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Family Relational Experiences During Major Transitions with a Chronic Illness

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Walden University
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Abstract

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MS, Walden University, 2006

BA, University of Texas at San Antonio, 2002

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Clinical Psychology

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Abstract

Although health care transitions have received some attention in the literature, few researchers have emphasized family relational experiences and communication during major changes while living with a chronic illness. The purpose of this phenomenological study was to understand the lived experience of parents and their adult children while transitioning from pediatric to adult care of a chronic illness. The bio-psychosocial theory, family systems theory, and attachment theory established the context for this study. A criterion-based sampling technique and snowball sampling were used to recruit 7 parents and 6 of their adult children aged 18 to 30 years who were diagnosed with cystic fibrosis or congenital heart disease, and who had either completed or were in the process of completing the transition from pediatric to adult healthcare. Semi-structured interviews were conducted, and content analysis was used to code and analyze themes that emerged from the experiences of participants. The themes that were identified included that parents were instrumental in maintenance of treatments during high risk periods of adolescence, healthy parent and child relations included collaboration that accommodated autonomy, and that early coaching helped reduce parental anxiety about non-adherence while increasing the self-efficacy of the child. This study contributes to positive social change by informing the design of current procedures to transition young adults with chronic illness by recommending flexibility in negotiations, early education, shadowing between facilities, and incorporating evidence-based practice based on feedback from each family member.

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Dedication

I dedicate this academic achievement to my mother Mary who supported me with her unconditional love, never ending prayers, and seasonal quotes to keep me motivated. To my siblings: Ken, Michael, Coleman, Desmond, Fergus, David, Nigel and Ruth who kept me humble and reminded me to “chill-ax” or laugh at myself occasionally. To my nephew Eric whose life and personal journey with cystic fibrosis served as the inspiration for this study. To the next generation of my family: Tara, Sarah, Philip, Nicole, David-James, Eric, Amy, Sylvia, Hazel, Geoffrey, Lee, Ben, Rose, Liam, Matthew, Oliver and Siobhan who are all smart, talented and beautiful young people. I look forward to watching the incredible journey ahead for each of you. To my friends and confidants, who stood with me through the sleepless nights, times of personal loss, and moments when I was ship wrecked by self-doubt. My success would not have been possible without all your faith in me. Thank you!

I include here a special word of appreciation for my good friend Dr. Renee Sullivan. We have laughed and cried through the years completing dissertation. Hoorah to both of us. We made it!

To the families who shared their stories with me, I shall never forget your kindness and willingness to help a total stranger. Your stories touched me deeply in a way that you can never imagine. I was deeply humbled by all of your generosity. I am eternally grateful to each of you!!!

Finally, I dedicate this journey to my father Desmond who has gone on to complete a new voyage for his soul. I hope I make you proud…

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Chapter 1: Introduction to the Study

Introduction

The transition from childhood to adult healthcare is a fundamental phase of any individual living with chronic illness. Adolescence is typically a time of developing independence from parents. Adolescence is also a period when the heightened perception of differentiation from others is accompanied with the development of personal identity, during which Erikson termed the phase of *learning identity* versus *role confusion* (Erikson, 1959). In adolescents with chronic illness such as cystic fibrosis (CF) or congenital heart disorders (CHD), parental involvement is often high, and has been shown to improve adherence and health outcomes (Mohlman-Berge & Patterson, 2004). Adolescents with CF or CHD often question treatments and oppose the decisions of parents and health providers, which can be detrimental to their health (Segal, 2008). It may be difficult for individuals with CF or CHD to remain optimistic about the future when they are aware that the future may include dependence on others, infertility, or premature death. Such worries may be expressed as anxiety or rebellion on the part of the youth in transition (Segal, 2008).

Parents and their children frequently do not agree on the process of gaining independence in disease self-management (Peeters, Hilberink, & van Staa, 2014). Parents may be perceived as overbearing, while they may see their children as overly confident and minimizing the consequences of having a chronic illness (Peeters et al., 2014). Tension between parents and children regarding self-care was found to be an issue in approximately 35% of patients who were deemed to be nonadherent to medical regimens

(Shaw, Palmer, Blasey, & Sarwal, 2003). Nonadherence is an important issue for chronically ill youth in transition, and family discord tends to increase this potentially dangerous behavior (DiMatteo, Haskard-Zolnierek, & Martin, 2012). Independence is needed to develop self-management skills for successful transition to adult health care when possible complicating factors include complex regimens, transplants (DeVito Dabbs et al., 2013), poor nutrition (Morton, 2009), chronic stress (Brown, Small, & Palmer, 2008), and depression (Brown et al., 2008).

