior will have a direct impact on one's motivation (Bandura, 1977). By using the human capabilities of self-evaluation, individuals are able to make judgments regarding future abilities for similar situations and establish a sense of self-efficacy for the type of situation (Bandura, 1977). An individual's sense of self-efficacy will directly affect one's motivation to pursue similar situational challenges.

Self-regulation is a set of skills for exercising control over variables that are manageable (Bandura, 1997). For example, affective self-regulation is the level of belief that people can manage their affect, which is an aspect of life that people can generally learn to control, unless there is a severe psychological dysfunction (Bandura, Caprara, Barbaranelli, Gerbino, & Pastorelli, 2003). Self-regulation plays an important role in motivation, because motivation relies on a system of self-evaluation and adjustment.

People tend to use self-regulation to navigate an activity and maintain motivation based on the self-evaluative judgments (Bandura, 1997). Bandura explains (1997) that individuals will estimate how much a behavior will cause a certain result; this is referred to as outcome expectations. Bandura (1997) stated, "... those who judge themselves highly efficacious will expect favorable outcomes, whereas those who expect poor performances of

themselves will conjure up negative outcomes” (p. 24). Therefore, Bandura (1997) suggests that self-efficacy, motivation, and outcome expectations will be predictive of behavior.

The application of SCT aims at changing and managing behavior (McAlister, Perry, & Parcell, 2008). SCT-based interventions are developed around the SCT principles of behavioral and social learning, self-regulation, and bolstering self-efficacy (McAlister et al., 2008). Within fertility research, SCT is often applied to contraception and increasing behaviors to prevent pregnancies (e.g. Chandra et al.). However, SCT is more widely applied to changing behaviors that contribute to chronic disease, such as heart disease; SCT has influenced the development of several well-known prevention programs aimed at reducing preventable chronic disease (McAlister et al., 2008).

For purposes of this study, a particular health behavior is not being targeted for change and the outcome variable being examined is *intent* and not *behavior*. Billari, Philipov, and Testa (2009) explain that measuring the birth of a child as a behavior does not account for, “... the complex sequence of acts that separates the decision to have a child from actual childbearing” (p. 443). There are several complex behaviors that are chosen in order to have a child, and therefore having a child cannot be simplified into one behavior. Schoen, Astone, Kim, Nathanson, and Fields (1999) demonstrated that intention to have a child are consistently and strongly correlated with future pregnancy behavior, and that certainty of intention has the greatest influence.

The Health Belief Model. The Health Belief Model (HBM) is a social cognitive framework that is used to understand and change health behaviors. Changing health beliefs, and therefore behaviors, has been the focus of HBM interventions (Rosenstock, 1966). The broad applicability and feasibility of HBM interventions have, in part, made HBM a popular framework for developing interventions that seek to change health behaviors.

The HBM postulates that beliefs and perceptions drive behaviors. Specifically, the model outlines the beliefs and perceptions related to risks and the associated benefits with decreasing those risks. Rosenstock, Strecher, and Becker (1988) suggest that several

concurrent factors must be in place for a behavioral change according to HBM. That is, there must be motivation to change, the acknowledgement of a possible health risk, and the recognition that a health behavior change will decrease the health risk.

According to Rosenstock (1966), these concurrent factors can be classified into four different perceptions, as well as a cue to act, and one's self-efficacy. The first major component of HBM is the concept of *perceived threat*, which is composed of two subcategories: *perceived susceptibility* refers to one's assessment of risk; that is, whether one believes he or she could be vulnerable to the disease (Rosenstock, 1966). *Perceived seriousness*, or *perceived severity*, is one's assessment of a disease's possible detriment; assessments can be based upon the degree of emotional reaction as well as the clinical and medical outcome possibilities (Rosenstock, 1966). The next major component incorporates *outcome expectations*, which are categorized as benefits or costs. *Perceived benefits and perceived costs* refer to how one assesses possible actions against the disease (Rosenstock, 1966). These are the assessments of the degree of benefit or cost making a change will yield (Rosenstock, 1966). The beliefs about certain actions to take for prevention or treatment will affect whether the person chooses to take the action (Rosenstock, 1966). While susceptibility and seriousness compel one to change his or her behavior and benefits and barriers are associated with how to change behavior, a *cue to act* is also a part of instigating change (Rosenstock, 1966). A cue is an event that will set off the behavioral change. For example, a heart attack may cue one to change her or his diet and exercise regimen. Furthermore, *self-efficacy*, or one's belief in his or her ability to make a change, may also moderate one's motivation and ability to implement change (Rosenstock, Strecher, & Becker, 1988).

Much like SCT, the HBM has also been applied in an effort to promote positive health behaviors. Also similar to SCT, fertility research using the HBM focuses on contraceptive use (e.g. Eisen, Zellman, & McAlister, 1992; Orr, Langefeld, Katz, & Caine, 1996). The interventions for increasing positive sexual health behaviors using HBM tend to be similar to the SCT in that they tend to target the four perceptions outlined in the HBM.

Champion and Sugg Skinner (2008) explain that HBM research has been limited by the variability in the measurement of these concepts and that they should be tailored to particular populations. Of the studies that have validated their measurements of HBM concepts, some have focused on promoting breast cancer screening and reducing risky sex behaviors (Champion & Sugg Skinner, 2008).

Although HBM extends beyond the constructs of SCT, it fails to incorporate the impact of the social environment's impact on individuals' health behaviors. Since this study aims to account for how others' perceptions may impact women's decision making, such as spouses and caregivers, the HBM model is not an appropriate framework for understanding and predicting pregnancy intention in women with CF. Much like the limitation to SCT, this study does not aim to change a behavior and therefore HBM is also not appropriate for that reason.

Theory of Reason Action and Theory of Planned Behavior. The Theory of Reasoned Action (TRA) shares basic constructs with SCT and HBM. TRA assumes that three components cause behavior. Beliefs influence one's *attitude* toward a certain behavior and combined with *social norms*, create *behavioral intent*, which precedes the actual behavior (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975). Contrasted to the HBM, the TRA incorporates the component of *social norms*, or how normative beliefs are established by one's social network and affect an attitude towards a behavior (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975).

Attitude. Attitude is an evaluative response to an object based on a bipolar continuum of positive to negative (Fishbein & Ajzen, 1975; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 2010). Fishbein and Ajzen (2010) suggest that attitudes have two underlying basic dimensions: instrumental/cognitive aspects and experiential/affective aspects. Instrumental or cognitive attitude aspects are those that reflect an individual's perception of whether the consequences of a behavior are positive or negative (Fishbein & Ajzen, 2010). Experiential or affective aspects are characterized by the positive or negative

experiences related with executing the behavior (Fishbein & Ajzen, 2010). Ajzen (1991b) explains that an attitude is relative to the summed product of the strength of each salient belief and one's subjective evaluation, resulting in a belief-based measure. This can be illustrated in the following equation:

$$A_b = \sum_{i=1}^n b_i e_i$$

A_b = the attitude

b_i = the individual's belief

e_i = the individual's evaluation of the outcome

n = the number of salient beliefs

Subjective Norms. Subjective norms are the guidelines influenced by social pressure that individuals use to influence whether they will perform a certain behavior (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975; Fishbein & Ajzen, 2010). Recently Fishbein and Ajzen (2010) have recognized that the initial formulation of subjective norms failed to fully encompass social pressure. Based upon other theoretical work, Fishbein and Ajzen (2010) suggest that subjective norms include injunctive as well as descriptive norms. Injunctive norms are the perceptions of what is socially acceptable or unacceptable based on an individual's social referents (Cialdini, Reno, & Kallgren, 1990). Injunctive norms are based on normative beliefs, which are similar to norms except that specific individuals, or referents, are identified in the belief. These beliefs are weighted with a "motivation to comply" with those specific referents (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 2010).

The motivation to comply is the degree to which an individual desires to obey the perceived social guidelines. However, Fishbein and Ajzen (2010) suggest that existing research has not supported a significant mediating impact of motivation to comply when asked about the specific behavior being measured. Instead, Fishbein and Ajzen (2010) suggest that researchers assess the weight of the referent's influence by asking about general levels of motivation to comply. However, since power may be domain-specific, such as a physician's influence on health beliefs, Fishbein and Ajzen (2010) suggest that some researchers may need to be domain-specific in this measurement. For purposes of this study,

referents who are important to the health and family planning domains may be better measures for the motivation to comply.

Descriptive norms are based on whether the individual thinks others are performing the behavior (Cialdini, Reno, & Kallgren, 1990). Whereas injunctive norms are based upon social agents that are specific to the individual, descriptive norms are based on generalized social agents (Fishbein & Ajzen, 2010). For purposes of this study, generalized social agents are specific to other women with CF. Weighing the influence of descriptive norms can potentially be measured by asking participants about their level of identification with the specific population (Fishbein & Ajzen, 2010).

By summing the products of the normative beliefs and motivation to comply, a belief-based measure of subjective norms can be calculated (Ajzen, 1991b). The components are included in the measure of subjective norms as illustrated in the following equation:

$$SN = \sum_{i=1}^n b_i m_i$$

SN = the subjective norm

b_i = the individual's belief

m_i = the individual's motivation to comply with referent

n = the number of referents

Perceived Behavioral Control. Ajzen and Madden (1986) proposed that the TRA did not account for individuals who may have a positive attitude toward a behavior and supportive social norms, but who are still unable to perform the behavior due to variables outside of their control. To account for this, *perceived behavioral control* was added to the model and renamed the Theory of Planned Behavior. Perceived behavior control is “the extent to which people believe that they are capable of performing a given behavior or attaining a certain goal” (Fishbein & Ajzen, 2010, p. 177). Perceived behavioral control encompasses both internal and external factors that contribute to individuals' assessment of their control over a behavior.

Fishbein and Ajzen (2010) identify two subcomponents of control: *capacity* and *autonomy*. Capacity is identified as the belief that one is capable of performing the behavior

or attaining the goal. Autonomy refers to the amount of control people perceive they have over the behavior or goal. *Control beliefs* influence the perception that barriers or facilitating circumstances will affect the individual's capability to perform the behavior (Ajzen, 1991). *Perceived power* is the individual's perception of the degree of challenge to achieving the behavior, given the barriers or facilitating circumstances (Ajzen, 1991).

Control beliefs and perceived power are calculated in the belief-based measure of perceived behavioral control by calculating the sum of the products across components.

$$PBC = \sum_{i=1}^n p_i c_i$$

PBC = perceived behavioral control
 p_i = the individual's perceived power
 c_i = the individual's control beliefs
 n = the number of salient beliefs

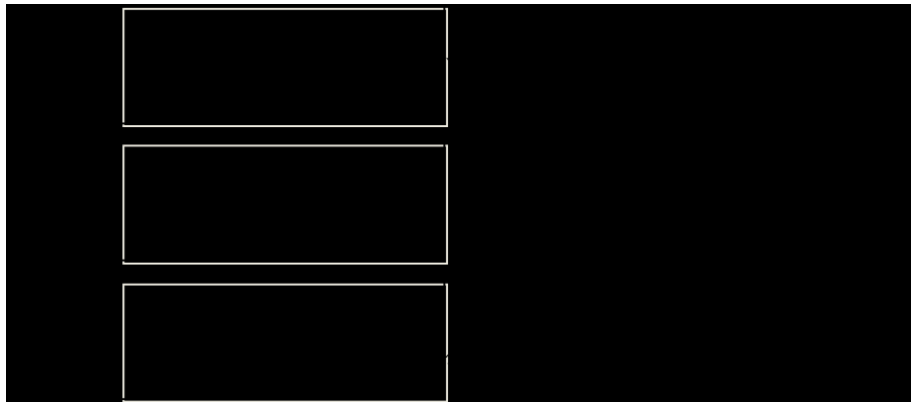


Figure 1. (Ajzen, 1991).

The Theory of Planned Behavior and CF

Perceived behavioral control is an especially significant variable in the analysis of pregnancy intention among women with CF. Schoen et al. (1999) explain that control may be mediated by factors from both within and outside an individual. Schoen et al. (1999) provide the example of fecundity as an internal limitation and an unwilling spouse as an external limitation (p. 791). As illustrated in this example, actual behavioral control influences the perception of control; fecundity will remove some or all of an individual's control over

pregnancy. Ajzen (1991) explains that perceived behavioral control is similar to the SCT concept of self-efficacy, and suggests that one’s perception of control is analogous to one’s belief in his or her ability to execute a behavior.

For patients with CF, control beliefs may be greatly influenced by their disease course. Ajzen (1991) explains that perceived behavioral control reflects, “... past experience as well as anticipated impediments and obstacles” (p. 188). While emerging-adulthood is a period of great excitement for most individuals, patients with CF have reported concerns related to finding medical specialists for management of their CF elsewhere, the impact of CF on relationships, the possibility of transplant, and a fear of dying young (Iles & Lowton, 2008). Furthermore, adults with CF are oftentimes forced into unemployment due to deteriorating health and demands of increased treatments (Blair et al., 1994). Although treatments may slow down the progression of disease, CF cannot be controlled and this fact may have a great impact on patients’ beliefs about their lives. Figure 2 illustrates how the TPB constructs will be applied to pregnancy intentions among women with CF.

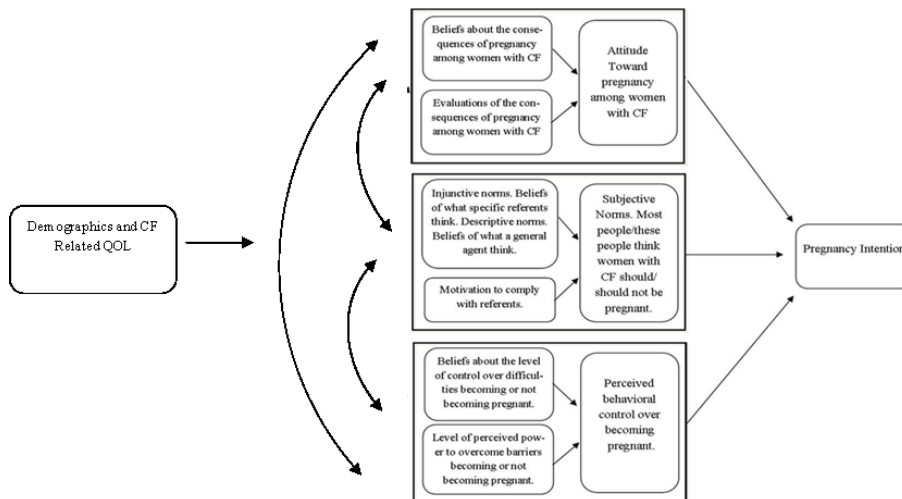


Figure 2.

Conclusion

The review of the literature revealed a major gap in the knowledge regarding the pregnancy intention of women with CF. Despite longer life spans of patients with CF and an increasing number of pregnancies among women with CF, little is known about the psychosocial factors that impact pregnancy decision-making among this special population. As treatments continue to improve and gene therapies are introduced, the lifespan of patients with CF is going to continue to lengthen and more patients with CF will be able to attain milestones in adulthood that were previously rare or impossible.

CF can have a range of impacts on one's physical functioning, which is interrelated and reciprocal to an individual's psychosocial functioning. Although the body of evidence regarding pregnancy among women with CF is growing, there still remains a significant deficiency in what is known about the psychosocial aspects. Providing comprehensive and holistic care to women with CF necessitates a basic understanding of the mechanisms underlying women's pregnancy decision-making. Because pregnancy may be detrimental to some women with CF and there are long-term psychosocial implications, understanding women's intention is important for reproductive counseling from CF care providers and reproductive health providers alike.

Despite differences in CF and HIV, the HIV population may lend information to the topic of pregnancy intention among women with a life-limiting, chronic disease. A number of predictors were identified in several studies on pregnancy intention among women with HIV. These predictors included: the presence or support of a partner, positive views of pregnancy in relation to motherhood, younger age, emphasis on traditional gender roles, and beliefs based on religious values.

Although there are a number of theoretical frameworks for understanding health behaviors, the Theory of Planned Behavior is the best model for this study. Social Cognitive Theory and the Health Belief Model are largely focused on changing an already established behavior; they are applied more frequently to fertility research that seeks to understand and

change contraceptive and sexual health practices. While the Theory of Reasoned Action is an appropriate fit, it does not include the variable of perceived behavioral control. For this population in the context of pregnancy intention, perceived behavioral control is an especially important variable. The Theory of Planned Behavior is the best fit with the aims of this study and the unique context.

Attitudes towards pregnancy may influence other affective aspects such as desire for a child. Although women with CF might assume that risks are minimal, there are several protocols that should be implemented in order for women with CF to have the best pregnancy she can have while protecting her own health. Women may understand some of the risks, but may not consider some of the longer-term implications such as the likelihood of having a shortened-lifespan and an increased dependency on others as CF progresses.

Some of the long-term implications may affect a CF patient's social support network. Spouses and significant-others have a substantial impact on pregnancy intention, however patients with CF require a great amount of support as the disease progresses. Support is necessary when women with CF require inpatient hospitalizations, whether for a few days or several weeks; this is especially true for mothers who may have children whom they must leave at home. CF care providers may also influence beliefs about pregnancy among women with CF.

Most individuals with CF are diagnosed in childhood and infancy. For patients with CF, living with a progressive, chronic disease may influence their perception of control in life and may also alter lifespan development. Whether these perspectives impact long-term life decisions, such as pregnancy intention, among women with CF is unknown.

Chapter 3
Methodology
Overview

The purpose of this study was to predict pregnancy intention among women with cystic fibrosis (CF) through the development, validation, and administration of a Theory of Planned Behavior (TPB)-based instrument using a cross-sectional study design. The goals of the study were to answer the following research questions: 1) What are the contributions of attitudes, social norms, and perceived behavioral control for women with CF in predicting pregnancy intention and do external variables significantly contribute to the prediction of pregnancy intention? 2) What are the pertinent influential behavioral beliefs, specific referents, and perceived power factors that influence these attitudes, social norms, and perceived behavioral control?

This mixed-methods research project consisted of two phases; formative qualitative research was conducted in an initial phase to inform the design of a quantitative survey instrument for the final phase. The quantitative survey instrument could not be completely designed until population-specific belief information was revealed through the formative research (Fishbein & Ajzen, 2010). During the formative research phase, I conducted elicitation interviews and the results from the elicitation interviews were analyzed and used to inform the primary research study in the final research phase. Once the quantitative survey instrument was designed, I pilot tested it and then distributed it to the larger population for data collection.

This process is illustrated in figure three and described, in detail, in this chapter.

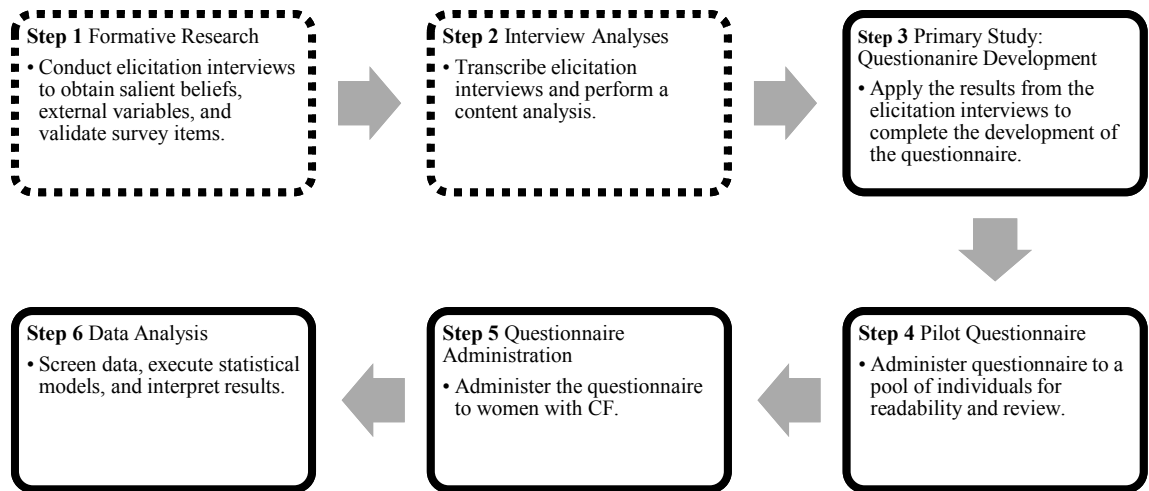


Figure 3. Study Process

Specifying the Research Population

The population of interest was women with CF who were age 18 and older at the time of the study and self-identified as “of childbearing age”, from the United States, read English, and have not had any biological children.