Given the complex health management issues in adolescents with CF (Withers, 2012), or CHD (van Staa, Jejeloo, van Meeteren, & Latours, 2011), it was important to find out as much as possible about the phase of transition from childhood health care to adult care. In particular, more research was needed to explore the relationship between parents and youth with chronic illness (Modi, Marciel, Slater, Drotar, & Quittner, 2008). For example, the perception of parental support has been found to reduce loneliness and depressive symptoms in individuals with congenital heart disorders (Luyckx et al., 2014). Likewise, it was found that adolescents reported higher incidents of feeling depressed and lonely when they perceived that their parents were not being supportive of their needs. Moreover, the findings of this research reported that fathers rather than mothers tended to encourage independence, while mothers were reported to assume most of the supervision of their child’s health care needs (Luyckx et al., 2014). Luyckx et al. suggested that future research was warranted to better understand differences in paternal and maternal involvement and how they might have a different effect on their child’s psychosocial development of independence.

Having a sense of personal control is important to individuals living with chronic disease; for example, there is evidence to suggest when individuals undergoing lung transplants held the view that they were in control, they were more likely to adhere to regimens following grafts (Burker, Phillips, & Giza, 2012). Parents can be important agents to inspire confidence and sense of personal control in their youth.

Gaining the perspective of the chronically ill individual and their parents might offer insight regarding possible obstacles in the transition process. Fernandes et al. (2014) gathered perceptions of chronically ill individuals ages 16 to 25 years and their parents regarding education and preparation for transitions to adult health care facilities while also looking at individual concerns and barriers with the process. Fernandes et al. reported that both parents and their children pointed to shortcomings with their experience of being coached for the transition from child care to adult health care. Furthermore, more than half of the parents and children in this study reported that they would not feel comfortable to transfer to an adult facility until the children were at least 25 years old. A commonly cited reason for not selecting to transfer sooner was the strength of the connection that both parents and their children had for the pediatrician who managed the disease since birth (Fernandes et al., 2014). There is a need for further study on the transition process in chronically ill adolescents, especially regarding the educational needs involved in the transition process. According to Fernandes et al. the delivery of coaching for the transition to adult care has not been consistent leaving both parents and their children often feeling anxious about the process. Therefore, further research was warranted to look at the communication process between parents and children given the importance of this relationship in the management of educational information in that transition, and was the focus of this study.

Background

Knopf, Hornung, Slap, DeVellis, and Britto (2008) investigated health decision-making in adolescents diagnosed with chronic illnesses to determine if they had the same opinions as their parents concerning treatment decisions. The first framework presented was the physician portrayed as the manager of health care and in authority. The second framework involved the patient becoming well-versed in treatment options, and their preferences considered. The third framework presented a joint form of decision-making where the physician and the patient labored together to find a solution. The authors reported that 37% of youth and 36% of parents favored the joint decision-making option (Knopf et al., 2008). The authors recommended that further qualitative research was warranted to gather a more comprehensive understanding of the communication between parents and adolescents when coping with chronic illness. Future research was recommended to determine the significance of eliciting the patient preferences, as this could be a central aspect of healthcare satisfaction and well-being.

Although individuals living with chronic illness may be forced into a dependent relationship with the healthcare system, they do not surrender all determination in their health care. Parents of children with chronic illnesses tend to be excessively protective in their parenting style, and this has the potential to generate dissonance in family communication (Peeters et al., 2014). Delmar et al. (2006) argued that the paradoxical relationship a patient endures while living with a chronic illness, such that independence and dependence often exists in the same time and space and places demands on the patient to find equilibrium between the two. Delmar et al. employed a phenomenological-hermeneutic method to comprehend the lived experience of 18 individuals aged 18 to 75 years suffering from chronic illness regarding how they make sense of illness that forces a need for others that conflicts with their desire to be in control of their own lives. Self-sufficiency, ownership of the disease, and self-discipline were found to be important in their coping (Delmar et al., 2006). The authors concluded that it was important for health workers to empower patients through consulting them concerning treatment. The focus of this study was on adult patients, not the family systems in which they live. Yet, the importance and preference for independence in this population was clearly indicated.