Protection of Human Subjects

I ensured the protection of human subjects by adhering to the study protocol (Project #1202657) approved by the University of Missouri Health Sciences Institutional Review Board (HSIRB). Human subjects included the patients participating in the formative research and those who completed the finalized survey questionnaire. There was minimal risk for human subjects participating in the study.

Instrument Development

Fishbein and Ajzen (2010) provide a detailed description of questionnaire construction using formative research to inform the final survey tool. Fishbein and Capella (2006) suggest that the uniqueness of behavior is based upon a population’s beliefs, which

can only be inferred from the responses of the target population. Therefore, a critical phase in the application of the TPB is to conduct elicitation interviews with people from the target population (e.g., women with CF) to identify the significant behavioral, normative, and control beliefs related to their pregnancy intention. From these responses, I identified salient beliefs and then developed a quantitative questionnaire for the primary study.

Formative Research

Individual semi-structured elicitation interviews were conducted with six individual females with CF who were age 18 and older. Although focus groups present many advantages, due to the infection control guidelines outlined by the CFF, individual interviews were required instead. Patients with CF are always encouraged to avoid contact with other patients with CF as much as possible in order to reduce the likelihood of passing harmful pathogens. The congregation of multiple patients with CF in a room together can increase the risk of pathogen transmission. Once they are colonized in a patient with CF, such pathogens may never be eradicated. Therefore, the CFF suggests patients with CF avoid meeting together and minimize the risk of cross contaminating others with CF. Furthermore, Fishbein and Ajzen (2010) warn against utilizing focus groups for identifying salient beliefs due to the risk of dominant participants promoting a rarely held belief.

Elicitation Interview Schedule.

The preliminary semi-structured interview schedule was based on the TPB constructs and included questions for possible direct measures as well as eliciting salient beliefs (Appendix B). These questions are modeled after Fishbein and Ajzen's elicitation interview protocol (see Fishbein & Ajzen, 2010, p. 451). The order of questioning started with broad, general questions and developed into more specific questioning. Participants were asked open-ended questions and prompted for additional information, when possible.

Attitudes: Outcome evaluation and behavioral beliefs. I first asked respondents about general questions regarding pregnancy. For the experiential attitude, women with CF were asked to comment on their positive or negative feelings about pregnancy. For example,

they were asked, “What are some of the reasons why people become pregnant?” Then I asked respondents more specific questions regarding CF such as, “What are some of the reasons why women with CF become pregnant?” In order to ascertain these feelings, participants were asked, “How do people feel about women with CF becoming pregnant?” Instrumental attitudes measured the positive or negative outcomes of a female patient with CF becoming pregnant. I asked participants to comment on benefits and disadvantages with separate questions. For example, to measure negative outcomes, I asked, “What are some reasons women don’t become pregnant?” I elicited positive outcomes from the question, “What are some reasons women with CF do become pregnant?”

Subjective Norms: Injunctive beliefs. I asked participants to identify the normative referents who influence their decision-making regarding pregnancy. Participants were asked to list the individuals or groups who would impact respondents’ pregnancy decision making. Questioning became more specific in order to identify injunctive normative referents. I asked respondents to identify “anyone else” who might have an opinion.

Perceived behavioral control: Control beliefs and perceived power. I asked respondents about perceived behavioral control in the similar general to specific questioning format. Respondents were asked, “What are some of the things that influence a woman’s decision to become pregnant?” and then “What are some of the things that influence women with CF to become pregnant?” Respondents speculated on how much control women have over becoming pregnant and then I asked the same question in relation to women with CF. Questioning narrowed to, “How much control do women with CF have over becoming pregnant?” I asked respondents to list any factors or circumstances that make it easy for women with CF to become pregnant and then to list any factors or circumstances that make it difficult.

External factors. I asked participants to contribute any other thoughts or comments they may have regarding the pregnancy intention of women with CF. I identified comments

and information that are external to the TPB constructs and consider them for inclusion in the standard questionnaire.

Sampling and Recruitment for Elicitation Interviews

I performed a nonprobability, purposive sampling of women with CF who attend an accredited CF center in the Midwest region of the United States. The sampling occurred with support and promotion from the CF social worker. During clinic visits, the CF social worker informed eligible women of the opportunity to participate and obtain permission for the primary investigator to contact those individuals. Women who were admitted for inpatient hospitalization were also informed of the opportunity to participate. With the patient's consent, I provided a detailed explanation of the study. A detailed informed consent form with contact numbers for additional information was reviewed with every patient who was interested in participating.

A purposive sample size was limited by eligible participants and participants' lack of interest. I employed snowball sampling techniques with participants, but did not receive any further referrals of interested patients. The number of eligible participants visiting clinic were scant in relation to the five months designated for interview recruitment. Patients with CF who feel well may not visit clinic very often or during a clinic visit they may be seeking care for symptoms related to their disease and thus may not feel well enough to participate. One interview participant commented that the length of the interview may impede interview recruitment, as well.

Data analysis

I collected data from six interviews using an audio recording device and destroyed all files once they were transcribed. Interviews were transcribed verbatim and imported into Dedoose® software for content analysis.

Primary Study Design

Preparing the Standard Questionnaire

Once the elicitation interviews were transcribed and analyzed, I completed the standard questionnaire. I validated all items constructed to directly assess the TPB constructs with the results of the elicitation interviews. Fishbein and Ajzen (2010) provide explicit instructions on question construction for each component and subcomponent of the TPB.

Definition and Measurement of Variables

Dependent variable. For purposes of this study, pregnancy intention, rather than pregnancy, was measured. The TPB suggests that intention is the strongest predictor of behavior as long as intentions “directly address the behavior of interest” (Fishbein & Ajzen, 2010, p.54). Recent research has indicated a highly significant correlation between pregnancy intention and pregnancy incidence (Chuang, Weisman, Hillemeier, Camacho & Dyer, 2009). Behavioral compatibility between the intention to become pregnant and becoming pregnancy are directly related; therefore behavioral incompatibility is not an issue for this study.

As discussed in Chapter 2, the common measurement of pregnancy intention has been established by the NSFG methodology. However, the NSFG methodology is a retrospective measure of intention following the delivery of a child, and this study aims to measure pregnancy intention before a pregnancy occurs. Therefore, pregnancy intention based on Chuang et al.’s (2009) prospective pregnancy intention definition, which encompasses pregnancies among women who consider a future pregnancy. Chuang et al.’s (2009) survey asks respondents: “Are you considering becoming pregnant within the next year, some other time in the future, or not at all” (p. 3). However, for purposes of this study the aim is only to measure any pregnancy intention for the future and the timeframe is specific only to one’s future. Fishbein and Ajzen (2010) suggest that the behavior of interest should be defined by “action, target, context, and time elements” (p. 29). Table one illustrates how pregnancy intention among women with CF is defined by these elements.

The behavior of interest was, therefore, the intention to become pregnant at any time in the future. I measured behavioral intention on a seven-point Likert scale (Very Likely to Very Unlikely), asking “How likely are you to try to become pregnant now or at any time in

the future?” I collapsed the seven response items into three categories: likely, undecided, and unlikely.

Table 1

Action, Target, Context, and Time Elements of the Behavior: Pregnancy Intention of Women with CF.

Action	Target	Context	Time
Intending	Pregnancy	The condition of CF.	Any time in the future

Table 1

Independent variables. This study design is composed of variables outlined by the TPB model, those identified as “theoretical variables” as well as other variables that are external to the model that are identified as “external variables”. The theoretical variables are conceptualized in detail in Chapter 2. External variables were derived from the elicitation interviews.

Ajzen (1991) explains that TPB variables are operationalized as both direct and indirect measures. Direct measures are items that directly ask participants to report their views on the respective component. Indirect measures are what Ajzen (1991) describes as “belief-based measures”; these measures account for the beliefs and corresponding subcomponent that essentially weights the belief. For example, the belief-based measure of subjective norms is determined by weighting normative beliefs with the motivation to comply. Belief-based measures are reported as a sum of the cross products of the salient beliefs and subcomponents. This procedure allowed me to test the hypothesized relationship between the two measures.

Attitude. Since attitude is a bipolar evaluation of the degree of favor or unfavorableness towards a concept, I evaluated direct measures using semantic differentials.

A semantic differential is a technique of measurement, which uses two polar adjectives to rate one's attitude. The adjectives tend not to be standardized, as a semantic differential is intended to be adapted to the context of particular research (Osgood, 1957, p. 76). I measured instrumental attitudes with a seven-point bipolar scale anchored by semantic differential terms such as "good" (+3) to "bad" (-3), "wise" (+3) to "foolish" (-3), and "beneficial" (+3) to "harmful" (-3). I asked women to respond to the stem, "For women with CF, becoming pregnant is..." with the aforementioned anchors.

Subcomponents: Evaluations and beliefs. Six clear attitudinal beliefs emerged from the elicitation interviews, which are explained in detail in Chapter 4. Fishbein and Ajzen (2010) suggest that a unipolar scale can measure belief strength (e.g. 1-7) and evaluations can be measured on a bipolar scale (e.g. -3 to +3). The beliefs were then multiplied by the outcome evaluation and resulted in the sum of the products.

Subjective norms. Using the same semantic differential approach applied to the other survey questions, I asked participants to respond to the prompt: "Most people who are important to me think I should become pregnant" with a seven-point bipolar scale anchored between "strongly agree" (+3) and "strongly disagree" (-3).

Subcomponents: Injunctive norms, motivation to comply, referents' influence. Results from the elicitation interviews identified six specific referents and corresponding injunctive normative beliefs. Participants were asked, "[specific referent] think I should become pregnant" with a seven-point bipolar scale anchored between "strongly agree" (+3) and "strongly disagree" (-3).

I weighted domain-specific questions regarding the motivation to comply with specific referents by asking respondents to rate their level of motivation to comply with specific referents on a unipolar seven-point scale. For example, respondents were asked to "When it comes to becoming pregnant, I want to do what [specific referent] thinks I should do." Anchored with a seven-point unipolar scale anchored between "strongly agree" (7) and "strongly disagree" (1). Fishbein and Ajzen (2010) explain that these response items must be

constructed on a unipolar scale because even though an individual may not want to comply with a specific referent, it does not suggest that the respondent wants to do the opposite of what the referent suggests.

Perceived behavioral control. Although actual control over a behavior or goal is difficult to measure, the perception of control is more accessible because respondents are reporting their own point of view. Perception and beliefs can be measured by asking direct questions. I asked respondents questions in the same aforementioned semantic differential approach for direct measures.

For standard measures of *capacity* components of perceived behavioral control, I asked respondents to rate: “If I decide I want to try, I can get pregnant if I want to.” This bipolar seven-item scale anchored from “Strongly Agree” (+3) to “Strongly Disagree” (-3). For direct measures of *autonomy* components of perceived behavioral control, I asked respondents: “My decision to become pregnant is up to me:” with anchors from “Strongly Agree” (+3) to “Strongly Disagree” (-3). As a result of some discussion during the elicitation interviews, I also added the questions “My decision NOT to become pregnant is up to me” and “Having CF would affect my decision to try to become pregnant” with anchors from “Strongly Agree” (+3) to “Strongly Disagree” (-3)

Perceived behavioral control subcomponents. Respondents identified four control beliefs that may affect the decision to become pregnant. For each control belief identified in the formative research phase, Fishbein and Ajzen (2010) suggest that corresponding perceived power and belief strength questions follow. For example, I asked participants to respond to the stem, “My medications and treatments would affect my decision to become pregnant” anchored between “Strongly Disagree” (1) and “Strongly Agree” (7). For belief power, I asked respondents to rate: “My medications and treatments would make it ...” and the responses can be anchored on a seven-point bipolar scale from “Very Easy” (+3) to “Very Difficult” (-3). Table 2 illustrates how each construct and subcomponent measured.

Table 2

Measurement Scales of Theoretical Independent Variables

Construct	Direct Measure	Beliefs	Weights
Attitude	Bipolar Scale (-3) to (+3)	Behavioral Beliefs Unipolar Scale (+1) to (+7)	Outcome Evaluation Bipolar Scale (-3) to (+3)
Subjective Norms	Bipolar Scale (-3) to (+3)	Normative Beliefs Bipolar Scale (-3) to (+3)	Motivation to Comply Unipolar Scale (+1) to (+7)
Perceived Behavioral Control	Bipolar Scale (-3) to (+3)	Control Beliefs Unipolar Scale (+1) to (+7)	Control Power Bipolar Scale (-3) to (+3)

Table 2

External variables. According to the TPB, external variables are not expected to contribute to behavioral intention over and above the TPB constructs. I identified Cystic Fibrosis related quality of life and basic demographic variables through the elicitation interviews. These are detailed further in Chapter 4.

CF related quality of life. Over and above any other theme from the elicitation interviews was the topic of how one's CF-related health would impact pregnancy intention. Therefore, the Questions of Life Satisfaction-Cystic Fibrosis (FLZ-CF) scale was utilized to measure this concept (Goldbeck, Schmitz, Henrich, & Herschbach, 2003). The FLZ-CF was created using a German population, but translated to English. Although there is a CF-related quality of life measure that is widely used in CF research in the United States (Quittner, Buu, Messer, Modi, & Watrous, 2005), the instrument consists of 44 items, which would have added considerably more questions. In comparison, the FLZ-CF has only 16 items and those items are worded more concisely, therefore I chose the FLZ-CF.

Demographics. I asked respondents to select the answers that best describe them. Demographic information will include basic questions regarding age, relationship status,

level of education, race/ethnicity, employment status, and annual household income. The operationalization of all variables is provided in Table 3.

Pilot Testing the Survey Questionnaire

I conducted an initial pilot test in order to ensure the integrity of the questionnaire before it is distributed to the population. The group of reviewers included academic faculty members, two CF social workers, a CF physician, five participants from the elicitation interviews, and five more women with CF who were recruited via online sources for people with CF. The two faculty members were experienced with the Theory of Planned Behavior and the Theory of Reasoned Action, thus providing expertise in evaluating content validity. I asked all respondents to access the survey questionnaire and remark on any web page navigation issues (e.g. broken links, poor presentation on a particular web browser); readability of the questions, including sentence construction and vocabulary; flow of the questions; clarity of the directions; and any other issues or suggestions regarding the design of the questionnaire. Nineteen reviewers is an acceptable sample for these purposes of survey review (Hertzog, 2008).

I also supplied a paper version of the survey to two reviewers. Some minor typos were detected, but all reviewers agreed the survey was appropriate and adequate. One woman with CF commented that the survey was not offensive, but that it did evoke

Table 3

Operationalization of Variables

Independent Variables	Definition
Attitude	Degree of favorableness or unfavorableness of a particular behavior.
Behavioral Outcome	Belief-based measure of attitude. Sum of the cross-products about the attitude toward consequences of becoming pregnant and the evaluation of those consequences.

Subjective Norms	Perception of what a person should or should not do based on social norms.
Social Influences	Belief-based measure of subjective norms. Sum of the cross-products of social referents and motivation to comply.
Perceived Behavioral Control	The perception of what an individual has control over when trying to execute a behavior or attain a goal.
Control	Belief-based measure of perceived behavioral control. Sum of the cross-products of the perception of obstacles making it difficult to perform or not perform a behavior and control over these obstacles.
Demographics (External variable)	Descriptive information such as age, race/ethnicity, relationship status, level of education, and income.
CF Related QOL (External variable)	A measure of degree to which CF-related health issues affect quality of life.
Dependent Variable	Definition
Pregnancy Intention	An intention to become pregnant at any time in the future (Chuang et al., 2009).

Table 3

some emotions related to her own mortality and she felt sad after the spur of this reflection. The most common feedback indicated that the survey was lengthy and people reported fatigue and difficulty focusing on the numerous questions. Some women with CF also reported that the questions seemed redundant and suggested removing some prompts to shorten the questionnaire.

Of the ten women with CF, only six completed the survey, rendering too small of a sample size to calculate reliability measures (Hertzog, 2008). Instead of contaminating the sample or risking multiple responses from individuals in an already small sample population, the survey was launched without reliability testing prior to its distribution. Reliability was calculated after distribution of the survey.

Internal consistency reliability, Cronbach's coefficient alpha, was calculating using SPSS 21.0 (IBM, 2012). Cronbach's coefficient alpha of 0.70 is considered acceptable

reliability (Tabachnick & Fidell, 2007), however there is some debate for this “rule of thumb” and Hair et al. (1998) suggest that 0.60-0.70 are the lower limits of acceptability. The Cronbach’s alpha for the TPB survey was 0.796, and Table 4 reports the reliability values for each subscale. There is concern for the reliability of behavioral beliefs, subjective norms, and both perceived behavioral control and control beliefs, however deletion of any item did not significantly improve the alpha level. The FLZ-CF scale has a Cronbach’s alpha of 0.80 and a split-half reliability of 0.72 (Goldbeck et al., 2003).

Data Collection Procedures

Sample size. I conducted an a priori power analysis using G*Power software version to calculate the sample size for multiple regression. I calculated a power of 0.8, with a significance level of 0.05, a medium effect size of 0.15, for the greatest number of possible predictors, 13, and I needed 131 participants. I calculated a power of 0.8, with a significance level of 0.05, a medium effect size of 0.15, for the least number of possible predictors, 7, and I needed 102 participants. I was able to recruit 147 participants and retained 103 after removing surveys that did not meet the inclusion criteria or had random missing data.

Table 4

Reliability of TPB items

Subscale	Cronbach’s Alpha
Attitude Direct Measure	.93
Behavioral Beliefs & Outcome Evaluations	.66
Subjective Norms Direct Measure	.67
Social Referents & Motivation to Comply	.92
Perceived Behavioral Control Direct Measure	.64
Control Beliefs and Power	.61

Sample recruitment. Nationally, there are over 110 CF care centers accredited by the Cystic Fibrosis Foundation (CFF), 95 adult CF care centers, and 50 affiliate programs (CFF, 2011). The CFF (2011) reported that in 2010 there were approximately 12,476 adults with CF who were in the CFF registry; 48.3% of that population is female. Therefore, there are approximately 6,000 women with CF who are age 18 or older. The small population of adult women with CF presented a challenge to reaching an adequate sample. Transition to adult care does not always occur at age 18; in fact, many patients with CF do not transition from pediatric to adult care until age 21 (CFF, 2011). Therefore, I promoted an online version of the survey to both pediatric and adult care center social workers.

The CF community has connected using a variety of platforms via the Internet. I utilized these platforms and yielded the greatest results from promoting the survey online. I posted the survey on a public Facebook group twice with permission from the group administrator. Another CF group, CF Mummies, posted the survey to their closed Facebook group as well as their private online community. CysticLife, a social network specifically for the CF community, also posted the survey to their Facebook group and private online community.

Survey administration. I administered the survey online via Qualtrics. The survey included a brief study description, including the purpose of the study, confidentiality agreement, and participant rights (Appendix C). I asked participants to read and consent prior to the launch of the survey (Appendix A).

I did not collect any identifying information, such as name, address, or social security number. However, IP addresses were initially collected in order to confirm respondents were from the United States. Once the responses were identified as US versus non-US, the IP addresses were deleted from the online host and data was downloaded.