Kennedy, Sloman, Douglass, and Sawyer (2007) discussed the procedures employed by a well-known successful pediatric to adult chronic illness transition program in the Royal Children's Hospital (RCH), Melbourne, Australia, to determine what constitutes a successful transition for young people living with chronic illnesses. It was determined that successful transitions adhered to a formal plan, had a human resource department to synchronize the process between the child and adult facilities, and encouraged a partnership between pediatric care personnel and adult providers (Kennedy et al., 2007). Despite the cooperation between pediatricians and adult care providers observed in the RCH program, collaboration does not always take place at other facilities (Kennedy et al., 2007). Kennedy et al. noted that irregular practices in transferring patients to adult care disrupted stability of care. The authors suggested there are inconsistencies in the transition of patients from childhood to adult care worldwide. A number of reasons were cited for disruptions in the transition process including a breakdown in partnership between providers accountable for the transition process and a failure to anticipate and put together a transition strategy (Kennedy et al., 2007). Several features were acknowledged in successful hospitals such as the official reassignment of patients to adult facilities in a well-timed approach, sponsorship by health professionals for the process of transition, allocation of personnel to handle the transition, teamwork between pediatricians, and the presence of contemporaries in adult units (Kennedy et al., 2007).

Reed-Knight, Blount, and Gilleland (2014) performed a literature review to determine what health care responsibilities investigators deemed essential in the transition process. They concluded that multiple factors might impact the transition such as maternal melancholy, health care familiarity, socioeconomic standing, insurance issues, and the accessibility of transition personnel. The authors indicated there is a need to clarify what constitutes successful transitions. Gorter, Stewart, and Woodbury-Smith (2011) commented on articles written about the transition of young people with chronic illness, and issues that have been rarely considered including the transition of patients based on age rather than grooming patients for a transition to adult care. Gorter et al. noted that the conventional biomedical model, while meeting the need to manage a disease, neglected individual care in the transition between pediatric and adult care. The authors suggested that it was necessary to assess the opinions and preferences of adolescents about the transition process in addition to developing written transition plans that are individualized for each patient.

Parents are responsible for preparing patients for taking over responsibility, making it essential to know how parents can help youth successfully transition to adult care (Reed-Knight et al., 2014). Dashiff et al. (2009) conducted research that focused on how protective mothers influence the development of self-sufficiency in children with type 1diabetes and concluded that maternal apprehension inhibits the development of autonomy in adolescents, including disease management. Dashiff et al. emphasized a need for research on the influence of parental anxiety on the independent performance of health care routines in adolescents with chronic illness.

Moola and Norman (2011) performed a qualitative study looking at transition experiences of youth with CF or CHD as well as their parents. The findings included themes centered on anxiety about worsening health and bereavement about the loss of time, but also resilience in parents and adolescents in regard to being determined to make the most of time available to them (Moola & Norman, 2011). While the findings of this study revealed themes about health concerns in the future, career restrictions, parenthood, and loss of time or restructuring of time, further research was warranted to look at how parents and their children conversed about declining health and planned for treatments. It was important to understand the stumbling blocks that could hinder the transition process, and understand patient concerns for the future so that incentives for the process could be strengthened if necessary (Moola & Norman, 2011). Less was known about how parents and their children handled conversations about deterioration of their children's health and if this was done in a timely manner or the result of a sudden decline in the child's health.

How parents and their children handled conversations about the deterioration of their children’s health was an important focus of this present study.

A significant part of the transitory process is the development of strategies for that transition to include the development of individual plans, standardized evaluations, and careful consideration concerning the personal aspirations of the individual living with chronic illness (Gorter, Stewart, & Woodbury-Smith, 2011). Early detection of issues such as cognitive impairments, intellectual disabilities, family relational issues or conduct problems all need to be screened for in order to help the youth in transition (Gorter et al., 2011). Tuchman et al. (2008) performed a secondary qualitative analysis of semi-structured interviews of adolescents with CF, sickle cell disease (SCD), juvenile rheumatoid arthritis, or inflammatory bowel disease to access adolescents’ feelings about transitioning from pediatric to adult care. Respondents who were part of a planned transition curriculum were prone to finish the transfer to adult care (Tuchman et al., 2008). Patients were more likely to feel hesitant about the experience when the transfer was unplanned. The involvement of parents in this process was not investigated, and they were not interviewed for the study.