Data Screening and Analyses

The first step in cleaning the data from the quantitative survey consisted of transforming some of the raw response data into bipolar measures using the SPSS recoding function, per the instructions of Fishbein and Ajzen (2010). Once these responses were transformed, I began data screening procedures.

Data screening. I executed descriptive statistics for the analysis as well as for data screening. I executed univariate descriptive statistics in order to review if continuous variables were within range, that medians and standard deviations are possible, that discrete variables were within range, and to check if coding was correctly programmed. Five univariate outliers were identified. I used Mahalanobis distance to identify three multivariate outliers and once I replaced univariate outliers using the winsorizing method, the multivariate outliers were no longer present. One case also had several missing values and it was deleted from analysis, thus removing the offending outliers from that case.

Missing values. I used SPSS missing values analysis to identify any patterns of missing values. I excluded cases with more than 25% of the survey missing data from analysis ($n=3$), leaving 104 responses. Two more cases were missing only one response each. One case had two missing values, regarding questions about partner influence. This participant also identified as “single” thus it was concluded this participant may have reported this intentionally and her response was removed. However, the remaining case did not have a logical pattern, so the one missing response for this case was replaced using mean substitution. One hundred and three responses remained for analysis.

Calculating variables. I used SPSS transformation procedures to calculate the mean score for direct measures, the weight score for beliefs, and the sum of the products for each. I also calculated the FLZ subscores and cumulative score according to the author’s instructions (Goldbeck et al., 2003). After analyzing demographic variables, I reduced some of those to eliminate minimal and zero-response categories and used dummy coding for the analyses due to low frequencies in categories. The dependent variable, pregnancy intention, was reduced from a 7-point scale into a dichotomous variable for the analysis of Research Question 1.

Univariate and Bivariate Analyses. I reviewed descriptive data for continuous variables and frequencies for categorical variables. I also conducted t-test and chi-square analyses to review differences between the “Likely” and “Unlikely” pregnancy intention groups.

Analysis of Research Question One. “What are the contributions of attitudes, subjective norms, and perceived behavioral control for women with CF in predicting pregnancy intention and do external variables significantly contribute to the prediction of pregnancy intention beyond the TPB constructs?” Because I am seeking to identify if the combination of independent variables (TPB constructs and external variables) predict membership into a dichotomous group (intend to become pregnant or do not intend to become pregnant), the binary logistic regression model is the best fit for the study aim.

$$pregint = \beta_0 + \beta_1 Att + \beta_2 SN + \beta_3 PCB + \beta_4 BehOut + \beta_5 SocInf + \beta_6 Control + \sum^n \beta_i \chi_i + E$$

Att = Direct measure of attitude

SN = Direct measure of subjective norms

PCB = Direct measure of perceived behavioral control

BehOut = Sum of the products of behavioral beliefs and evaluations

SocInf = Sum of the products of normative beliefs and motivation to comply

Control = Sum of the products of control beliefs and perceived power

E = FLZ-CF, demographics (age, income, employment, marital status, race)

Assumption testing and evaluation of limitations. Logistic regression offers flexibility in assumption testing that is not available in discriminant analysis and multiple regression. In logistic regression models, predictors do not have to be normally distributed, linear, or have equal variance within each group (Tabachnick & Fidell, 2007). The logistic regression model must meet the assumptions of independence of observations and linearity of the log odds. The first assumption is met by the study design; that is, none of the variables are dependent upon one another. The linearity in the logit measured in the main analysis. Determining how well the fitted model describes the data, tests the second assumption; goodness-of-fit tests such as the likelihood ratio test indicate the appropriateness of a model and the Wald statistic tests the significance of independent variables. Although the logistic

regression model is more tolerant than a multiple linear regression model, there are still several limitations that must be addressed during analysis.

High parameter estimates and standard errors may indicate that there are not enough cases relative to independent variables (Tabachnick & Fidell, 2007). When the sample is too small relative to the number of variables, some categories may need to be combined or deleted. This issue of “overfitting” may be more difficult to identify in logistic regression than in multiple regression.

Because multivariate normality and linearity among independent variables may increase the power of the model (Tabachnick & Fidell, 2007), I examined univariate and multivariate outliers. I analyzed univariate outliers using frequency distributions for categorical variables. For continuous variables, I identified univariate outliers by calculating z-scores and identifying cases in excess of +/- 3.29 cutoff. For multivariate outliers, I evaluated and calculated Mahalanobis distance for each case using a $p < .001$ for the χ^2 value.

I also examined multicollinearity diagnostics among predictor variables. I first reviewed the correlations among variables, then executed linear regressions using each independent variable as the dependent variable in order to attain tolerance values. Tolerance statistics are provided in order to test for multicollinearity of IVs. The 0-1 scale for tolerance indicates if variables are in the cutoff for multicollinearity. Finally, I reviewed condition indices for one last confirmation.

The dependent variable was collapsed into three categories from the original seven-point scale: likely, undecided, and unlikely for analysis in a multinomial logistic regression model. However, upon execution of this model, several issues became apparent due to many implausible results, including large parameter estimates and extremely large standard errors. The statistical software indicated there was a possible convergence failure based on a quasi-complete or complete separation. Allison (2008) explains that issues of separation are more commonly attributed to small sample sizes and/or an evident split in the dependent variable.

Upon review of the frequencies and histogram of the dependent variable, there is a clear split related to the relatively low frequency of responses in the “undecided” category (n=10). Due to this issue, the “undecided” category was added to the “unlikely” category and a dichotomous dependent variable was created. I decided to collapse “undecided” into “unlikely” in order to be conservative in my estimation. As a result, I executed a binary logistic regression to address the first research question.

Analysis of Research Question Two. “What are the pertinent influential behavioral beliefs, specific referents, and perceived power that influence these attitudes, subjective norms, and perceived behavioral control?” For the second research question, three of the variables that were independent variables in the first model become dependent variables (attitudes, subjective norms, and perceived behavioral control). In order to test which subcomponents have the greatest impact on their respective component, I executed two independent Ordinary Least Squares (OLS) regressions for each. Furthermore, in order to test whether any external variables impact these beliefs, I ran the models with external variables: sum score on FLZ-CF and demographics (age, income, employment, marital status, race).

$$Attitude = A + \beta_1 Belief_1 + \beta_2 Belief_2 \dots \beta_k Belief_k$$

$$Attitude = A + \beta_1 Belief_1 + \beta_2 Belief_2 \dots \beta_k Belief_k + \beta_k External\ var_k$$

$$SubjectiveNorms = A + \beta_1 referent_1 + \beta_2 referent_2 \dots \beta_k referent_k$$

$$SubjectiveNorms = A + \beta_1 referent_1 + \beta_2 referent_2 \dots \beta_k referent_k + \beta_k External\ var_k$$

$$PerceivedBehavioralControl = A + \beta_1 ControlBelief_1 + \beta_2 ControlBelief_2 \dots \beta_k ControlBelief_k$$

$$PerceivedBehavioralControl = A + \beta_1 ControlBelief_1 + \beta_2 ControlBelief_2 \dots \beta_k ControlBelief_k + \beta_k External\ var_k$$

Assumption testing and evaluation of limitations. Whereas assumption testing is more flexible in logistic regression, in OLS regression there are two sets of assumptions that

must be met (Pedhazur, 1997). Some assumptions of regression are addressed by ensuring the research design fits the regression assumptions and the rest are issues associated with the data that have to be tested. The first three assumptions are concerned with the raw scale variables. They include: (1) the values of the independent variables are fixed; (2) the independent variables are free from measurement error; (3) there is a linear relationship between the independent variables and the dependent variable. The remaining five assumptions are concerned with the residuals: (4) the mean of the residuals for each observations on the dependent variable is zero; (5) independence of errors; (6) the independent variables are not correlated with errors; (7) the errors are normally distributed; (8) homoscedasticity of errors. Some assumptions of regression are addressed by ensuring the research design fits the regression assumptions and the rest are issues associated with the data that have to be tested (Mertler & Vannatta, 2005).

In order to evaluate the assumptions and limitations, I evaluated several aspects of the data (Tabachnik & Fidell, 2007), including: (1) an adequate ratio of cases to independent variables; (3) absence of outliers among the independent and dependent variables; (4) absence of multicollinearity and singularity; (5) normality, linearity and homoscedasticity of residuals; (6) independence of errors; and (7) absence of outliers in the solution.

Summary

This study was based on the Theory of Planned Behavior using formative research to design a quantitative survey. Initial in-depth interviews with women who have CF helped identify the unique beliefs and issues specific to the population. Women with CF and other experts in the field of CF were influential in improving the instrument's content validity through expert feedback and pilot testing.

A total of 147 surveys were completed online, with 103 meeting criteria for the final analyses. Data were prepped and cleaned, with little alteration to the data for final analyses. The results of the analyses described above are reported in Chapter 4.

Chapter 4

Results

This study involved using the Theory of Planned Behavior to identify factors contributing to pregnancy intention among women with CF. I collected data from women with Cystic Fibrosis, who did not currently have any current children, age 18 and older and of childbearing age, from the United States. During the formative phase of research, six women were interviewed and reported their attitudes, subjective norms, and perceived behavioral control beliefs on pregnancy among women with CF, which influenced the construction of a survey instrument. The survey was administered online, and a total of 103 responses were obtained to address the research questions for this study.

Chapter 4 presents the results of the formative research phase and the pertinent beliefs, which informed the final instrument. Then, the results from the preliminary descriptive statistical analyses are presented. Finally, the results from the analyses designed to answer the first and second research questions are discussed. Two research questions were posed in Chapter 1:

1) What are the contributions of attitudes, subjective norms, and perceived behavioral control for women with CF in predicting pregnancy intention and do external variables significantly contribute to the prediction of pregnancy intention beyond the TPB constructs?

2) What are the pertinent influential behavioral beliefs, specific referents, and perceived power factors that influence these attitudes, subjective norms, and perceived behavioral control?

Formative Research

Six women with CF completed in-depth interviews. They ranged from age 19-53 and four were intending to become pregnant, had biological children, or were currently pregnant.

Table 5

Elicitation Interview Participants

Participant	Intention*	Age	Race/Ethnicity
001	Yes*	23	White Not Hispanic
002	Yes	26	White, Hispanic
003	Yes*	32	White Not Hispanic
004	No	53	White Not Hispanic
005	Yes	19	White Not Hispanic
006	No	28	White Not Hispanic

*Women who already had biological children or were currently pregnant at the time of the interview.

Attitudinal Beliefs

Six attitudinal beliefs emerged from the elicitation interviews. Participants reported their beliefs that women with CF becoming pregnant were: endangering their own health; endangering the health of the future child; burdening family and friends; creating a sense of normalcy for their own lives; and leaving a legacy of themselves.

Endangering their own health. Respondents explained that they believed by becoming pregnant, women with CF could negatively impact their own health, both immediately, during pregnancy, and also may cause a permanent decline in health.

Endangering the health of the potential child. The ability for women with CF to provide adequate nutrients during pregnancy and the toxicity of CF medications and treatments were also reported concerns.

Burdening family and friends. Due to the eventual decline in health that women with CF will experience, according to the respondents, the responsibility of caring for a child

may be deferred to other family members. Respondents explained that pulmonary exacerbations may impact a woman's functioning and may also require inpatient hospitalizations. They also mentioned an early death is also possible and such a tragedy could burden her family with grief and the responsibility of raising her children.

Passing on the CF gene. Participants were very aware that even if the children of women with CF did not have CF, they still might carry the gene. They were concerned that women with CF may have children with CF if the partner was a carrier. However, this concern extended to the possibility that the children could be carriers and continue passing on the disease.

Normalcy. During the elicitation interviews, many respondents articulated the notion that having a child was a "normal" developmental milestone that women with CF wanted to achieve in adulthood. Several women explained that by not having children, they were succumbing to the disease and allowing it to define them as abnormal.

Legacy. During the interviews, the respondents articulated that having a child may carry forward a part of them, after they have died. The women explained that a child or children may allow them to make a mark on the world and be a comfort to their remaining family.

Social Referents

In addition to the patient herself, all six participants identified the spouse/significant other as the most influential person when deciding to have a child. Each participant was asked if religious leaders and community and culture influenced pregnancy intention and all denied their influence. Only one participant agreed that in-laws had an influence and that it was not any different from their own family's influence.

Table 6

Social Referents Ranked

001	002	003	004	005	006
Sig Other	Sig Other	Sig Other	Sig Other	Sig Other	Sig Other
Family/Friends*	CF Doc	Parents	CF Doc/PCP*	Mom	CF-Doc
CF Team	Mom	Best Friend	Friends/Family*	CF-Doc	Family/Friends*
OB	OB	OB/CF Doc*		Siblings	
PCP	Father/In- Laws			Friends	
	Friends				

**Participants ranked both at the same level of influence.*

Power Beliefs

In general, participants perceived there to be a high degree of control over intending *not* to become pregnant. However, there was some confusion whether they have control over intending to become pregnant. Three out of the six participants mentioned difficulty conceiving due to CF. Due to the unique issues related to pregnancy and to Cystic Fibrosis, I included a question regarding one's control over becoming pregnant as well as a question regarding one's control over not becoming pregnant in the direct measures of control. Four power beliefs emerged from the elicitation interviews, indicating which obstacles respondents believed would make pregnancy more or less likely. These five were included in the final survey instrument: Cystic Fibrosis related complications; medications and treatments; supportive partner; supportive family; financial security.

Cystic Fibrosis related complications. Respondents believed that CF may inhibit their ability to conceive a child and was thus a great obstacle to natural conception.

Medications and treatments. Respondents explained that the degree of time, money, and side effects of CF-related medications and treatment regimens may impact one's decision to become pregnant. Some medications may have adverse side-effects that impact one's ability to become pregnant, are not safe for pregnancy, or affect functioning. The financial and time cost related to CF medications and treatments may also impact one's decision. Daily treatments require a lot of time during one's day.

Supportive partner. Respondents believed that having a partner was not only essential for the actual conception, but also for long term support and needs as a parent. Many reported that this was no different than any other woman deciding to become pregnant.

Supportive family. Interviewees reported that having a supportive family was important for the decision to become pregnant. They explained that this social support was important in times of illness or in case of death.

Financial security. Respondents reported that being financially secure may also influence the decision to become pregnant, especially since some women with CF may not be physically capable of working full-time or may be collecting disability insurance payments.

External Factors

Factors beyond the TPB constructs consistently reflected one dominating theme, that of the health of the woman. This external variable is discussed in more detail in Chapter 3.

Primary Study

The final version of the study was distributed online using Qualtrics®. One hundred and forty-three surveys were submitted. After removing those that did not meet inclusion criteria or were missing substantial data, 103 surveys remained.

Descriptive Statistical Results

A total of 103 results from women with CF were included in the final analyses for this study. Descriptive statistics for the demographic and background characteristics of the sample are shown in Table 7.

Most of the participants were married (53.4%), with 33.0% in a relationship and 13.6% single. The most frequent level of education was some college/trade school/associate's degree (52.4%), followed by an undergraduate degree (28.2%). Nearly all of the participants were White/Caucasian (97.1%), which is reflective of the CF population (CFF, 2013). A total of 18.4% of the participants listed their employment status as not employed, with 29.1% employed full time with no disability funds, and 23.3% totally disabled. The most common levels of income were between \$40,001 and \$69,999 (27.2%), under \$20,000 (26.2%), and over \$70,000 per year (21.4%). The participants ranged in age from 18 to 45 years old with a mean of 27.36 years old ($SD = 5.72$).

Table 8 shows descriptive statistics for the measures of attitude, subjective norms, and perceived behavioral control. For the direct measures, the means for subjective norms ($M = .10$, $SD = 1.94$) and behavioral control ($M = 1.35$, $SD = 1.11$) were positive, while the mean for attitude ($M = -.73$, $SD = 1.64$) was negative. The scores and means for the other variables were reviewed to ensure that all variables were within valid limits.

Descriptive statistics for the pregnancy intention variable are shown in Table 9. The sample was approximately equally split between those who stated that pregnancy was unlikely (43.7%) and likely (46.6%), with the remainder (9.7%) stating that they were undecided. Due to issues created by the relatively small number of individuals in the undecided group ($n = 10$), the unlikely and undecided groups were combined to provide a dichotomy for subsequent analyses.

Table 7

Demographic and Background Characteristics of the Participants (N = 103)

	<i>n</i>	%
Relationship status		
Single	14	13.6
In a relationship	34	33.0
Married	55	53.4
Level of education		
High school/GED	10	9.7
Some college/Trade School/Associates Degree	54	52.4
Undergraduate degree (Bachelor's Degree)	29	28.2
Graduate degree (Master's Degree, PhD, MD)	10	9.7
Race/ethnicity		

White/Caucasian, not Hispanic or Latino	100	97.1
Other	3	2.9
Employment status		
Not employed	19	18.4
Employed part-time (with no disability funds)	14	13.6
Employed full-time (with no disability funds)	30	29.1
Totally disabled	24	23.3
Employed part-time with disability funds	10	9.7
Employed full-time with disability funds	3	2.9
Other	3	2.9
Income		
Under 20,000 a year	27	26.2
20,0001-40,000 a year	14	13.6
40,001-69,999 a year	28	27.2

Over 70,000 a year	22	21.4
Unknown	12	11.7

M	SD
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Age	27.36	5.72
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Table 8

Descriptive Statistics for Attitude, Subjective norms, and Behavioral Control Measures (N = 103)

Variable	Minimum	Maximum	M	SD
Attitude direct measure	-3.00	3.00	-.73	1.64
Subjective norms direct measure	-3.00	3.00	.10	1.94
Perceived behavioral control direct measure	-1.50	3.00	1.35	1.11
Products of behavioral beliefs and evaluations	-117.00	45.00	-48.48	29.86
Products of normative beliefs and motivation to comply	-126.00	117.00	10.23	48.03
Products of control beliefs and perceived power	-93.00	93.00	9.21	33.17
“endangering their own health” belief	-21.00	7.00	-13.92	6.44

Variable	Minimum	Maximum	M	SD
Normalcy belief	-21.00	21.00	1.51	9.79
“Endangering the child’s health” belief	-21.00	6.00	-11.79	6.17
“Legacy” belief	-18.00	21.00	3.20	11.24
“Passing on the CF gene” belief	-21.00	.00	-15.00	6.72
“Burdening family and friends” belief	-21.00	3.00	-12.88	7.14
Social referent, Partner	-21.00	21.00	2.97	12.14
Social referent, Mother	-21.00	21.00	1.00	9.40
Social referent, Father	-21.00	21.00	.93	8.48

Variable	Minimum	Maximum	M	SD
Social referent, other family members	-21.00	21.00	1.40	7.88
Social referent, CF physician	-21.00	21.00	.99	9.82
Social referent, friends	-21.00	21.00	2.94	7.29
Medications and Treatments	-21.00	21.00	-7.24	9.51
Supportive partner	-21.00	21.00	8.28	10.86
“CF related complications” control belief	-9.00	9.00	-3.41	4.03
Supportive Family	-21.00	21.00	6.71	9.83
Financial Security	-21.00	21.00	4.87	9.76

Variable	Minimum	Maximum	M	SD
CF-Related QOL	-57.00	143.00	35.49	39.02

Table 9

Descriptive Statistics for Pregnancy Intention (N = 103)

Pregnancy Intention	n	%
Unlikely	55	53.4
Likely	48	46.6

Chi-square and t-test analyses were conducted to compare the two groups of the dependent variable. Two significant differences were found in the analyses (Table 10) First, there was a statistically significant difference in mean age $t(101) = 2.683, p < .01$. Women who intended a pregnancy were younger ($M=25.83$) than women who did not intend a pregnancy ($M=28.7$). Next, there was a significant difference in employment status between the groups $\chi^2(6, N=103)=22.70, p<.001$. More women who intended a pregnancy were unemployed.