Any number of factors may influence the transitory process. van Staa et al. (2011) conducted semistructured interviews with 24 youth aged 15 to 22 years suffering with chronic illness in the Netherlands. Twenty-four parents and 17 healthcare workers were also interviewed. Participants were diagnosed with haemophilia, diabetes mellitus, spine bifida, CHD, CF, juvenile rheumatoid arthritis, or sickle cell disease. Only the haemophilia department had a planned transition program (van Staa et al., 2011). There were no reported problems with ease of access to assistance in adulthood, and this was mainly because universal medical support and insurance remain in effect in the Netherlands (van Staa et al., 2011). This hospital had a pediatric and adult unit in the same facility, lending itself to an easier transitory process and abbreviated communication circuit (van Staa et al., 2011).

The significance of the interplay between the numerous actors involved in the transitory process cannot be overlooked. To understand this process, Kirk (2008) performed qualitative interviews with 28 youth ages between 8 and 19 years requiring various medical technologies including gastrostomy/jejunostomy, intravenous drug therapies, mechanical ventilation, tracheostomy, oxygen therapy, parenteral nutrition, and peritoneal dialysis. Kirk recommended coordination between agencies and professionals as well as evaluations to determine aptness for transfer to an adult program. When participants experienced multiple transitions at the same time they were more likely to report feeling overwhelmed, and many parents and young people believed they were ill-equipped for the transitory process. A key theme that emerged was the failure to provide a personalized plan. Individuals may not always transfer within the same facility; thus, the stability of service could be compromised for reasons including the failure to plan or synchronize care between facilities.

Fletcher-Johnston, Marshall, and Straatman (2011) employed a Delphi technique to recognize the concerns with healthcare transitions in adolescents with chronic illness among clinicians and educators in Canada. Thirty-eight participants contributed to determine the most pressing concerns in relation to the intricacies of healthcare transitions for adolescents (Fletcher-Johnston et al., 2011). The researchers identified five questions that were deemed to be a priority for future research:

1. What skills and knowledge do adolescents need to learn in order to better manage their chronic illness and enable successful transition to adult health care and adulthood? How would they best like to learn these skills and knowledge?
2. How do we measure a successful transition or evaluate a transition programme?
3. What are the factors that influence healthcare transitions (not just adherence) and also how do these various factors influence each other?
4. Does a ‘successful transition’ lead to improved health outcomes in adulthood?
5. What are the potential successes or risk factors for successful transitions (i.e. type of illness, age of child, family involvement, level of support systems, and progression of illness)? (p. 879)

Fletcher-Johnston et al. (2017) influenced this study which explored the perceived experiences of young adults and their parents regarding the transitory process, to determine what aspects of their communication may have been problematic or contributed to a smooth transition. The focus was on how communication about the transitory process was perceived by the participants, which consisted of young adults with CF or CHD and their families who were going through or had been through the transitory process.

Problem Statement

In the past, the projected life span for many children born with chronic illness was meager, resulting in a lack of anticipated need for medical services beyond the childhood years (Reed-Knight, Blount, & Gilleland, 2014). Recent increases in life expectancy go hand in hand with an awareness of the connection of life span to adherence with medical treatment (Segal, 2008). Adolescence is a time when individuals diagnosed with CF or CHD have tended to exhibit lower adherence rates to health practices (van Staa, Jedeloo, van Meeteren, & Latours, 2011).

The transition from pediatric to adult health care has often resulted in interruptions of relationships and mental shifts from previously accepted wisdom of parents and health professionals (Segal, 2008). This transition also corresponds with puberty, when adolescents experience an increase in desire for self-government (Segal, 2008). Adolescents living with chronic illness may experience feelings of anger about being different from their peers, potential complications related to their illness, or their own mortality. This anger may be associated with anxiety and rebellion (Segal, 2008).

A review of the literature provides inconsistent evidence indicating the optimal role parents should play in the lives of their children with chronic illnesses. According to Foster et al. (2001), adherence to health regimens declines in adolescence. Parental involvement is often interpreted as helpful; however, that involvement may be simultaneously rebuked by adolescents (Foster et al, 2001). Patterson, Budd, Goetz, and Warwick (1993) found that families that place less emphasis on independence show greater conformity with health practices. There is a dearth of research in regard to the decision-making processes within the context of the parent/child relationship in this population (White, Miller, Smith, & McMahon, 2009). In particular, there was a clear and significant gap when it came to understanding the role of the parent/child relationship in the transition from pediatric to independent adult care in individuals with chronic illness such as CF or CHD (Miller, 2009).

To date, researchers studying youth with chronic illness have focused on adherence to medical regimens, such as chest physical therapy in CF (Quittner, Espelage, Levers-Landis, & Drotar, 2000), attitudes regarding the timing of transfer of care (Tuchman, Slap, & Britto, 2008), and parental anxiety tied to the development of adolescent autonomy (Dashiff, Vance, Abdullatif, & Wallander, 2008). There has been a lack of in-depth qualitative inquiries into how parents and their children communicate about complex medical decisions, discuss the illness, and negotiate during times of conflict. The problem that was addressed in this qualitative study was that little was known about how parents and adolescents communicated during the various stages of chronic illness (Knopf, Hornung, Slap, DeVellis, & Britto, 2008), and less was known about the psychological impact this communication had on the wellness of the patient and family members (Street & Soldan, 1998). Knopf et al. recommended qualitative research methodology be used to gather a more comprehensive understanding of the communication between parents and adolescents when dealing with chronic illness. It is important to understand how parents prepare their chronically ill children for transfer of care and cultivate independence in their children.

The progression from adolescent to adult care requires the advancement of self-care skills. It is critical for providers, caretakers, and the adolescents to know when and how to identify and communicate transitional needs (Tuchman, Slap, & Britto, 2008). Gorter, Stewart, and Woodbury-Smith (2011) indicated that practically all research regarding youth with chronic illness pointed toward challenges during the transitory phase. Youth in transition have been susceptible to non-adherence to medical regimens, and this could significantly impact their health (Kennedy, Sloman, Douglass, & Sawyer, 2007). Unfortunately, with their longing for self-determination, adolescents with chronic illnesses often encounter emotional challenges that might include questioning treatments or opposing the opinions of parents and health professionals (Segal, 2008). Previous research has concluded that although parental support increases adherence to medical regimens, adolescents need to be encouraged to develop independence (Lindsay-Withers, 2012). The pursuit of independence might often be a paradox for youth with CF or CHD because these diseases make dependence unavoidable (Lindsay-Withers, 2012). The family needs to find a balance in a relationship where there is a desire for independence and a chronic illness that often dictates dependence on others. This is likely to create tension, and was therefore worthy of further investigation in the context of chronic health care needs.

Mothers of children with chronic illness may experience apprehension about transition issues, which may inhibit the promotion of autonomy in the adolescent (Dashiff et al., 2008). Dashiff et al. concluded there was a need for research on the influence of parental anxiety on independent health behaviors in adolescents with chronic illness. In addition, Mohlman-Berge and Patterson (2004) found that 60% of the children with CF in their study experienced emotional regulation issues that appeared to be directly related to the apprehension of the mother. Less is known about the impact fathers have on the emotional regulation of youth with CF or CHD, making this important in future research.

Purpose of the Study

The purpose of this phenomenological qualitative study was to cultivate an understanding of how individuals with the diagnosis of CF or CHD and their parents communicated as they progressed through adolescence managing a chronic illness, and moved through the challenges of transitioning from childhood to adult care. This study examined the lived experiences of young adults, aged 18 to 30 years, with CF or CHD, who were in transition from pediatric to adult health care or who had completed the transition, and one or both parents, in order to develop a better understanding of how these families fostered independence while encouraging medical adherence. It was essential to understand how young adults and their parents navigated the phase of transition while maintaining parental support.

Research Questions

Research Question 1: How do parents and young adults aged 18 to 30 years with CF or CHD describe their experience of negotiating who is responsible for health care tasks during the transitory process from pediatrics to adult care?

Research Question 2: How do parents and young adults aged 18 to 30 years with CF or CHD describe their experience of negotiating when and how young adults gain responsibility for health care tasks?

Research Question 3: How do parents and young adults describe the quality of their communication when they discuss who is responsible for health care tasks and medical decisions?

Research Question 4: How do parents and young adults aged 18 to 30 years with the diagnosis of CF or CHD describe the quality of their relationship during negotiations about health care decisions and transfer of responsibility?

Conceptual Framework

Multiple conceptual frameworks were chosen to guide this study. The most prominent was the bio-psychosocial model, which was postulated by George Engel, and classified as the interface of genetic, social, psychological, and medical conditions (Engel, 1977). Engel noted that social factors and personal behaviors of patients influence the course of an illness (Stacy, Laumann, Levinson, & White, 2003). It is important for healthcare professionals to consider multiple factors that are internal and external to the patient, such as personal beliefs, family unit, and accessibility to resources in disease management (Rolland & Williams, 2005). The family system is an important element of this model.