Research Question 1

The first research question of this study was: What are the contributions of attitudes, subjective norms, and perceived behavioral control for women with CF in predicting pregnancy intention and do external variables significantly contribute to the prediction of pregnancy intention beyond the TPB constructs?" The dependent variable was pregnancy intention and the independent variables were attitudes, subjective norms, perceived behavioral control, products of behavioral beliefs and evaluations, products of normative beliefs and motivation to comply, and products of control beliefs and perceived power. The external variables were age, relationship status, education, race, employment status, income, and CF quality of life satisfaction, as measured by the FLZ-CF. For the demographic variables, dummy variables were created for entry into the regression models using the following coding: for relationship status, 0 = *single or in a relationship* ($n = 48$) versus 1 = *married* ($n = 55$); for education, 0 = *less than a bachelor's degree* ($n = 64$) versus 1 = *bachelor's degree or higher* ($n = 39$); for race/ethnicity, 0 = *Caucasian* ($n = 100$) versus 1 = *other* ($n = 3$); for employment status, 0 = *not employed* ($n = 46$) versus 1 = *employed* ($n = 57$); and for income, 0 = *not more than \$40,000 per year* ($n = 53$) versus *more than \$40,000 per year* ($n = 50$). Age and life satisfaction were entered as continuous variables, and pregnancy intention was dichotomized as 0 = *unlikely or undecided* ($n = 55$) and *likely* ($n = 48$).

In a preliminary set of analyses, the correlations among the independent variables (attitudes, subjective norms, perceived behavioral control, products of behavioral beliefs and evaluations, products of normative beliefs and motivation to comply, and products of control

beliefs and perceived power) were computed to examine potential multicollinearity problems. These correlations are shown in Table 11.

According to Tabachnik and Fidell (2007), variables that correlate greater than .60 should be examined further, though concern is most often indicated for correlations greater than .80. Several of the correlations were statistically significant, with the highest correlation being between the direct measure of subjective norms and the products of normative beliefs and motivation to comply, $r = .83, p < .001$. Further diagnostics reported that the tolerance for these two variables was 0.55. Tolerance values are considered acceptable if they are above .10 (O'Brien, 2007) or VIF is between 0.00-1.00 (Tabachnick & Fidell, 2007). For the remaining correlations, tolerance values ranged from .28 to .84, which was one indication that multicollinearity was not a problem. Intercorrelation may occur with the TPB items, as Ajzen (2014) explains that while they differ conceptually, empirically they may result in significant correlations since they are affected by the same information when people form beliefs. Furthermore, the variables that intercorrelated were essential to the theory and hypothesis test. Therefore, no independent variables were excluded from the logistic regression analysis. The Hosmer–Lemeshow goodness of fit test was performed and was not statistically significant, $\chi^2(8) = 4.18, p = .841$. This indicated that the model was well-calibrated (Hosmer & Lemeshow, 2000).

Table 10

Summary of Participant Characteristics by Pregnancy Intention (N = 103)

Demographic Characteristic	Unlikely (N=55)	Likely (N=48)	p -value*
Age (years)			
Mean (standard deviation)	28.7 (6.6)	25.83 (4.1)	.009
Race			
Caucasian	52	48	.10
Other	3	0	
Education			
Less than high school/ High school/GED	5	5	.31
Some college/trade school	28	26	
College degree	16	13	
Graduate degree	6	4	
Marital status			
Married	25	30	.12
In a Relationship	23	11	
Single	7	7	
Employment			

Employed FT (w/disability)	1	2	
Employed PT (w/disability)	10	0	
Employed FT (w/no disability)	11	19	.001
Employed PT (w/no disability)	8	6	
Not employed	7	12	
Other	0	3	
Income			
< \$20,000	21	6	.12
\$20,001-40,000	7	7	
\$40,001-70,000	13	15	
Over \$70,000	10	12	
Unknown/not reported	4	8	

*Chi-square analysis for categorical variables, *t*-test for mean age.

Table 11

Correlations Between All Independent Variables

Variable									
1. Attitude Direct Measure									
2. Social Norms Direct Measure	.521**								
3. Perceived Behavioral Control Direct Measure	.018	.102							
4. Behavioral Beliefs	.533**	.514**	.140						
5. Social Referents	.531**	.828**	.104	.531**					
6. Control Beliefs	.299**	.174	.166	.338**	.212*				
7. FLZ-CF	.203*	.099	.160	.057	.133	.132			

The results from the logistic regression models are shown in Table 12. Overall, the logistic regression model was statistically significant, $\chi^2(13) = 82.82, p < .001$. This indicated that the independent variables were predictive of pregnancy intention (Cox & Snell $R^2 = .55$, Nagelkerke $R^2 = .73$). With the addition of the independent variables to the model, the percentage of cases correctly classified increased from 53.4% (in the baseline model) to 87.4%. This considerable improvement is indicative of a well fitted model when the predictor variables are included.

In the logistic regression model, pregnancy intention was coded as 0 = *unlikely* or *undecided* and 1 = *likely*. This means that independent variables with $\text{Exp}(B)$ values greater than one were associated with an increased likelihood of being likely to intend pregnancy. Three of the six independent variables were statistically significant: the direct measure of attitude, the weighted measure of subjective norms, and employment status.

Due to the limited sample size and the risk of being underpowered, the analysis was computed again with only the significant variables in the model. The results are reported in Table 13. With only the significant predictors, the regression model $\chi^2(3) = 68.806, p < .001$, indicating the independent variables still predicted pregnancy intention (Cox & Snell $R^2 = .487$, Nagelkerke $R^2 = .651$). With the addition of the independent variables to the model, the percentage of cases correctly classified increased from 53.4% (in the baseline model) to 85.5%. This remains a considerable improvement, as is indicative of a well fitted model when the predictor variables are included.

First, the direct measure of attitude was statistically significant, $\text{Wald}(1) = 5.06, p = .025, \text{exp}(B) = 2.57$. The $\text{exp}(B)$ value of 1.95 indicated that higher scores on the direct measure of attitude were associated with a higher likelihood of being likely to intend to become pregnant. That is, more positive attitudes towards pregnancy, an OR of 2.57 (95% CI: 1.60-4.12) indicates the likelihood of being classified as intending a pregnancy

increases by 2.57 times. Second, the products of normative beliefs and motivation to comply was statistically significant, $Wald(1) = 15.61, p = .000, \exp(B) = 1.04$. The $\exp(B)$ value indicated that participants with higher scores on the products of normative beliefs and motivation to comply measure had a higher likelihood of being likely to intend pregnancy. That is, greater normative beliefs and motivation to comply with those beliefs, an OR of 1.04 (95% CI: 1.02-1.06) indicates the likelihood of being classified as intending a pregnancy increases by 1.04 times. In addition, one of the external variables, employment status, was statistically significant, $Wald(1) = 6.31, p = .012, \exp(B) = .16$. The $\exp(B)$ value of .16 indicated that those participants who were employed (coded as 1) were less likely to intend to become pregnant. That is, being unemployed, an OR of 0.16 (95% CI: .04-.672), indicates the likelihood of being classified as intending a pregnancy increase 0.16 times.

Based on these results, the answer to the first research question was that among women with CF the direct measure of attitudes and products of normative beliefs and motivation to comply made a significant contribution to predicting pregnancy intention. In addition, one of the external variables, employment status, made a significant contribution to predicting pregnancy intention, with employed participants being less likely to intend to become pregnant.

Research Question 2

The second research question was: What are the pertinent influential behavioral beliefs, specific referents, and perceived power factors that influence these attitudes, subjective norms, and perceived behavioral control? There were three dependent variables for this research question: attitudes, subjective norms, and perceived behavioral control. Two linear regression models were computed for each of the three dependent variables. For each dependent variable, one regression model was computed without the

Table 12

Results from Binary Logistic Regression Analysis Model 1(N = 103)

Independent variable	B	S.E.	Wald	df	p	Exp(B)	95% CI	
							Lower	Upper
Attitude direct measure	.67	.30	5.06	1	.025	1.95	1.077	3.358
Subjective norms direct measure	-.01	.35	.00	1	.980	.99	.506	1.964
Perceived behavioral control direct measure	.37	.35	1.14	1	.286	1.45	.717	2.693
Products of behavioral beliefs and evaluations	.02	.02	2.35	1	.125	1.02	.998	1.059
Products of normative beliefs and motivation to comply	.04	.02	4.57	1	.033	1.04	1.003	1.084
Products of control beliefs and perceived power	.02	.01	2.01	1	.156	1.02	.991	1.050
Age	-.08	.09	.69	1	.406	.93	.795	1.110
Relationship status	.56	.99	.32	1	.573	1.75	.111	4.230
Education	.23	.76	.10	1	.757	1.26	.183	3.544

Race/ethnicity	-22.54	18562.69	.00	1	.999	.00	.000	.
Employment status	-1.90	.89	4.58	1	.032	.15	1.343	40.326
Income	.64	.84	.58	1	.445	1.90	.099	2.574
Life satisfaction	-.01	.01	.29	1	.587	.99	1.077	3.358
Constant	2.75	2.31	1.42	1	.234	15.63	.506	1.964

Notes. Pregnancy intention was coded as 0 = *unlikely* or *undecided* and 1 = *likely*. For the demographic variables, the following coding was used: for relationship status, 0 = *single* or *in a relationship* ($n = 48$) versus 1 = *married* ($n = 55$); for education, 0 = *less than a bachelor's degree* ($n = 64$) versus 1 = *bachelor's degree or higher* ($n = 39$); for race/ethnicity, 0 = *Caucasian* ($n = 100$) versus 1 = *other* ($n = 3$); for employment status, 0 = *not employed* ($n = 46$) versus 1 = *employed* ($n = 57$); and for income, 0 = *not more than \$40,000 per year* ($n = 53$) versus *more than \$40,000 per year* ($n = 50$).

Table 13

Results from Binary Logistic Regression Analysis Model 2 (N = 103)

Independent variable	B	S.E.	Wald	df	p	Exp(B)	95% CI	
							Lower	Upper
Attitude direct measure	.943	.242	15.243	1	.000	2.568	1.599	4.123
Products of normative beliefs and motivation to comply	.041	.011	15.611	1	.000	1.042	1.021	1.064
Employment status	1.808	.720	6.311	1	.012	6.096	1.488	24.975
Constant	-.996	.530	3.534	1	.060	.370	1.599	4.123

Notes. Pregnancy intention was coded as 0 = *unlikely or undecided* and 1 = *likely*. For the demographic variables, the following coding was used: for relationship status, 0 = *single or in a relationship* ($n = 48$) versus 1 = *married* ($n = 55$); for education, 0 = *less than a bachelor's degree* ($n = 64$) versus 1 = *bachelor's degree or higher* ($n = 39$); for race/ethnicity, 0 = *Caucasian* ($n = 100$) versus 1 = *other* ($n = 3$); for employment status, 0 = *not employed* ($n = 46$) versus 1 = *employed* ($n = 57$); and for income, 0 = *not more than \$40,000 per year* ($n = 53$) versus *more than \$40,000 per year* ($n = 50$).

demographic variables and health related quality of life satisfaction scores (FLZ-CF), and one was computed with the five demographic variables and FLZ-CF score. For the demographic variables, the same aforementioned dummy-variable coding was used: for relationship status, 0 = *single or in a relationship* ($n = 48$) versus 1 = *married* ($n = 55$); for education, 0 = *less than a bachelor's degree* ($n = 64$) versus 1 = *bachelor's degree or higher* ($n = 39$); for race/ethnicity, 0 = *Caucasian* ($n = 100$) versus 1 = *other* ($n = 3$); for employment status, 0 = *not employed* ($n = 46$) versus 1 = *employed* ($n = 57$); and for income, 0 = *not more than \$40,000 per year* ($n = 53$) versus *more than \$40,000 per year* ($n = 50$). Age and life satisfaction were entered as continuous variables, and pregnancy intention was dichotomized as 0 = *unlikely or undecided* ($n = 55$) and *likely* ($n = 48$).

For each linear regression model, three assumptions were tested: correlation matrices were examined for correlations above .80, tolerance was computed for the independent variables, and condition indices were examined in the regression output to assess problems associated with multicollinearity, and homoscedasticity and the normality of the residuals were examined graphically. Prior to presenting the results from the linear regression analyses, the results from the assumption-testing procedures are presented.

Multicollinearity. For the analyses with the direct measure of attitudes as the dependent variable, two of the significant correlations exceeded 0.60, though they did not exceed 0.80. “Burdening family and friends” was correlated with “endangering their health” ($r=.665$, $p<.01$) and close to the cutoff with “endangering the health of the child” ($r=.595$, $p<.01$). There were no significant correlations approaching 0.60 with any of the external variables. Tolerance statistics ranged from .46 to .81 in the model without the external variables and from .41 to .91 in the model with the external variables. Condition

indices were at the upper limits of 8.797 in the model without the external variables and 11.265 for the model with the external variables. Therefore, all variables were retained in both models since none exceeded the tolerance or condition indices limits upon further inspection.

For the analyses with the direct measure of subjective norms as the dependent variable, every social referent correlated with one another above the 0.60 threshold, indicating concern for multicollinearity (Table 14). The variable “other family” correlated with the referents of mother, father, and friends. Furthermore, tolerance ranges for this variable, when regressed onto the other variables were barely over .10 (0.13, 0.13, 0.15) and the condition index was 24.59. Several diagnostics were executed to determine the most offending variables and “father” and “other family” were dropped from the analysis due to multicollinearity. After these variables were dropped, tolerance values ranged from .35 to .49, with a condition index of 3.84 in the model without the external variables and from .32 to .89 and a condition index of 18.48 in the model with the external variables.

For the analyses with the direct measure of perceived behavioral control as the dependent variable, all significant correlations were less than 0.60 with the exception of the variable “supportive family” correlating with “supportive partner” ($r=.771$, $p<.01$) and “finances” ($r=.615$, $p<.01$). Further investigation into tolerance values indicated that the tolerance values were 0.32 for supportive family, 0.39 for supportive partner, and 0.50 for finances. Furthermore, tolerance values ranged from .32 to .68 in the model without the external variables and the condition index was 4.88 and tolerance values from .29 to .86 in the model with the external variables with a condition index of 7.249. Based on the analysis of collinearity diagnostics, it was concluded that multicollinearity did not present a substantial problem for the linear regression analyses

Table 14

Correlations of Social Referents

	1.	2.	3.	4.	5.	6.
Partner						
Mother	.653**					
Father	.627**	.913**				
Other Family	.638**	.884**	.893**			
CF Physician	.625**	.682**	.678**	.666**		
Friends	.657**	.742**	.720**	.798**	.719**	

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

Homoscedasticity. Figures 4 through 9 show plots of the regression residuals versus the predicted scores for each of the six regression models. Homoscedasticity is demonstrated when the size of the residuals (in absolute value as shown on the y-axis) does not vary based on the predicted value (x-axis). These six figures are generally indicative of homoscedasticity with both small and large residuals found across the x-axis. Figure 5 (the plot of standardized residuals and standardized predicted values for the regression analysis with the direct measure of perceived behavioral control as the dependent variable and with the external variables) could be interpreted as showing some level of heteroscedasticity, but this is largely due to one small residual at the lower end of the predicted value scale. Based on these figures, it was concluded that the assumption of homoscedasticity for the residuals was met.

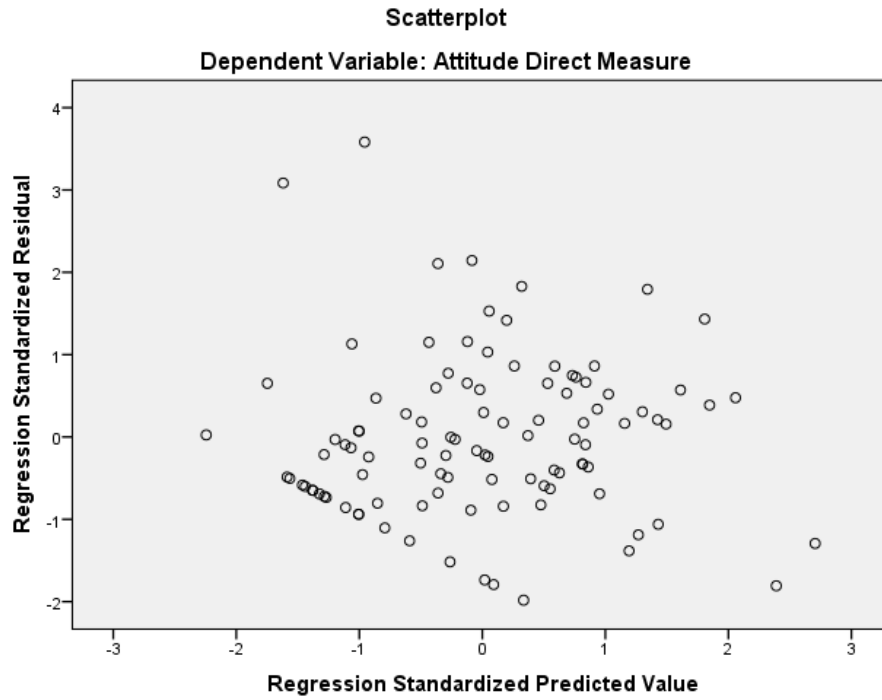


Figure 4. Plot of standardized residuals and standardized predicted values for the regression analysis with the direct measure of attitudes as the dependent variable and without the external variables.

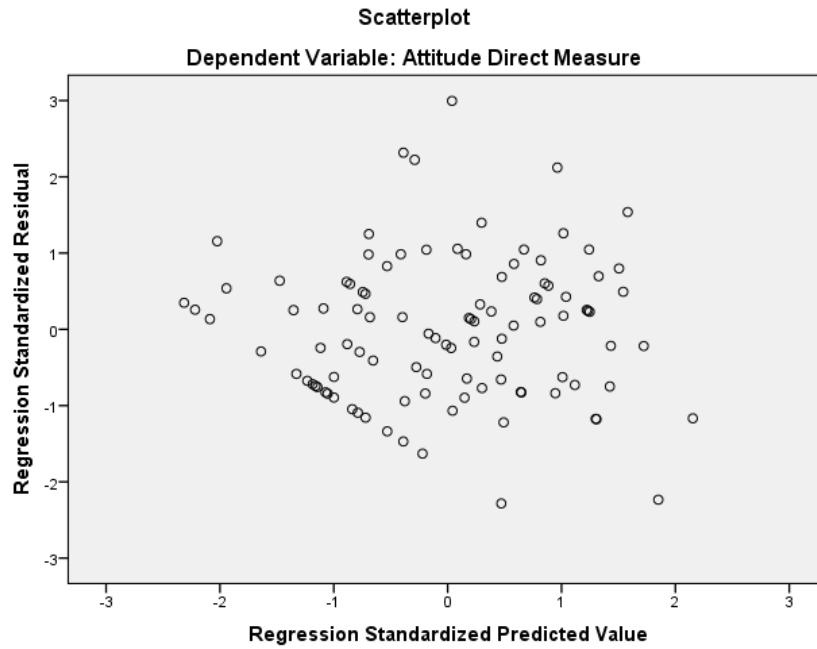


Figure 5. Plot of standardized residuals and standardized predicted values for the regression analysis with the direct measure of attitudes as the dependent variable and with the external variables.