John Bowlby’s theory of attachment (Bowlby, 1969) was also employed as a framework for this study. Bowlby developed the theory of attachment after observing the varied influence personal hardships such as chronic disease, psychological disorders, or a frightening experience as a child imposed on the physical and social well-being of an individual into their adult years (Hooper, Tomek, & Newman, 2012).

The family systems theory, proposed by Murray Bowen (1976), also provided a framework for this study, as it offered insight concerning the complexity of communication and relations often generated within the triad of physician, patient, and family scenarios (Shapiro, 2001).

Principles from the bio-psychosocial model, attachment theory, and family systems theory were all relevant to the dialogue that was the focus of this research, which looked at how parents and individuals diagnosed with chronic illness communicated with their families about the transition from pediatric to adult health care, and complex medical decisions such as transplants, and self-care skills.

The current study utilized principles from the bio-psychosocial, attachment, and family system frameworks by organizing interview questions to address multiple components within these models. I focused on multiple factors that could influence perceptions of the communication process which included: physical, psychological, social, and societal influences, with a specific focus on family relationships.

Nature of the Study

The intent of this qualitative, phenomenological study was to examine communication within families during the transitional experiences of adolescents and young adults diagnosed with CF or CHD. Participants included six pairs or triads, of which three pairs included parent(s) and their child diagnosed with CF ages 18 to 30 years who were either in the process of transitioning or had transitioned from pediatrics to an adult health care program: and three pairs included parent(s) and their child diagnosed with CHD ages 18 to 30 years who were in the process of transitioning or had transitioned from pediatrics to an adult health care program. Participants were interviewed about their experiences with regard to the transition process as well as how they attempted to balance the need for independence, the parental need to protect their child, and any issues related to negotiating their interests to each other. A qualitative, phenomenological design made it possible to capture their lived experiences, and helped establish themes concerning perceptions of the process of becoming independent while maintaining parental support. Participants were engaged in semi-structured interviews via phone interviews concerning their experiences communicating about complex medical decisions and how they negotiated while managing or discussing the chronic illness. Parents and each adult child were interviewed separately.

Definition of Terms

Activated attachment system: This is when a system becomes activated the individual feels in jeopardy of experiencing a loss, separation or rejection within the attachment system (van Ecke et al., 2006).

Active participant: According to the Child Transitional Communication (CTC) Model is an individual who finds themselves included in the communication process. This position is not assigned a positive status unless it is the position that a participant wishes to occupy at a given time and within a given context (Lambert, Glacken & McCarron, 2010). For example, if a participant chooses not to participant in decision making with regard to medical decisions then they are still described as an active participant in the communication process.

Adherence: Is defined as when a patient's stays on suggested medications and follows health activities specified by their health care provider (DiMatteo, Haskard-Zolnierek, & Martin, 2012).

Adolescence: A phase of swift changes socially, emotionally, and cognitively for the adolescent between the ages of 12-18 years (Kostakou et al., 2014).

Avoidant individual: According to the attachment theory this individual will act in a manner to inhibit feeling insecure in family relationships by concealing their emotions from others within the system (van Ecke et al., 2006).

Bystander: A bystander according to the Child Transitional Communication (CTC) Model is an individual who finds themselves excluded from the communication process. (Lambert et al., 2010). This position is not assigned a negative status unless it is a position that a participant does not wish to occupy at a given time and within a given context (Lambert, Glacken & McCarron, 2010). For example, if an individual would like to participate in decisions with regard to their illness, but is prevented from doing so, then they are in the position of a bystander and determined to be excluded from the communication process.

Clash: A conflict of interest or disagreement between parents and youth (Peeters, Hilberink, & van Staa, 2014).

Communication: According to the Child Transitional Communication (CTC) Model children inhabit one of two stances with regard to engaging in communication, the first is that of a bystander, and the second is that of an active participant (Lambert, Glacken & McCarron, 2010). Furthermore, according to the (CTC) Model the phrase *transitional* portrays the short-term and continual transformation of children's posture within society and with regard to the communication process (Lambert et al., 2010).

Cohesion: A time where parents and adolescents reach agreement (Kostakou et al., 2014).

Differentiation: According to Bowen's intergenerational family systems theory is the separation and development of self-determination (van Ecke et al., 2006).

Dismissive: According to the attachment theory is when an individual steps back from the activation in the attachment system (van Ecke et al., 2006).

Fusion: According to Bowen's intergenerational family systems theory is the failure to find equilibrium within the family system between being together and moving away which results in fear and apprehension (van Ecke et al., 2006).

Independence: Involves self-government, and involves taking responsibility for one's own decisions, but can also include allowing others to be involved in decisions (Delmar et al., 2006).

Non-adherence: Is defined as the cessation or interruption by a patient to stay on suggested medications or follow health activities specified by their health care provider (DiMatteo et al, 2012).

Preoccupied: According to the attachment theory means an individual will develop an intense sensitivity and make numerous efforts to maintain equilibrium within the family system (van Ecke et al., 2006).

Secure attachment: According to Bowlby's attachment theory involves separation and development of self-governance and is similar to Bowen's term of differentiation (van Ecke et al., 2006).

Secure individual: According to Bowlby's attachment theory this individual will take the necessary steps to feel secure in the event that apprehension is made active by the attachment system (van Ecke et al., 2006).

Self-care agency: The competence and the motivation to carry out activities necessary to sustain health and help manage symptoms of disease (DeVito Dabbs et al., 2013).

Transition: Is the movement of patients from a pediatric health care system to an adult care facility and is likely to involve a culmination of phases known as the *transitory process* (Kennedy, Sloman, Douglass & Sawyer, 2007).

Transitory process: Is a description of the procedures involved with the transfer of patients from a pediatric health care system to an adult care facility while also considering the impact of biological, psychological, social, and environmental issues that can impact the movement of patients between facilities (Gorter et al., 2011; Kennedy et al., 2007; Kirk, 2008; Moola & Norman, 2011; van Staa et al., 2011).

Unresolved: According to the attachment theory is when an individual feels perplexed and stumped about what to do to see that their needs are met (van Ecke et al., 2006).

Assumptions

It was assumed that participants were honest in their responses. Also, it was assumed that all the participants understood the questions as asked or were able to request clarification, and that they were competent to express their experiences with the transitory process, any difficulties or conflict they experienced, and how they resolved these issues.

Scope and Delimitations

In preparation for this study, participants received a letter with full disclosure of the purpose for performing the study. Participants were adults living with the diagnosis of CF or CHD and, the parent(s) of a young adult living with the diagnosis of CF or CHD. The interview questions inquired about experiences with the transition process, how the young adults achieved independence while seeking support from parents, the nature of communication about the process between the young adult and their parents, if they experienced conflict in the process and how disagreements were resolved.

Limitations

This qualitative study had a number of limitations. The small sample size was a limitation of this study. Participants for this study included five dyads consisting of one parent and one adult child diagnosed with CF and one triad consisting of two parents and one adult child diagnosed with CF. It was intended that the participants for this study would include six pairs, or triads, of which three pairs would include parent(s) and their child diagnosed with CF who had either completed, or were in the process of transitioning from a childhood health care facility to an adult health program: and three pairs would include parent(s) and their child diagnosed with CHD who had either completed, or were in the process of transitioning from a childhood health care facility to an adult health program. None of the potential participants diagnosed with CHD who contacted me met the inclusion criteria. Purposeful sampling was used to ensure that only patients diagnosed with CF or CHD, and their parents were selected as respondents for this study. The findings of this study cannot be used to make generalizations about other chronic illnesses. Another limitation of this study was that participants were recruited from online support groups, and generalizations cannot be made beyond the recruited sample. It was not anticipated that this study would be able to detect every difficulty in communication between parents and young adults. Future research will be needed to examine themes that emerged in this study.

Significance of the Study and Contribution to Social Change

This research can be a factor for positive social change by contributing to the knowledge base regarding how parents and young adults with chronic illnesses achieved independence in medical care. The findings of this research may help guide others about how to communicate about important issues and negotiate transfer of care during transitions. The findings may offer insight about how adolescents with chronic illness participate in the management of their disease within the context of their families. The results might benefit adolescents with chronic illness as well as their families through gaining understanding of communication during the transition process. Health care professionals might also benefit, as understanding the communication process between adolescents with chronic illness and their families can help them make treatment decisions about psychosocial and behavioral interventions that may benefit their patients. In turn, any findings that promotes better health in chronically ill individuals' benefits society through improved productivity and lowered health care costs.

Summary

Transitions between childhood and adult care programs are a concern for all those involved in the process, with particular attention now being placed on the family system (Peeters et al., 2014). This chapter introduced the current research study, in which interviews were conducted with parent(s) and young adults diagnosed CF or CHD in regard to the transition from pediatric to adult care.