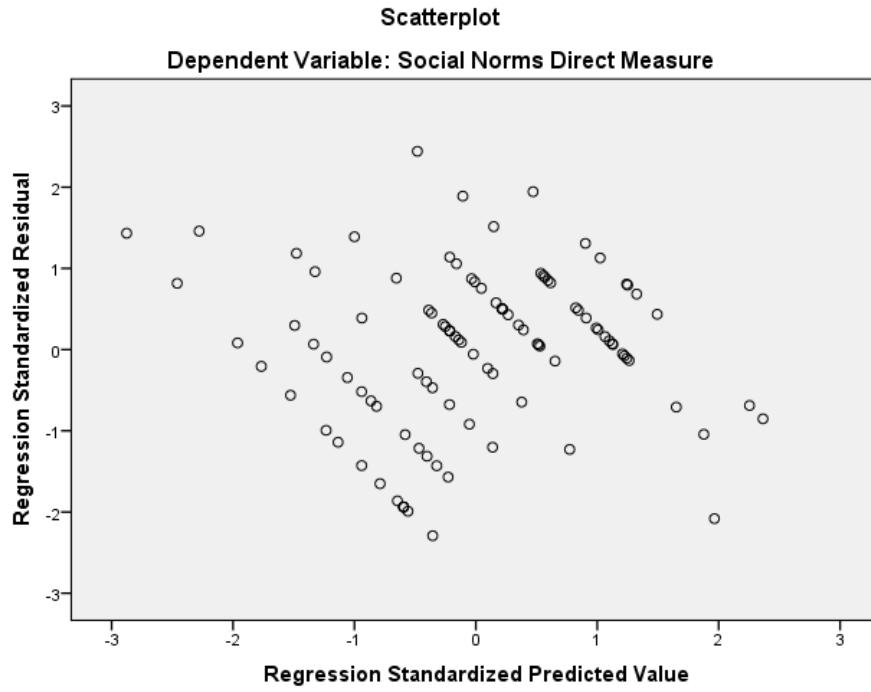


Figure 6. Plot of standardized residuals and standardized predicted values for the regression analysis with the direct measure of subjective norms as the dependent variable and without the external variables.

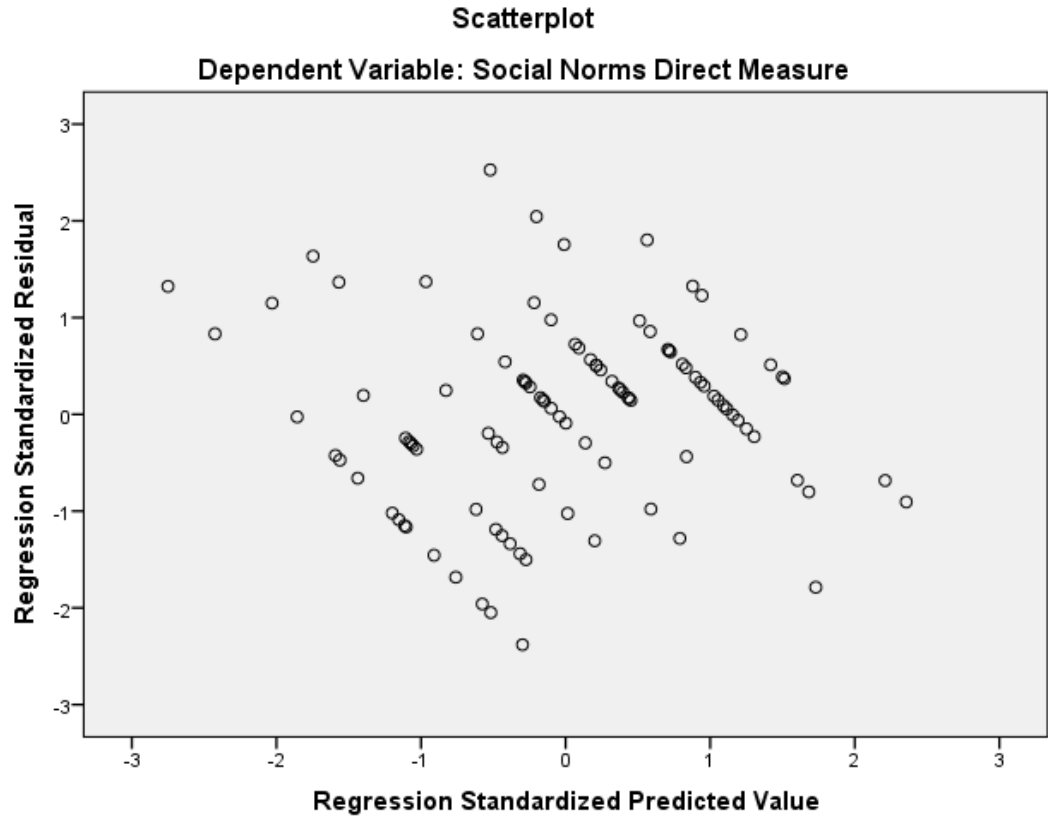


Figure 7. Plot of standardized residuals and standardized predicted values for the regression analysis with the direct measure of subjective norms as the dependent variable and with the external variables.

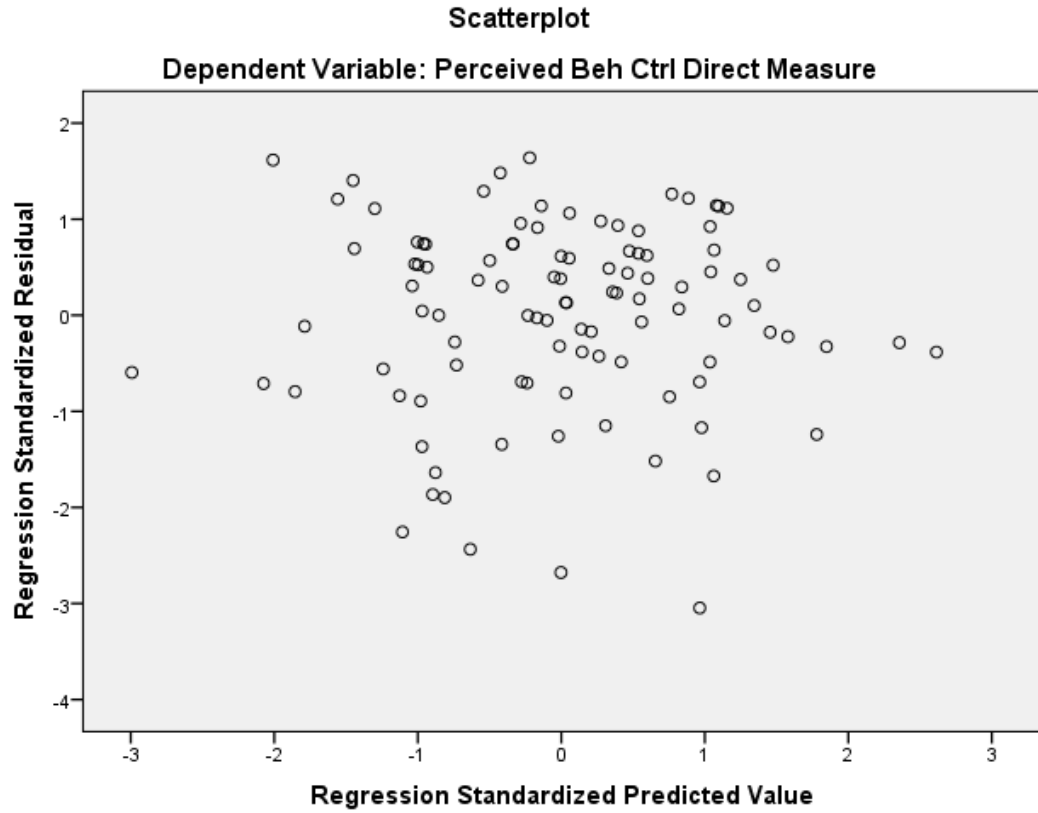


Figure 8. Plot of standardized residuals and standardized predicted values for the regression analysis with the direct measure of perceived behavioral control as the dependent variable and without the external variables.

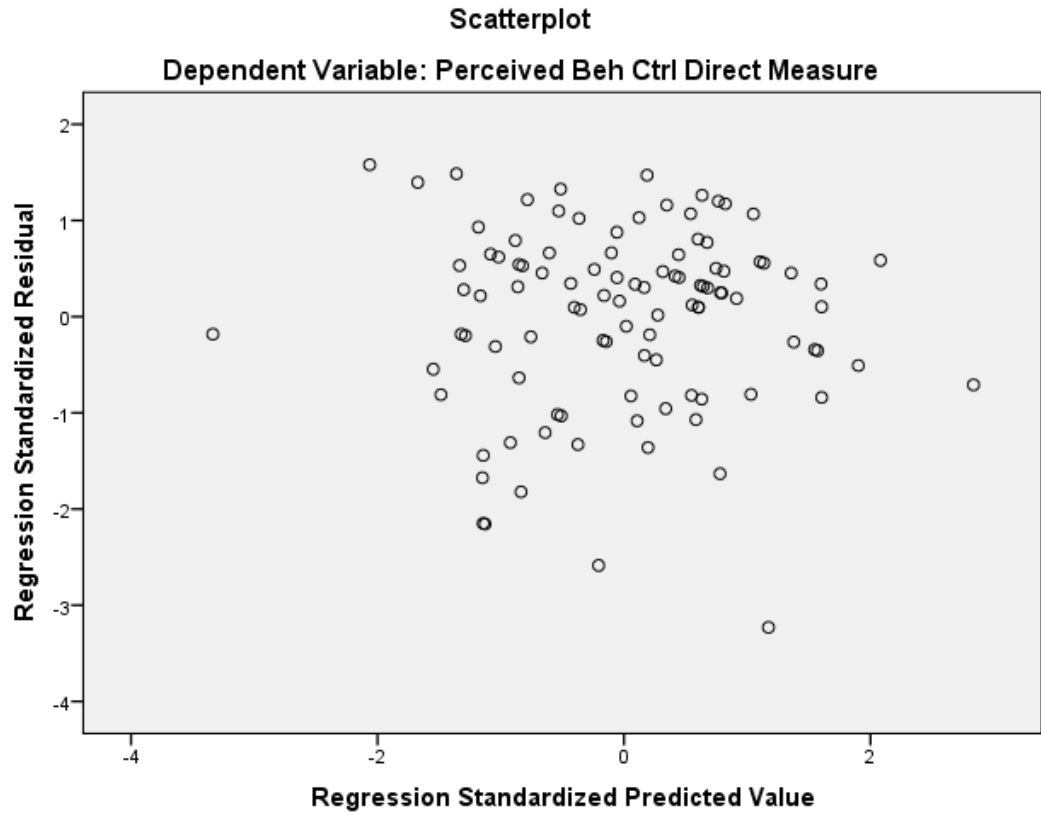


Figure 9. Plot of standardized residuals and standardized predicted values for the regression analysis with the direct measure of perceived behavioral control as the dependent variable and with the external variables.

Normality of errors. The normality of errors was assessed by creating histograms of the residuals for each of the six linear regression models. These histograms are shown in Figures 10 through 15. Figures 10 through 13 show normality for the residuals in both regression models involving direct measures of both attitudes and subjective norms. In Figures 14 and 15, there is some evidence of slight non-normality for the residual histograms with some negative skewness in both distributions. However, even these two figures show mild deviations from normality, and therefore the planned regression analyses were performed and are interpreted in the next section.

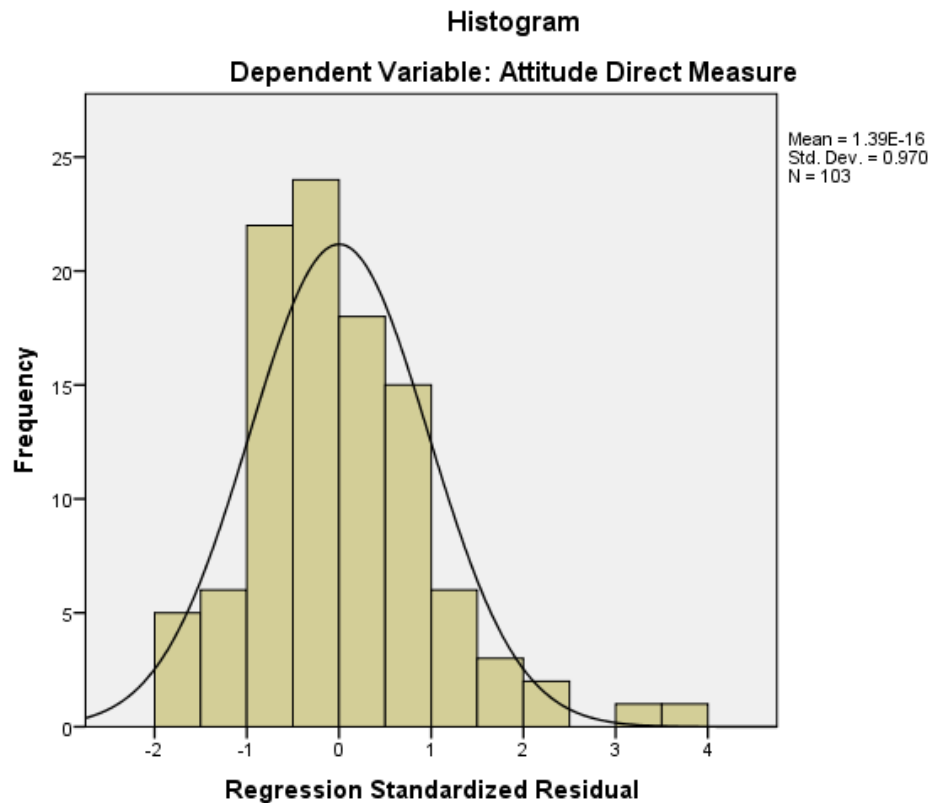


Figure 10. Histogram of standardized residuals for the regression analysis with the direct measure of attitudes as the dependent variable and without the external variables.

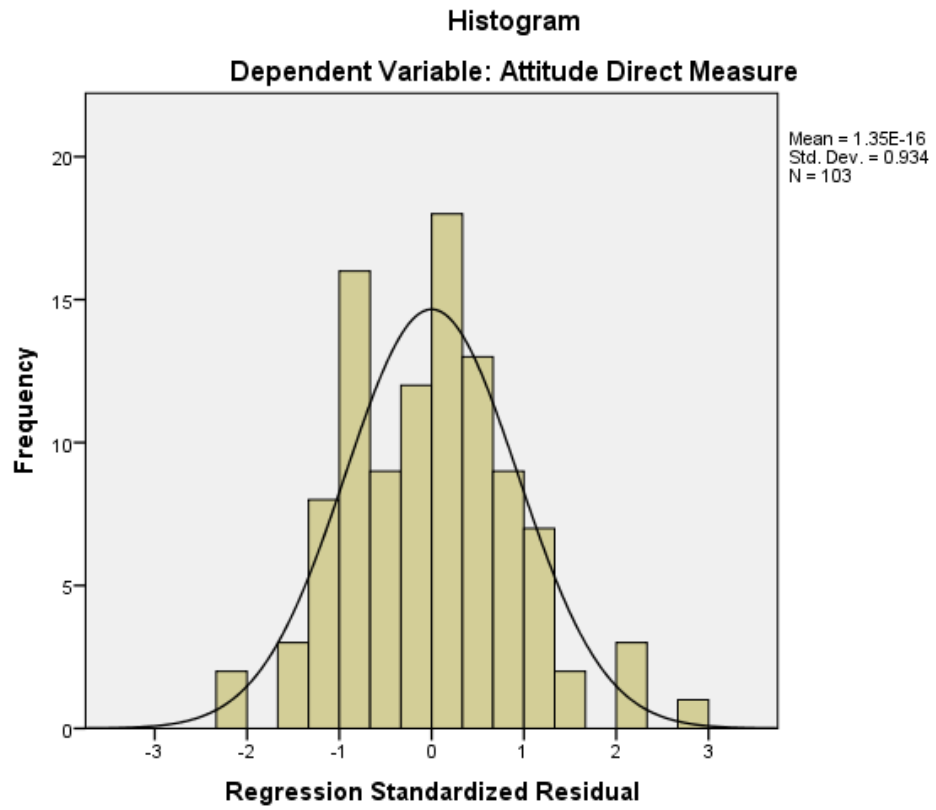


Figure 11. Histogram of standardized residuals for the regression analysis with the direct measure of attitudes as the dependent variable and with the external variables.

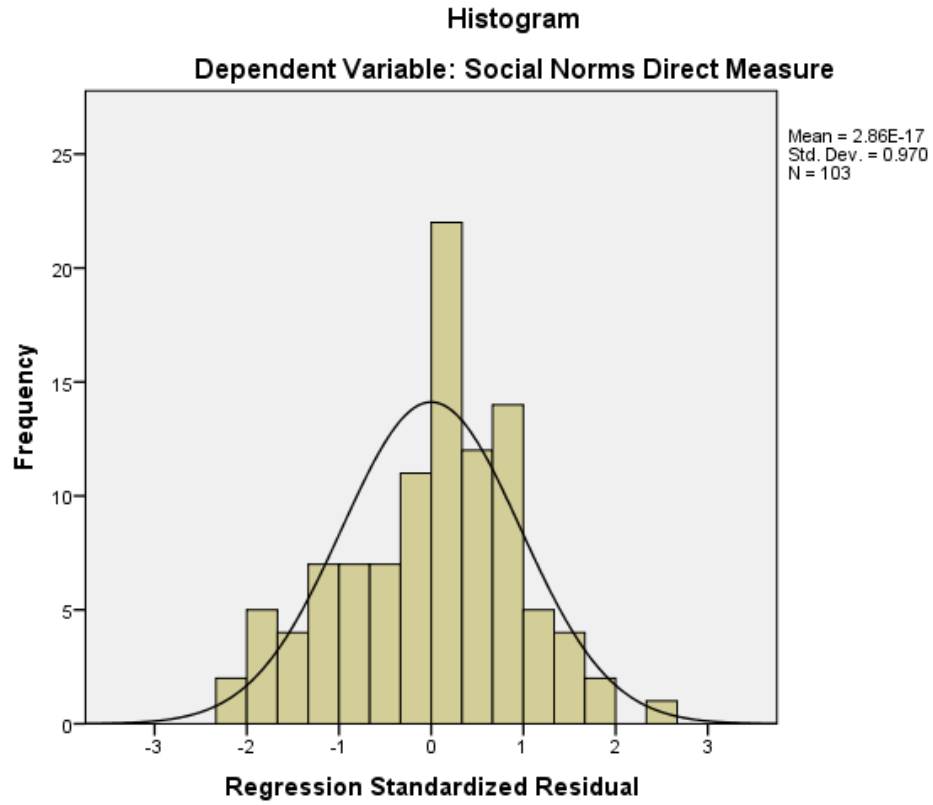


Figure 12. Histogram of standardized residuals for the regression analysis with the direct measure of subjective norms as the dependent variable and without the external variables.

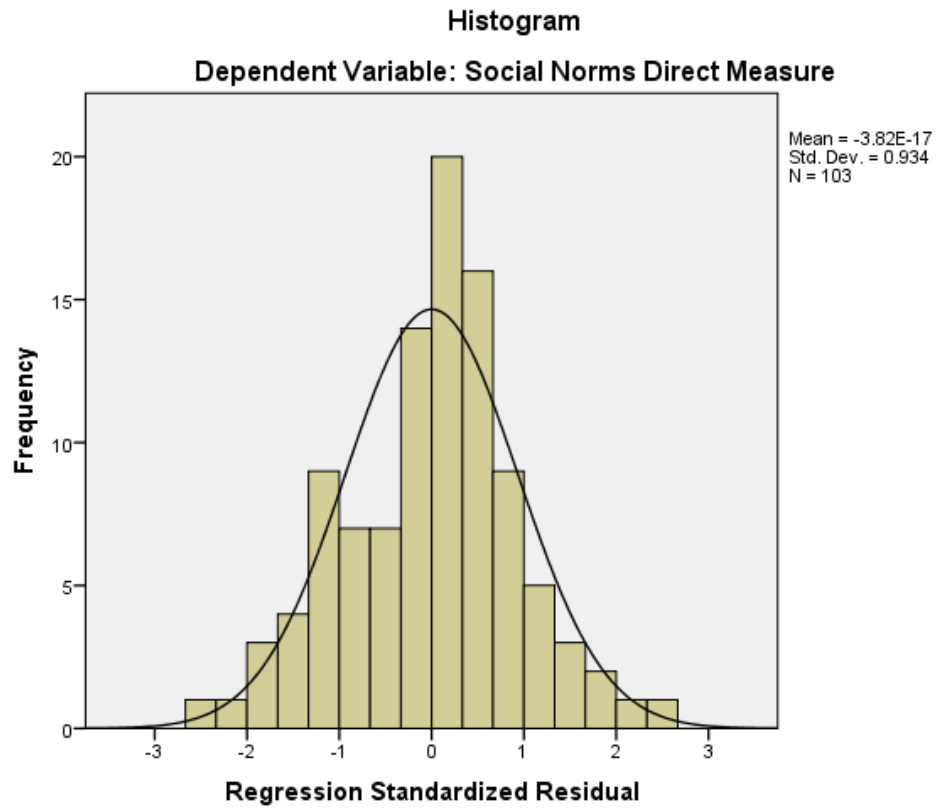


Figure 13. Histogram of standardized residuals for the regression analysis with the direct measure of subjective norms as the dependent variable and with the external variables.

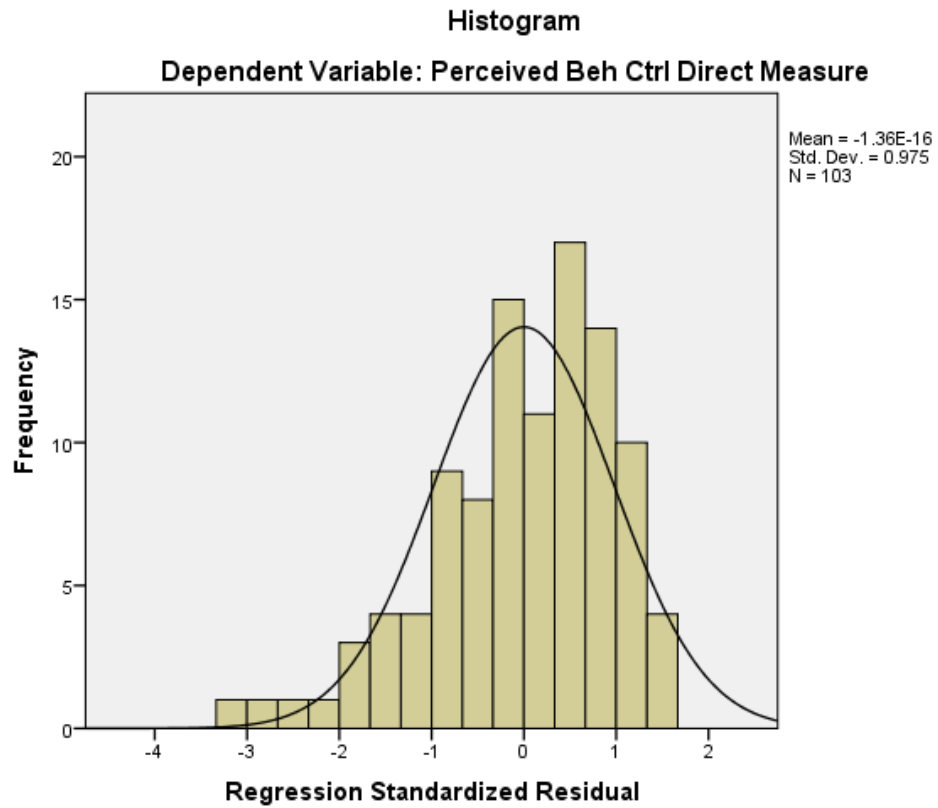


Figure 14. Histogram of standardized residuals for the regression analysis with the direct measure of perceived behavioral control as the dependent variable and without the external variables.

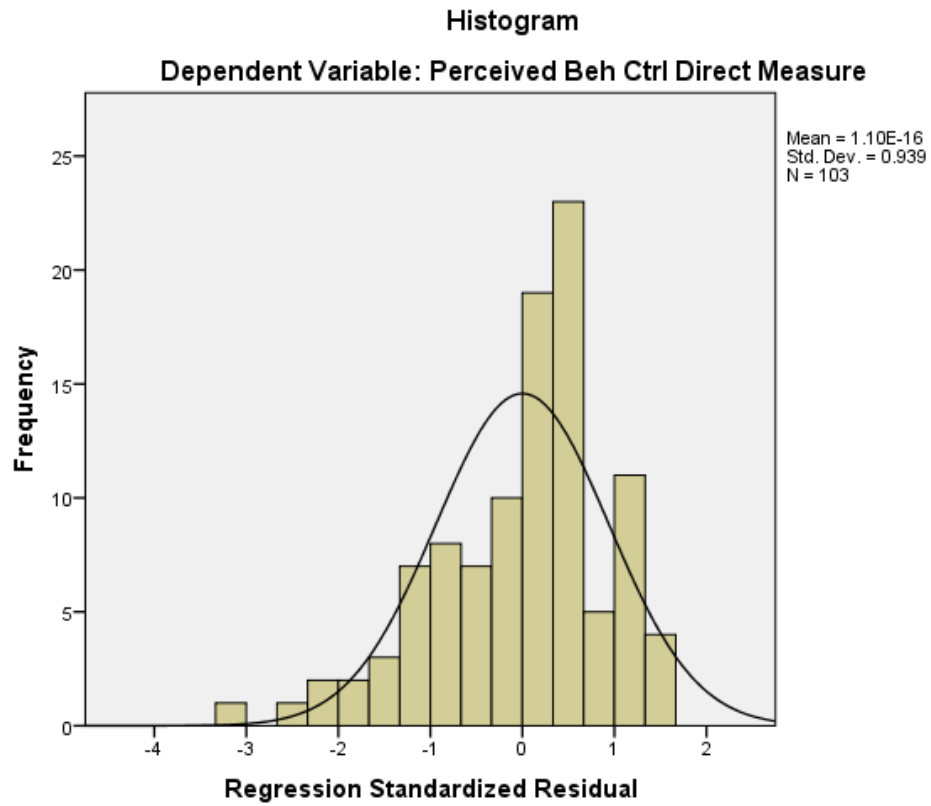


Figure 15. Histogram of standardized residuals for the regression analysis with the direct measure of perceived behavioral control as the dependent variable and with the external variables.

Regression results for direct measure of attitude. The first two linear regression analyses had the direct measure of attitudes as the dependent variable. The first model did not contain the external variables while the second model did include the external variables. The results from all models are shown in Table 15. For Model 1 (without the external variables), the overall model was statistically significant, $R^2 = .39$, $F(6, 96) = 10.29$, $p < .001$. The R^2 of .39 indicated that 39% of the variance in the direct measure of attitude was explained within the model. Individually, three of the independent variables were statistically significant. Higher scores on the direct measure of attitudes were associated with higher scores on the “endangering their own health” belief scale ($\beta = .23$, $p = .042$), higher scores on the “legacy” belief scale ($\beta = .21$, $p = .018$), and higher scores on the “burdening family and friends” belief scale ($\beta = .29$, $p = .014$).

In Model 2 (with the external variables), the R^2 increased by .11 ($\Delta F(7, 89) = 2.94$, $p = .008$) for an overall R^2 of .51 ($F(13, 89) = 7.00$, $p < .001$). “Endangering their own health” belief and “legacy” belief were still statistically significant, although “burdening family and friends” belief was no longer statistically significant. Among the external variables, only one was statistically significant: higher scores on the direct measure of attitudes were associated with younger age ($\beta = -.25$, $p = .011$).

Due to the limited sample size and the risk of being underpowered, the analysis was computed again with only the significant variables in the model. In model 3, the R^2 decreased from model 1 by .08 ($\Delta F(7, 89) = 2.94$, $p = .008$) for an overall R^2 of .31 ($F(3, 99) = 16.32$, $p < .001$). The results were the same as the original model 2: “Endangering their own health” belief and “legacy” belief were still statistically significant, although “burdening family and friends” belief was no longer statistically significant. Among the

external variables, age was still statistically significant: higher scores on the direct measure of attitudes were associated with younger age ($\beta = -.17, p = .04$).

Table 15

Standardized Regression Coefficients from Regression Analyses with the Direct Measure of Attitudes as the Dependent Variable (N = 103)

Independent variable	Model 1	Model 2	Model 3
“Endangering their own health” belief	.23*	.21*	.45*
“Normalcy” belief	.00	.00	
“Endangering the health of the child” belief	.18	.19	
“Legacy” belief	.21*	.21*	.24*
Passing on the CF gene belief	-.13	-.07	
“Burdening family and friends” belief	.29*	.17	
Age		-.25*	-.17*
Relationship status		.16	
Education		.14	
Race/ethnicity		-.04	
Employment status		.02	
Income		.12	
Life satisfaction		.14	
R^2	.39	.51	
F	10.29***	7.00***	

* $p < .05$, ** $p < .01$, *** $p < .001$.

Regression results for direct measure of subjective norms. The next two linear regression analyses had the direct measure of subjective norms as the dependent variable. Again, Model 1 did not contain the external variables while Model 2 did contain the external variables, and the results from all models are shown in Table 16. Model 1 was statistically significant, $R^2 = .68$, $F(4, 98) = 52.36$, $p < .001$. The R^2 of .68 indicated that 68% of the variance in the direct measure of subjective norms was explained within the model. In Model 1, three of the independent variables were statistically significant: higher scores on the direct measure of subjective norms were associated with higher scores on the social referents, “partner” ($\beta = .16$, $p = .05$), “mother” ($\beta = .47$, $p = .00$), and “friends” ($\beta = .23$, $p = .02$).

In Model 2 (with the external variables), the R^2 increased by .02 for an overall R^2 of .70 ($F(11, 91) = 19.79$, $p < .001$). The social referent, “partner” was no longer significant ($\beta = .12$, $p = .16$), but “mother” ($\beta = .44$, $p < .001$) and “friends” ($\beta = .24$, $p = .02$) were still statistically significant in Model 2. In addition, age was statistically significant ($\beta = -.14$, $p = .049$). This indicated that younger participants tended to have higher scores on the direct measure of subjective norms.

The model was executed again, as was with the previous models, with significant variables only due to the issue of being underpowered. In Model 3, the R^2 increased by .12 for an overall R^2 of .82 ($F(3, 99) = 67.97$, $p < .001$). The external variable, “age” was no longer significant ($\beta = -.10$, $p = .11$), but “mother” ($\beta = .51$, $p < .001$) and “friends” ($\beta = .33$, $p < .001$) were still statistically significant in Model 3. This indicated that the mother and friends of women with CF influenced subjective norms regarding pregnancy.

Table 16

Standardized Regression Coefficients from Regression Analyses with the Direct Measure of Subjective norms as the Dependent Variable (N = 103)

Independent variable	Model 1	Model 2	Model 3
Social referent, partner	.16*	.14	
Social referent, mother	.47**	.43***	.51**
Social referent, CF physician	.07	.08	
Social referent, friends	.23*	.22*	.33**
Age		-.15	-.10
FLZ-CF		-.07	
Relationship status		.01	
Education		.09	
Race/ethnicity		-.03	
Employment status		.06	
Income		.02	
R^2	.68	.70	.82
F	52.36***	19.79***	67.97***

* $p < .05$, ** $p < .01$, *** $p < .001$.

Notes. For the demographic variables, the following coding was used: for relationship status, 0 = *single or in a relationship* ($n = 48$) versus 1 = *married* ($n = 55$); for education, 0 = *less than a bachelor's degree* ($n = 64$) versus 1 = *bachelor's degree or higher* ($n = 39$); for race/ethnicity, 0 = *Caucasian* ($n = 100$) versus 1 = *other* ($n = 3$); for employment status, 0 = *not employed* ($n = 46$) versus 1 = *employed* ($n = 57$); and for income, 0 = *not more than \$40,000 per year* ($n = 53$) versus *more than \$40,000 per year* ($n = 50$).

Regression results for direct measure of perceived behavioral control. The final two linear regression analyses had the direct measure of perceived behavioral control as the dependent variable. Model 1 did not contain the external variables while Model 2 did contain the external variables. The results from these two models are shown

in Table 17. Model 1 was statistically significant, $R^2 = .13$, $F(5, 97) = 2.97$, $p = .015$. The R^2 of .13 indicated that 13% of the variance in the direct measure of perceived behavior control was explained within the model. In Model 1, two of the independent variables were statistically significant: higher scores on the direct measure of perceived behavior control were associated with lower scores on the Supportive partner scale ($\beta = -.32$, $p = .040$) and lower scores on the “CF related complications” control belief scale ($\beta = -.23$, $p = .049$).

In Model 2 (with the external variables), the R^2 increased by .07 ($\Delta F(7, 90) = 1.05$, $p = .404$) for an overall R^2 of .20 ($F(12, 90) = 1.85$, $p = .051$). Neither the increase in R^2 (from Model 1 to Model 2) nor the overall Model 2 R^2 was statistically significant. In Model 2, the two statistically significant variables from Model 1 were no longer statistically significant (supportive partner and “CF related complications” control belief). In addition, none of the external variables were statistically significant in Model 2.

Summary of Findings

This chapter contained a description of the results from this study. The first research question in this study was: What are the contributions of attitudes, subjective norms, and perceived behavioral control for women with CF in predicting pregnancy intention and do external variables significantly contribute to the prediction of pregnancy intention beyond the TPB constructs? The results indicated that: (a) higher scores on the direct measure of attitude were associated with a higher likelihood of being likely to intend pregnancy, (b) higher scores on the products of normative beliefs and motivation to comply measure were associated with a higher likelihood of being likely to intend pregnancy, and (c) participants who were employed were less likely to be likely to intend pregnancy. Therefore, the answer to the first research question of this study was that among women with CF the direct measure of attitudes and products of normative beliefs

Table 17

Standardized Regression Coefficients from Regression Analyses with the Direct Measure of Perceived Behavioral Control as the Dependent Variable (N = 103)

Independent variable	Model 1	Model 2
Medication and treatments control belief	-.05	.02
Supportive partner control belief	-.32*	-.29
CF related complications control belief	-.23*	-.23
Supportive family control belief	.12	.09
Financial Security control belief	.20	.17
Age		-.12
Relationship status		-.16
Education		-.04
Race/ethnicity		-.01
Employment status		.07
Income		.04
Life satisfaction		.10
R^2	.13	.20
F	2.97*	1.85
ΔR^2		.07
ΔF		1.05

* $p < .05$, ** $p < .01$, *** $p < .001$.

Notes. For the demographic variables, the aforementioned coding structure was used again for this model.

and motivation to comply made a significant contribution to predicting pregnancy intention. In addition, one of the external variables, employment status, made a significant contribution to predicting pregnancy intention, with employed participants being less likely to intend pregnancy.

The second research question was: What are the pertinent influential behavioral beliefs, specific referents, and perceived power factors that influence these attitudes, subjective norms, and perceived behavioral control? In the analysis of the direct measure of attitudes, the results showed that higher scores on the direct measure of attitudes were associated with higher scores on the “endangering their own health” belief and higher scores on the “legacy” belief scale. In addition, higher scores on the direct measure of attitudes were associated with younger age. In the analysis of the direct measure of subjective norms, the results indicated that higher scores on the direct measure of subjective norms were associated with greater influence from mothers and friends. Finally, in the analysis of the direct measure of perceived behavioral control, the results showed that higher scores on the direct measure of perceived behavior control were associated with lower scores on the supportive partner scale and lower scores on the “CF related complications” control belief scale. In the next chapter, these results are discussed in the context of past research and recommendations are offered for policy, practice, and future research.

Chapter 5

Discussion

The purpose of this research was to examine pregnancy intention among a sample of women with Cystic Fibrosis (CF). A total of 103 women with CF, from the United States, without biological children, between the ages of 18-45, completed an online survey based on the Theory of Planned Behavior. This chapter contains a review and analyses as they relate to current literature in CF and pregnancy intention among women with HIV. The limitations of the study are also discussed and recommendations for future research, policy and practice are made.

Results

Descriptive and frequency data will be discussed prior to the discussion of the two research questions. The literature surrounding this topic is so sparse that the descriptive and frequency data present substantial value. Each research question and the accompanying analyses will be reviewed following the descriptive and frequency data discussion.

Descriptive data

Overall, the sample was similar to the adult population of people with CF (CFF, 2013). Gender specific data is not available, thus comparisons to the population should be interpreted with caution. The relationship profile is particularly important for pregnancy intention, since traditional conception requires a male counterpart. Although gender specific data is not available, this sample does differ from the relationship profile of both men and women with CF age 18 and older (CFF, 2013). Only 13.6% of this sample considered themselves “single” whereas 54.9% of adults with CF age 18 and older identify as single. For purposes of this study, it was important to ascertain levels of relationship that would yield more information, thus the category of “single” meant

anyone who was not currently in a relationship. The CFF data may describe people who are “single” even though they may identify as being in a relationship, though not living together.

The sample resembled more closely the adult population in the education profile. Twenty-nine percent of adults with CF over age 18 have an undergraduate degree (CFF, 2013), where the current sample had 28.2%. However, the current sample differed in the remaining categories, having more participants in the “some college” category (52.4% versus 33.7%) and slightly more in the “graduate degree” category (9.7% versus 5.7%). CF is the most commonly inherited disease in Caucasian populations and the sample demographics reflect this tendency. For all people with CF, 94.1% of the population is Caucasian (CFF, 2013), whereas this sample was 97.1% Caucasian. Therefore, the current sample reflected a similar proportion of Caucasians as the whole CF population. Finally, employment status was similar to the adult population of those with CF. The sample of women with CF were mostly employed full-time, which is similar to the adult population (29.1% versus 33.6%) and had somewhat similar disabled proportions (23.3% versus 17.0%) (CFF, 2013). This study did not differentiate between part-time employment and student status, whereas the CFF data does make this distinction.

The descriptive and frequency data accumulated as part of the survey provide a cross-sectional analysis of women with CF, between the ages of 18-45 in the United States. Gender-specific data is limited in the literature, thus this demographic information may lend value to describing this subset of women with CF. Next, frequency and descriptive data will be discussed in the context of the dichotomized groups of likely and unlikely to intend pregnancy.

Pregnancy Intention. Of the 103 women with CF surveyed in this analysis, 46.6% of respondents reported intending to become pregnant. This data provides the first

estimation of pregnancy intention among women with CF from the United States. Currently, retrospective data from the CFF reporting number of pregnancies per year is the only measure for pregnancy among women with CF, and does not differentiate between first or subsequent pregnancies, so a comparison to the population is not possible with the available data. However, a recent Gallop poll shows that among the general population, 40% of men and women surveyed in the US, age 18-44, who do not have children hope to have children someday (Newport & Wilke, 2013). While this information is not generalizable to the current sample, it does offer a point of comparison to illustrate that rates of pregnancy intention for women with CF may be somewhat similar to healthy controls. Regardless, this comparison should be interpreted with caution.

This trend has also been reported among women with HIV. The intention or desire to become pregnant or continue a pregnancy does not seem to be affected by HIV status (Finocchiaro-Kessler, Sweat, et al., 2012; Finocchiaro-Kessler, Sweat, et al., 2010; MacCarthy et al., 2012). Similar rates of pregnancy desire and intention are reported among women with HIV as is in the general population (Finocchiaro-Kessler, Sweat, et al., 2012). Although CF and HIV are greatly important in the lives of these women and the process of family planning, the diseases do not seem to supersede the drive for pregnancy and thus, children.

Bivariate analyses resulted in some statistically significant differences between those intending to become pregnant and those who are not intending to become pregnant. Employment status, income, and age differed between the groups; unemployed, lower income, and younger respondents were related to the likelihood of intending to become pregnant. Employment has been documented to decrease the likelihood of pregnancy (Budig, 2003), and younger age and lower income are well documented predictors of

pregnancy. Employment status and age remained significant in some of the multivariate analyses and these variables are further discussed in the context of the literature in the next section.

Research Question One

The overall logistic regression model was statistically significant, indicating statistically significant prediction of pregnancy intention among the sample of 103 women with CF. However, the hypothesis that attitudes, subjective norms, and perceived behavioral control for women with CF will predict pregnancy intention was not fully supported. Furthermore, the hypothesis that external variables will not significantly contribute directly to the prediction of pregnancy intention beyond attitudes, subjective norms, and perceived behavioral control was also not supported.

The only direct measure that was predictive of pregnancy intention was attitudes; more favorable attitudes towards pregnancy among women with CF indicated a greater likelihood of pregnancy intention. This is congruent with theoretical assumptions that more favorable attitudes will result in a greater likelihood of behavioral intention (Fishbein & Ajzen, 2010). Favorable attitudes have also been associated with the desire for future pregnancy among young women with HIV (Murphy, Mann, O’Keefe, Rotheram-Borus, 1998).

Although the direct measure for subjective norms was not significant, the products of normative beliefs and the motivation to comply were significant. This may suggest that the direct measure did not fully capture the concept or the study was underpowered to identify a weak contribution. Previous research with women who have HIV have reported that social norms and a woman’s support network influence pregnancy intention, but that the finding was weak (Craft et al., 2007).

Neither the direct measure nor the products of control beliefs and perceived power were significant. This may be understood in the context of pregnancy and the logistical consideration that the behavior requires two parties. Therefore, control over pregnancy intention is highly dependent upon the consent of a partner for traditional conception. This may also be indicative of the overall misunderstanding and confusion women with CF may have regarding their own fertility (Cambridge, 2013). Furthermore, in a multivariate analysis of women with HIV and pregnancy intention, perceived control was not found to be a significant predictor either (Finocchiaro-Kessler, Sweat, et al., 2012). Finocchiaro-Kessler, Sweat, and colleagues (2012) explained that bivariate analyses suggested those who had absolute control over pregnancy decision making were significantly less likely to intend or desire pregnancy. This may illustrate the issue that a great deal of control over the decision to pursue a pregnancy could be related to the absence of a partner, which traditional conception is dependent upon. This finding may also indicate a limitation with the TPB model and suggest that, possibly, the TRA may have been a better fit.

Although external variables were not hypothesized to contribute to the model, employment status actually did contribute. In fact, employed respondents were less likely to intend to become pregnant. Previous research from a large UK sample of women with CF correlated unemployment with a greater likelihood of having a pregnancy (Boyd, Mehta, & Murphy, 2004). However, this study was retrospective after birth and the authors suggested they were more likely to be unemployed because the women stayed home to care for their children. Overall, employment reduces the likelihood of pregnancy among women (Budig, 2003), suggesting that this finding may correspond with trends in the general population and may not be specific to women with CF.

Research Question Two

The overall models testing the pertinent influential behavioral beliefs, specific referents, and perceived power factors that influence attitudes, subjective norms, and perceived behavioral control were statistically significant.

Attitude and pertinent beliefs. Three behavioral beliefs were statistically significant in the regression model for attitude. First, the belief that becoming pregnant may burden one's social support network was found to contribute the greatest amount to the model. That is, the degree to which a woman with CF believed this to occur, impacted her attitude towards pregnancy intention among women with CF. This is supported by previous literature, which suggests that social support is important for the well-being of a mother with CF (Tuchman & Gisone, 2010). Cammidge (2013) reported mothers with CF had feelings of guilt due to their reliance on partners and other family members to assist in the care of their children. Mothers with CF also reported establishing adequate support networks prior to motherhood, after having the foresight to know they would need this additional support (Cammidge, 2013). This issue was also expressed in qualitative work with women who have HIV, where women reported being concerned that their health and death may burden their families with caring for the children (Kirshenbaum et al., 2004).

Next, the belief that becoming pregnant may endanger her health was found to contribute to the measure of attitude. That is, the degree to which a woman with CF believed pregnancy may negatively affect her health, impacted her attitude towards pregnancy intention among women with CF. Although the question targets pregnancy, it may be difficult to extrapolate whether respondents believed pregnancy would impact their health or if they also equated pregnancy with motherhood. While pregnancy does impact the health of a woman with CF (Whitty, 2010), mothers with CF report struggling to maintain treatment adherence, particularly when caring for a newborn baby (Cammidge, 2013). Women with HIV consistently reported that personal health issues

influence family planning decision-making (Craft et al., 2007) and further qualitative work also found concerns specific to decreased health during pregnancy (Kirshenbaum, 2004).

Finally, the belief that having a child would contribute to the woman's legacy was found to contribute to the attitude measure. That is, the degree to which a woman with CF believed having a child would leave a legacy for herself, impacted her attitude towards pregnancy intention among women with CF. Pregnancy and motherhood is a time that causes one to reflect on her own mortality (Nelson, 2003) and mothers with CF have reported a keen awareness of their limited lifespan (Cambridge, 2013), thus the idea of having a legacy after they are deceased may appeal to women with CF who intend to become pregnant. Nelson's (2003) meta-synthesis suggests that this reflection on mortality is a common occurrence for women who do not have a chronic illness, thus it may be of equal or greater importance for women with CF. Child and Maxwell (2009) presented an anecdotal case of a woman with HIV who was clear in asserting that her legacy would continue through a child once she died, which was similar to several statements made by respondents in the elicitation interviews of the current study.

Although the remaining three beliefs (endanger the health of the child, normalcy, and passing on the CF gene) emerged from the elicitation interview data, they were not found to contribute to the attitudinal variable. One respondent chose to indirectly provide feedback regarding one of these belief questions by posting on a closed Facebook group where the study link was distributed (personal communication, 2013 August 26). The respondent was offended by the stem of "endangering the health of the child" and felt as though the survey was denigrating women with CF. Although this was not echoed from other participants, some did agree that the stem was harsh. This feedback may indicate that the stem was phrased too harshly or poorly and may have been a poorly constructed

stem or simply not a widely-held belief from the population, despite the terminology originating from the elicitation interviews. The concern with the potential child's health and the ability to provide for the child during pregnancy is a concern of some women with HIV (Craft et al., 2007), particularly the issue of vertical transmission of HIV. However, this is not a strong support for the use of the belief with women with CF since transmission of the diseases is so different.

The belief that pregnancy would contribute to a feeling of being “normal” or “like everyone else” was also found not to be a statistically significant contributor to the attitudinal variable. This may be accounted for by previous research that suggests mothers with CF felt similar to healthy mothers (Cambridge, 2013), thus the notion of being “normal” may not apply if they already perceive themselves as so. While this may not be an issue for women with CF, pursuing pregnancy as a sense of normalcy has been reported by women with chronic illness (Tyler-Viola & Lopez, 2014).

Finally, the belief that passing on the CF gene would contribute to the attitudinal variable was not supported. Despite this result, some women in Cambridge's (2013) study mentioned feelings of guilt when discussing their children as possible CF gene carriers. This was not a strong theme in Cambridge's study, thus both studies may be underpowered to identify this variable or it may truly not contribute to attitudes.

Despite the hypothesis that external variables would not contribute to the model, younger age did contribute to more positive attitudes towards pregnancy intention. Although the contribution was small, it was statistically significant. Initial bivariate analysis support this finding in that it also reported a statistically significant difference in age between those likely to intend to become pregnant and those unlikely; those likely to intend a pregnancy were younger ($M = 25.83$) than those who were unlikely to intend a pregnancy ($M = 28.69$). This is not a surprising result since a shortened lifespan may

create a sense of urgency not experienced in a healthy population. One respondent in the elicitation interviews detailed her own quest for a child since adolescence and cited a feeling of urgency due to her health and shortened lifespan. Research with women who have HIV support this finding, also reporting that younger age is related to a greater likelihood of intention and desire for pregnancy (Craft et al., 2007; Stanwood et al., 2007). Furthermore, a study of young women with HIV ($M=19.9$ years) suggested that even at a time that vertical transmission of HIV was much more likely, they still held positive attitudes towards pregnancy (Murphy et al., 1998).

Fishbein and Ajzen (2010) posit that background factors, such as demographic variables like age, may have an effect on the target behavior through the theoretical variables. That is, age should influence the beliefs, which should still predict the outcome. Further analysis of age and the pertinent beliefs revealed that younger age was correlated with the “burdening family and friends” belief; that is, as age decreased, the belief that having a child would burden one’s family and friends increased. This may be related to less independence in younger adults, particularly in the CF population. People with CF require involvement from their family members into adulthood and research suggests that family involvement decreases only minimally when adults with CF live independently (McGuffie, Sellers, Sawicki, & Robinson, 2008).

Subjective norms and pertinent referents. Results for those pertinent social referents suggested that the model was significant. Partner, mother, and friends were indicated as the significant contributors to subjective norms. The importance of a partner’s influence is well documented in previous literature. Cammidge’s (2013) findings suggest that mothers with CF value their partner’s support and guidance. This result is also supported by data on women with HIV, who also cite their partners as important influences on pregnancy decision-making (Craft et al., 2007; Finocchario-

Kessler, Mabachi, et al., 2012; Finocchiaro-Kessler, Sweat et al., 2012; Sowell et al., 2002;). However, when the “partner” referent was added to model two, it was no longer significant whereas age was significant and contributed a small amount of variance. The final model only indicated that “mother” and “friends” were influential in the subjective norms of women with CF. This contrasts to the preexisting literature that suggests that a woman’s partner is the most influential person. However, in one recent study of adult CF patients, spouses accounted for just over half of the family caregivers, indicating that around 44% of family caregivers are parents, siblings, or friends (McGuffie, 2008). What’s more, 42% of CF adults receiving care from their parents who were not living with them were also married (McGuffie, 2008), suggesting that family involvement in CF care continues into adulthood, oftentimes despite a change in the next of kin role. This may contribute to the unique finding in the current study, in that people with CF tend to have greater family involvement well into adulthood. Furthermore, the “partner” variable was significant in the initial model, thus suggesting that there may be a methodological error or suppression or confounding effects in the statistical model which affected the variable.

The lack of significance for the CF physician as a pertinent social referent is also in opposition of previous literature. Cammidge (2013) reports that women value the CF care team’s support and recommendations for pregnancy and motherhood. Furthermore, Craft et al. (2007) found that women with HIV value their healthcare team’s recommendations even above their partners’ and discussed pregnancy with their healthcare team more than their other family members outside of their partners.

Perceived behavioral control and pertinent beliefs. The control beliefs were significant in the overall regression model for perceived behavioral control, though only accounting for 13% of the variance. Control beliefs related to having a supportive partner

and CF-related complications both contributed to whether women with CF perceived they had control over becoming pregnant or not. The presence of a supportive partner may relate back to the point that traditional conception is only possible with a partner. CF-complications may also relate to some of the confusion that women articulated in the elicitation interviews over challenges to fertility.

Theoretical Implications

The direct measure of attitude contributed the most to the model, suggesting that attitudes towards pregnancy intention among women with CF may influence the behavioral intention more than other components. Although normative beliefs and motivation to comply contributed to the model, they accounted for much less than attitudes. This is an expected finding according to Fishbein and Ajzen (2010) and they explain that the degree of contribution may differ according to the topic. Although social norms exist for the topic of pregnancy, ultimately it may be considered a matter between a woman and her partner since literature for both CF and HIV suggest that partners contribute a great deal to the decision making process. Perceived behavioral control seemed to have no influence in the model and may be related back to issues of the target behavior requiring another individual to participate and also to confusion over fertility and CF. This may also indicate that the TPB was, in fact, not the best fit for this topic. Since perceived behavioral control was not nearing significance and seemed to clearly have no contribution, this may not be pertinent for the topic with this population. In fact, the TRA, which does not include perceived behavioral control, may have been a more appropriate model for this topic and population.

External variables should not have contributed to the model above theoretical variables. However, both age and employment status were statistically significant in different models. As directed by Fishbein and Ajzen, analyses to explore relationships

between the external, background factors and the beliefs resulted in significant correlations that may suggest age influences beliefs, thus indirectly influencing pregnancy intention.

Cystic Fibrosis related quality of life, as measured by the FLZ-CF®, was not statistically significant in any model. This result suggests that health related quality of life may not impact one's decision to pursue a pregnancy. Despite this result, women with CF who have poor lung function (<60% FEV¹) are cautioned against pregnancy (Edenborough et al., 2010). Furthermore, the decline and disease trajectory of CF can be difficult to predict (Orenstein, 2003), so a person with CF may experience a rapid, unexpected decline with little explanation. Research from women with HIV and pregnancy intention reports similar results. Finocchiaro-Kessler, Sweat, (2012) and colleagues reported no relationship between pregnancy intention and subjective measure of health. Barnes et al. (2009) reported that HIV-related health conditions were less influential than personal reasons when understanding family planning among women with HIV. However, Chen et al. (2001) explained that HIV health status affected one's desire for children, so if a woman does not have the desire to have children, she will not intend to become pregnant.

Study Limitations

Diligent efforts were made to reduce threats to the validity of the study, however the results must be interpreted within the context of the study limitations. Limitations are present in both the formative research phase as well as the primary study. Although this is an exhaustive discussion of the limitations, all limitations may not be accounted for fully.

The Theory of Planned Behavior, while valuable, did impose some limitations to the study. Due to time and feasibility constraints, it was not possible to test the target behavior, pregnancy. Instead, pregnancy intention was utilized and a true prospective

design with longitudinal follow up would have improved the study. The theory may have also been limited by the topic; that is, there was considerable discussion in the pilot phase regarding control over becoming pregnant. As described in Chapter 3, this dilemma was addressed by adding two questions regarding control over become pregnant and control over not becoming pregnant. Since traditional conception requires the consent of a male counterpart, control over becoming pregnant was confusing for respondents.

Furthermore, the question over whether CF actually decreases fertility also confused respondents. The addition of the question of control over not becoming pregnant was added to account for this issue, however it may have only negated the responses provided regarding control over becoming pregnant and may account for a lack of contribution to the statistical models.

The formative research phase, and thus the entire study, is limited by the small convenience sample of women (n=6). The participants in this phase were recruited from one CF clinic and this recruitment strategy may affect the external validity, limiting the generalizability to all US women with CF. The small sample size may affect the accuracy of the elicited beliefs and beliefs that may be present may not have been accounted for in this limited sample. Saturation may not have occurred with so few interviews. Glaser and Strauss explain that saturation occurs when, “no additional data are being found whereby the (researcher) can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated . . .” (p. 65). Guest, Bunce, and Johnson (2006) suggest that interview structure, question content, and homogeneity of a group impact data saturation. Guest et al. (2006) explain that in order to reach saturation with the fewest participants, the interview questions should remain constant across participants, the content of the questions should cover knowledge or experiences that are widely-shared with the population and the participants

should be more homogenous than heterogeneous. The interview schedule did not change for the interviews, and although some of the six women with CF had pregnancies and some did not, motherhood and pregnancy are a common human experience that adult women encounter. Finally, although one participant considered herself no longer in her childbearing years, the other five women did consider the topic applicable to them. Guest et al. (2006) further explain that if the researcher's goal is to identify shared perceptions, beliefs, and behaviors among a relatively homogenous group, then saturation should be attained by interviewing 12 individuals (Guest et al., 2006). However, Guest et al. (2006) were able to identify meta-themes as early as six interviews.

Other issues that may impact both the formative research and primary research include those reporting biases related to self-reported surveys. Self-report measures are vulnerable to participants with strong feelings about the topic, which may be applicable to the topic of pregnancy and parenthood. Furthermore, since the topic of pregnancy is related to sex and personal health, respondents may have been influenced by social desirability factors. Participants may have responded in an effort to meet perceived social standards of someone who intends or does not intend to become pregnant.

Sufficient sample size was not attained to reach .80 power for all of the models in both research questions. Although the models were modified and executed using those significant variables in the final models, the full models could not be evaluated with every variable. This limits the generalizability of the results, but this is an issue that is prevalent in previous psychosocial and biomedical research in CF due to the challenges of a small sample population (e.g. Driscoll, Schatschneider, McGinnity, & Modi, 2012). The FDA considers CF an "orphan disease" since it affects fewer than 200,000 people nationwide (FDA, 2012) and biomedical research was largely underpowered prior to the development of a the CFF's CF Therapeutics Development Network which was

developed for the purpose of promoting clinical trials with sufficient power (Rowe, Borowitz, Burns, Clancy, Donaldson, Retsch-Bogard ... Ramsey, 2012.) Reaching the population is a challenge and the best yield came from online sources with the assistance of allies in the CF community. However, collecting data online presents its own limitations, including the fact that the participants' CF diagnosis cannot be confirmed.

Multicollinearity was an issue, particularly for the subjective norms data. Although the diagnostic criteria were not met, throughout the analysis there were issues with the variables of "father" and "mother" and "other family". Though this was accounted for by reducing "father" and "other family" into a new scale, there may be a flaw with the survey item "other family members". It may have been interpreted as inclusive of one's familial social network, rather than the original intention of defining family members outside of parents and partner. This may also indicate an issue with the dependent variable of pregnancy intention. If a woman with CF has not discussed the future possibility of pregnancy, is not in a relationship or in a relationship that she feels is long-term, or simply does not intend to become pregnant, subjective norms may simply not apply. In fact, the mean scores for the direct measure of subjective norms and for each social referent are close to neutral (range 0.93-2.97). More evidence that this may be due to poor survey design is that respondents did indicate that having a "supportive partner" was a significant control belief. The instrument reliability was also not ideal and it was not properly recalibrated prior to launching the survey.

Future Research

This study provides evidence of factors which may predict pregnancy intention among women with CF. Replication is necessary not only for the weight of converging evidence, but to seek a well powered analysis in both the formative and primary research stages. Based on the findings of this study, the Theory of Planned Behavior may be a

viable theoretical foundation for understanding pregnancy intentions among women with CF, but the Theory of Reasoned Action should also be considered and tested.

Further endeavors into qualitative and quantitative models may provide more information and understanding of the topic. Qualitative research is needed to explore more fully the constructs which may govern the decision of women with CF to become pregnant. A grounded theory approach or pragmatic use of multiple qualitative tools may provide greater insight into this process of decision making and its effects on women with CF and those who care for and provide services for the population. Quantitative models may further the knowledge on the topic, and may be particularly useful in conjunction with biomedical data.

Some particular findings of interest may provide avenues for future exploration. Women with CF who were employed were less likely to intend to become pregnant and further analysis into the cause of this result may reveal greater understanding into women with CF. More exploration may also be warranted for understanding why younger women with CF have better attitudes towards intending to become pregnant and subjective norms. The concept of urgency, as described by some women in the elicitation interviews, may provide more insight into these results. Further qualitative work may aid in addressing the “why” of these results.

Questions about fertility issues among women with CF may also merit further exploration. In the elicitation interviews some women emphasized this issue multiple times. Although there is no epidemiological data to suggest a lower prevalence of pregnancy rates among women with CF versus healthy women, theoretically conception may be more difficult. The lack of clarity on the issue and the perceptions of women with CF regarding their own fertility warrants further examination.

Further comparisons may also be pursued, such as those comparing the US sample with European, Canadian, or Australian populations or comparisons using a prospective analysis of young women prior to having children and following up later after they have had children. Additional tools, such as more in-depth CF-related quality of life measures, may also be utilized to explore the topic. Since the medication that treats the defective CFTR protein, Kalydeco®, was approved during the course of this study a new avenue to pursue may include the impact of taking this medication on the decision-making process. This variable may have a great effect and as this medication and medications of this type are approved for other CF gene mutations, behavioral understanding of those with CF may drastically and swiftly change.

The results of the contribution of “legacy” to the model and the mentions of urgency to fulfill one’s life, directs future research into issues of mortality among women with CF. Whether women, or adults in general, with CF make choices or live differently due to a heightened sense of mortality may provide insight into decision-making. This may also be an avenue to explore among the whole CF population and qualitative work may assist in documenting whether mortality is heightened among those with CF and whether that affects their life course.

Finally, the influence of friends and family may also merit further inquiry, since this may be a population-specific phenomenon which affects practice and approach to care. Further confirmation of the influence of a larger support network could potentially influence practice and CF-care policy, thereby improving quality care. A framework of “caregiver coalitions” where the caregiver is an additional party to the care process, may be a new avenue to explore in adult CF care.

Contribution to Policy and Practice

This study provides the first quantitative evidence for understanding psychosocial aspects of pregnancy intention among women with CF. As such, the policy and practice implications for CF healthcare professionals, specifically CF social workers and psychologists, may be great. The results may also contribute to the evidence base for understanding pregnancy intention among other orphan disease populations and chronic illness populations.

CFF guidelines require an annual psychosocial assessment by a social worker at least annually to identify any psychosocial needs, and family planning should be reviewed and discussed in outpatient adult clinic (Yankaskas, Marshall, Sufian, Simon, & Rodman, 2004). Cammidge (2013) found that mothers with CF wanted supportive conversations with their CF treatment team in regards to motherhood and also noted that many women perceived their teams to be surprised and inexperienced at broaching the topic with them. The current study's findings may assist CF healthcare providers in knowing what factors are important to women with CF when discussing a potential pregnancy. Clinical interventions using family planning educational materials are wanted by women with CF (Cammidge, 2013) and women with CF report a lack of sexual and reproductive health knowledge (Gage, 2012). Although clinical policy guidelines include a discussion of family planning with adult CF patients, this study's results suggests that including the partner and family, beginning this process early, and discussing parenthood and employment are important in the discussion since these factors may contribute to pregnancy intention. Pregnancy among women with CF is also important for high-risk obstetrical (OB) care policies. Edenborough and Morton (2010) suggest women with CF should be considered "high-risk" and followed by a high-risk OB team in conjunction with a CF team, thus effective collaboration may include educating an OB team on the distinct needs of women with CF who are pregnant.

The significance of the social referents of mother and friends on the subjective norms variable emphasizes the importance of including a female patient's social support network into care planning. A mother with CF may require significant support (Delelis et al., 2008; Edenborough, 2008) and the findings of this study suggest social support factors into pregnancy decision-making. Clinic policies and practice interventions should include education for family members and partners of women with CF, as appropriate for each patient's particular social support composite.

Finally, there was some confusion mentioned in the elicitation interviews regarding fertility for women with CF. This may have affected the control variable, as previously discussed, and presents a particular opportunity for clinic interventions. Although Edenborough et al. (2008) have created a thorough compilation of guidelines for pregnancy among women with CF, this information should be updated and translated into materials that are accessible to women with CF and their families. As previously mentioned, women with CF lack information about sexual and reproductive health (Gage, 2012) and they desire to have the information and conversations with their CF care team (Cambridge, 2013). Many CF centers in the US have created their own educational materials, however the quality and evidence base used to create such materials is unknown and may vary greatly.

Social work practice in CF care can utilize the findings of this research to further evidence based practice. Psychosocial perspectives are especially sparse in the literature and, therefore, practice with women with CF is limited. Social workers have a unique perspective and set of skills that are invaluable to the holistic care approach that is adopted by CF care. Social workers are committed to the autonomy and self-determination of clients, and as such, they retain a special role on the CF care team: that

of patient advocate. As a patient advocate, social workers can exercise social justice, the defining value of social work.

By increasing awareness of the pertinent factors that influence women with CF to intend pregnancy, social workers can connect patients and families to the support and resources they require throughout the patient's lifespan. Women with CF encounter the same life decisions as healthy women and social workers can provide the psychosocial care and advocacy to assist in creating care plans that promote each patient's unique life goals. Furthermore, CF social workers can promote distributive justice by contributing to a greater equality for women with CF, even among the CF care team and health care settings that they work in. Although CF is an "orphan disease" the findings and implications for practice may also apply to other chronic disease populations, and thus, for disability rights.

Conclusion

This study aimed to use the Theory of Planned Behavior to examine pregnancy intention among women with CF. Nearly half of the 103 women surveyed reported intending to become pregnant; a significant finding suggesting that pregnancy intention among women with CF may be closer to or even greater than that of the general population. The sample seemed to resemble the adult population with CF, though data is limited and a precise comparison was not possible.

The first research question was: "What are the contributions of attitudes, subjective norms, and perceived behavioral control for women with CF in predicting pregnancy intention and do external variables significantly contribute to the prediction of pregnancy intention beyond the TPB constructs?" The overall logistic regression model was found to be statistically significant, but only the direct measure of attitude, the products of normative beliefs and the motivation to comply, and employment status were

significant predictors. Employment status, an external variable, did not contribute greater than the TPB constructs.

The second research question was: “What are the pertinent influential behavioral beliefs, specific referents, and perceived power that influence these attitudes, subjective norms, and perceived behavioral control?” Each model that was executed was found to be statistically significant, indicating that at least some of the beliefs elicited in the formative research phase contributed to each variable. For the variable of attitude, the belief of “burdening family and friends”, the belief of “endangering her own health”, and the belief that having a child would contribute to one’s “legacy” were found to contribute to the attitude variable. Furthermore, the external variable of age contributed to the variable, where younger age contributed more positive attitudes. For the variable of subjective norms, “mother” and “friends” were pertinent social referents to the variable. Finally, control beliefs of “having a supportive partner” and “CF-related complications” were pertinent beliefs contributing to the variable of perceived behavioral control. However, this contribution was minimal and may account for the lack of contribution of perceived behavioral control in the first research question.

Although “partner” was not a strong and clear social referent, it did appear to make contributions to the models in more subtle ways through different models. Past literature and logic support that a partner is influential in this decision-making process, thus this influence should not be discounted by the results in this study. Instead, what is striking is the influence that others, such as mothers and friends, have in the lives of women with CF. While partners likely have a great deal of influence on pregnancy intention, it seems that women with CF draw from a larger network of influence.

Despite several limitations with the sample and study design, the current study provides significant value for women with CF and those who provide care for the

population. This is likely the first quantitative survey to explore pregnancy intention among women with CF. The descriptive and frequency results provide information that has been limited and provides the groundwork for future research. The findings provide insight into how “normal” women with CF see themselves and how similar they truly are to other women.

The similarities between women with CF and healthy women are really more remarkable and numerous than the differences. Research, policy, and practice with women with CF should respect that women with CF are women first, with similar goals and desires as any other person. Social workers have a particular investment in promoting the autonomy and self-determination of clients. As advocates, social workers have the skills and knowledge to empower the patient and assist the CF care team to create patient-centered care plans, so that when and if women with CF consider pregnancy they are appropriately supported and counseled.

Appendix A

Consent Form to Participate in a Research Study

This is a *research study*. *Research studies* include only people who choose to participate. As a study participant you have the right to know about the procedures that will be used in this research study so that you can make the decision whether or not to participate. The information presented here is simply an effort to make you better informed so that you may give or withhold your consent to participate in this research study.

You are being asked to take part in this study because you have been identified or have identified yourself as a female patient with CF who is age 18 or older.

In order to participate in this study, it will be necessary to give your consent.

Study Purpose

The purpose of this study is to investigate ways to improve care for women with Cystic Fibrosis.

What's Involved

If you take part in this study, you will be asked to provide your opinion about pregnancy among women who have Cystic Fibrosis.

Length of the Study

You will be in the study until the interview is completed OR, if you choose to contribute, after you have reviewed a survey that will be created for further research. **You can stop the interview/survey at any point or you may decide not to review the future survey.**

Participant Rights

Participation in this study is voluntary. You do not have to participate in this study. Leaving the study will not result in any penalty or loss of benefits to which you are entitled.

Whom do I call if I have questions or concerns?

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll, you may contact the University of Missouri Health Sciences Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181 or email at irb@missouri.edu.

You may ask more questions about the study at any time. For questions about the study or a research-related injury, contact Ashley Gage, MSW at 573-424-9338 or gagela@health.missouri.edu

Please print or save a copy of this consent form for you to keep.

Appendix B

Pregnancy Intention Interview Guide

We are interested in what you think about why women with CF have children and how they go about making decisions about becoming pregnant and having children. There are no wrong answers. We just want to know what you think.

- You were invited to participate because your opinions are important to us.
- There are no wrong answers.
- We are audio recording this session because we don't want to miss any of your comments. However, all names are being removed from tape recordings and transcriptions and no reports will include names or any other identifying information.
- The audio recordings will be destroyed at the end of this study.

Attitudes Related to Pregnancy

1. What are some of the reasons why people become pregnant?
2. What are some of the reasons why women with CF get pregnant?
(**Probe:** Do women with CF decide to get pregnant or is it something that just happens? Do you think that reasons for getting pregnant are different from reasons from having children? If so, what differences do you think there are?)
4. What are the reasons that some women with CF don't get pregnant?
5. When you think about women with CF becoming pregnant what comes to mind?
6. How do people feel about women with CF becoming pregnant?
7. How do you feel about women with CF becoming pregnant?
8. Are there any other things you want to say about why people do or don't decide to get pregnant?

Perceived Social Influences for Becoming Pregnant

9. Who are some of the people or groups who influence people's decisions about having a child?
10. Who do you (or who would you) talk to about the decision to have a child?
 - a. Who would approve of you becoming pregnant?
 - b. Who would disapprove of you becoming pregnant?(**Probe:** if none of these mentioned, ask: "How about...?")
 - c. Partner
 - d. Family
 - e. Mother-in-law
 - f. Friends
 - g. Religious leaders
 - h. Community members or neighbors
 - i. PCP
 - j. OB/GYN
 - k. CF Team (**Probe:** who on the CF team?)
11. How important are the opinions about each of these people that we have talked about for having a child (**Probe** for each one)
12. Sometimes we look to others when we are not sure what we should do. When it comes to thinking about becoming pregnant, list the individuals or groups who you might look to for guidance.
13. Are some of these people more influential than others?
(**Probe** for each one: Who would you say is the most influential? What are reasons you think they are most influential? Who next?)

Perceived Behavioral Control

Now we want to ask you about how easy or difficult it is to do some things.

14. How much control do women have over becoming pregnant?
(**Probe:** a. what is within their control? B. What is it not within their control?)
15. How much control do women with CF have over becoming pregnant?
16. What are some of the things that make it difficult for women with CF to get pregnant?
17. What are some of the things that make it easy for women with CF to get pregnant?

The Influence of CF on Reproductive Decision Making

Now we want to talk about the influence of CF on reproductive decision-making

17. How might CF influence people's decisions to get pregnant?
(**Probe:** Do you think it makes a difference?)
18. What sorts of things would people think differently about getting pregnant and having children if they have CF?
19. How has CF affected people's decision-making about getting pregnant and having children?
20. What are some of the reasons that woman with CF would want to become pregnant and have children? (**Probe:** If none of the following are mentioned ask about...)
 - a. Be "normal" like everyone else
 - b. The joys of motherhood
 - c. Leave a legacy (have someone to carry on name)
 - d. To please partner or mother in law or significant others
 - e. If there is someone to care for the child if the parent passes away
 - f. Religious reasons
21. What are some of the reasons that women living with CF would decide not to have children? (**Probe:** If none of the following are mentioned ask about...)
 - a. Negative reaction of others (partner/family/providers)
 - b. Sorry about the possible transmission of CF gene to baby
 - c. Worry about their personal health and their ability to care for a child
 - d. No one is available to care for the children
22. How would the community view a woman who has CF becoming pregnant?

Conclusion

26. Is there anything else that you would like to say about what goes through people's minds that makes it likely or unlikely for women with CF to become pregnant?

Appendix C

Quantitative Survey

Pregnancy Among Women with Cystic Fibrosis

Q1 How likely are you to try to become pregnant now or at any time in the future?

- Very Unlikely (1)
- Unlikely (2)
- Somewhat Unlikely (3)
- Undecided (4)
- Somewhat Likely (5)
- Likely (6)
- Very Likely (7)

Q2 Given that I have CF, trying to become pregnant would be:

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)
Beneficial:Harmful (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Good:Bad (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wise:Foolish (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3 By becoming pregnant, I would:

	Very Unlikely (1)	Unlikely (2)	Somewhat Unlikely (3)	Undecided (4)	Somewhat Likely (5)	Likely (6)	Very Likely (7)
be endangering my health. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel more like everyone else without CF. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be endangering the health of the child. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have a child to carry on my legacy and lineage. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be passing on the CF gene. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be burdening my friends and family who may have to care for the child when I become sick or pass away. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4 Endangering my own health is:

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)
Desirable:Undesirable (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q5 Endangering the health of my children is:

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)
Desirable:Undesirable (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q6 Shortening my life is:

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)
Desirable:Undesirable (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7 Passing on the CF gene is:

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)
Desirable:Undesirable (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q8 Burdening my friends and family who may have to care for my child or children is:

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)
Desirable:Undesirable (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q9 Becoming more like everyone else is:

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)
Desirable:Undesirable (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q10 Having a child to carry on my legacy and lineage is:

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)
Desirable:Undesirable (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q11 _____ think that I should become pregnant:

	Strongly Agree (1)	Agree (2)	Somewhat Agree (3)	Neither Agree nor Disagree (4)	Somewhat Disagree (5)	Disagree (6)	Strongly Disagree (7)
Most people who are important to me ... (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My partner/spouse ... (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My mother ... (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My father ... (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My other family members ... (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My CF physician(s) ... (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My friends ... (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q12 When it comes to becoming pregnant, I want to do what ...

	Strongly Agree (1)	Agree (2)	Somewhat Agree (3)	Neither Agree nor Disagree (4)	Somewhat Disagree (5)	Disagree (6)	Strongly Disagree (7)
Most people who are important to me think I should do. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My partner/spouse thinks I should do. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My mother thinks I should do. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My father thinks I should do. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My other family members think I should do. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My CF physician(s) think I should do. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My friends think I should do. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q13 How common is it for women with CF to become pregnant?

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)
Extremely Common:Extremely Uncommon (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q14 When it comes to becoming pregnant, I want to do what most women with CF would do.

- Strongly Disagree (1)
- Disagree (2)
- Somewhat Disagree (3)
- Neither Agree nor Disagree (4)
- Somewhat Agree (5)
- Agree (6)
- Strongly Agree (7)

Q15 If i decide I want to try, I can get pregnant if I want to.

- Strongly Disagree (1)
- Disagree (2)
- Somewhat Disagree (3)
- Neither Agree nor Disagree (4)
- Somewhat Agree (5)
- Agree (6)
- Strongly Agree (7)

Q16 My decision to become pregnant is up to me.

- Strongly Disagree (1)
- Disagree (2)
- Somewhat Disagree (3)
- Neither Agree nor Disagree (4)
- Somewhat Agree (5)
- Agree (6)
- Strongly Agree (7)

Q17 My decision to NOT become pregnant is up to me.

- Strongly Disagree (1)
- Disagree (2)
- Somewhat Disagree (3)
- Neither Agree nor Disagree (4)
- Somewhat Agree (5)
- Agree (6)
- Strongly Agree (7)

Q18 Having CF would affect my decision to try to become pregnant.

- Strongly Disagree (1)
- Disagree (2)
- Somewhat Disagree (3)
- Neither Agree nor Disagree (4)
- Somewhat Agree (5)
- Agree (6)
- Strongly Agree (7)

Q19 The following would affect my decision to try to become pregnant.

	Strongly Disagree (1)	Disagree (2)	Somewhat Disagree (3)	Neither Agree nor Disagree (4)	Somewhat Agree (5)	Agree (6)	Strongly Agree (7)
My medications and treatment (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a supportive partner (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a supportive family and/or friends (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having access to financial resources. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q20 Having CF makes the decision to try to become pregnant:

- Very Difficult (1)
- Difficult (2)
- Somewhat Difficult (3)
- Neutral (4)
- Somewhat Easy (5)
- Easy (6)
- Very Easy (7)

Q21 My medications and treatments make the decision to try to become pregnant:

- Very Difficult (1)
- Difficult (2)
- Somewhat Difficult (3)
- Neutral (4)
- Somewhat Easy (5)
- Easy (6)
- Very Easy (7)

Q22 Having a supportive partner makes the decision to try to become pregnant:

- Very Difficult (1)
- Difficult (2)
- Somewhat Difficult (3)
- Neutral (4)
- Somewhat Easy (5)
- Easy (6)
- Very Easy (7)

Q23 Having a supportive family or friends makes the decision to try to become pregnant:

- Very Difficult (1)
- Difficult (2)
- Somewhat Difficult (3)
- Neutral (4)
- Somewhat Easy (5)
- Easy (6)
- Very Easy (7)

Q24 Having access to financial resources makes the decision to try to become pregnant:

- Very Difficult (1)
- Difficult (2)
- Somewhat Difficult (3)
- Neutral (4)
- Somewhat Easy (5)
- Easy (6)
- Very Easy (7)

Q68 Please assess the following statements (consider the last 4 weeks). How important is it for you ...

	Not Important (1)	Somewhat Important (2)	Quite Important (3)	Very Important (4)	Extremely Important (5)
... to be free of breathing difficulties/coughing? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... to be free of abdominal pain/digestive trouble? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... to enjoy eating? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... to find restful sleep? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...to maintain an normal daily routine despite therapy? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... to carry out daily therapy consistently? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... to be needed by others? (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... that people in your environment show that they understand your situation? (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... not to experience any disadvantage because of your disease? (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q69 Please check off how satisfied you are with single aspects: How satisfied are you ...

	Not Satisfied (1)	Rather Not Satisfied (2)	Rather Satisfied (3)	Quite Satisfied (4)	Very Satisfied (5)
..with the extent of breathing difficulties/coughing? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with the extent of abdominal pain/digestive trouble? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... while you are eating? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with your sleep? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with the integration of therapy into your daily routine? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with your consistency with daily therapy? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with being needed by others? (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with the understanding for your situations shown by the people in your environment? (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with being free of disadvantage? (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q56 How old are you?

Q57 What is your relationship status?

- Single (1)
- In a relationship (2)
- Married (3)
- Separated (4)
- Divorced (5)
- Widowed (6)
- Other (7)

Q58 What is your highest level of education?

- Less than high school (1)
- Currently in high school (2)
- High school/GED (3)
- Some college/Trade School/Associates Degree (4)
- Undergraduate degree (Bachelor's Degree) (5)
- Graduate degree (Master's Degree, PhD, MD) (6)

Q59 What is your race/ethnicity?

- White/Caucasian, not Hispanic or Latino (1)
- White/Caucasian, Hispanic or Latino (2)
- Black or African American (3)
- Asian (4)
- More than one race (5)
- Other (6)

Q60 What is your employment status?

- Not employed (1)
- Employed part-time (with no disability funds) (2)
- Employed full-time (with no disability funds) (3)
- Retired (4)
- Totally disabled (5)
- Employed part-time with disability funds (6)
- Employed full-time with disability funds (7)
- Other (8)

Q61 Annual household income

- Under 20,000 a year (1)
- 20,0001-40,000 a year (2)
- 40,001-69,999 a year (3)
- Over 70,000 a year (4)
- Unknown (5)

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VITA

Lauren “Ashley” Gage was born November 17, 1982. She graduated from Camdenton High School in Camdenton, Missouri in 2001. In May of 2006, she graduated from Columbia College with a BA in psychology. Following her undergraduate degree, she worked in the private business sector before entering graduate school at the University of Missouri for her Master of Social Work degree. She completed her MSW in May of 2009 and entered the doctoral program at the University of Missouri in August of 2009. During this time, she worked as a PRN medical social worker for the University of Missouri Health Care System. She primarily worked with pediatric services. In January 2011, Ashley began as a graduate research assistant on the ACTIVE study in the University of Missouri Department of Family and Community Medicine. In January of 2012, she began full-time employment as a Senior Research Specialist on the ACTIVE study, completing the position until the study ended. Ashley successfully defended her dissertation on June 20, 2014, and accepted a tenure-track faculty position with the University of Nebraska-Kearney. Ashley plans to focus on teaching and maintaining an active research agenda, including further exploration into issues among the Cystic Fibrosis population and issues surrounding end-of-life.