Chapter 1 provided an introduction to the study and included a statement of the problem, the background of the problem, the purpose of the study, a conceptual framework, the nature of the study, the research questions, a definition of terms, the assumptions, the scope, limits and delimiters, the significance, and the implications for social change of the study. The purpose of this study was to investigate the experience of families of young adults with CF or CHD who had transitioned or were currently undergoing the transition from pediatric to adult health care, with the intention of gathering information about the communication process and parent/child relationship during the transition process. The rationale for using individuals diagnosed with CF or CHD was that individuals with either of these conditions would have some degree of dependence on others to provide care for them their entire lives.

Chapter 2 will familiarize the reader with the current literature on the issues surrounding transitions between childhood health care and adult care programs in the following categories: transitional care, family involvement, psychosocial support, independence/dependence, adherence/non-adherence, and risk factors.

Chapter 2: Literature Review

Introduction

Chapter 2 includes the search strategy for literature relevant to the topic under discussion in this study, the conceptual framework, and an overview of CF, psychosocial factors in CF, an overview of CHD, psychosocial factors in CHD, statistical and research data, and research questions for this study. The purpose of this phenomenological qualitative study was to understand the experience of parents and patients as they progressed through adolescence managing a chronic illness, while juggling multiple challenges of transitioning from childhood health care to adult care where self-care is anticipated.

Literature Search Strategy

Literature for this study was identified using the following search terms: *Chronic illness in youth and conflict with parents, transitions from childhood health care to adult care, decision making in chronic illness, adherence and non-adherence in chronic illness, parenting stress and chronic illness, family relations and chronic illness, independence and dependence in chronic illness, autonomy, body image, cystic fibrosis, congenital heart disease, chronic diseases of childhood*. The following databases were used: PsycARTICLES, PsycINFO, SocINDEX with Full Text, MEDLINE with Full Text, and ProQuest Central, and Walden Dissertations.

Prevalence and Prognosis of CF and CHD

CF is a genetically transmitted chronic illness more typically experienced in the Caucasian population, with a pervasiveness of as many as 1 in 2,500 births being reported

(Withers, 2012). Approximately 10% of cases of CF will go undetected until the adult years (Sueblinvong & Whittaker, 2006), and as many as 80% of individuals living with this disease eventually succumb to respiratory malfunction (Flume & Van Devanter, 2012). CF is brought about by an alteration in the cystic fibrosis trans-membrane conductance regulator (CFTR) gene (Sueblinvong & Whittaker, 2006). CF has the capacity to severely reduce the functioning of the lungs and the gastrointestinal system due to abnormal secretions of mucus (Withers, 2012). The death of individuals with CF was very abrupt in the past (Sueblinvong & Whittaker, 2006); however, the lifespan of those born with CF after the year 2000 is anticipated to be older than 50 years of age (Withers, 2012).

CHD is another severe chronic illness of childhood, with a pervasiveness of as many as nine in 1000 births being reported (van der Linde et al., 2011). Individuals living with CHD will often present with a wide assortment of cardiac abnormalities or lesions: some are minor and may be rectified as the individual matures, while others may be very acute, resulting in numerous operations and hospitalizations over the lifetime of the individual (Berant, Mikulincer, & Florian, 2003). Approximately 90% of individuals living with CHD will live into their adult years (Luyckx et al., 2014).

Conceptual Framework

Biopsychosocial Model

In Chapter 1 the theoretical frameworks that provide a base for this study were reviewed. One of these theories is the bio-psychosocial model of health, which was proposed by George Engel (1977) as it relates individual and social variables to physical and medical concerns. Engel (1977) noted that there were shortcomings with the biomedical classification of health and disease and became concerned with the variation in the progression, presentation, and management of disease (Engel, 1977). In particular, Engel noted that social factors and personal behaviors appear to influence the course of a disease (Stacy, Laumann, Levinson, & Waite, 2003). With the focus on the cause and origin of disease, and little attention on the motivation and well-being of patients, illness often prevailed despite medical intervention. While the bio-medical model provides information about the progression of illness, it does little to improve our understanding of the psychosocial impact a disease can have on the individual and family members (Rolland & Williams, 2005). The bio-psychosocial model provides a means to go beyond the deterioration and succession of an illness, permitting analysis of the individual experience with an illness, insight into how family members are impacted by an illness, and information about management issues with regard to treatment (Rolland & Williams, 2005). The bio-psychosocial model is frequently employed in studies looking at chronic illness because the principles of this theory acknowledge that the individual is not only living with a chronic illness, they are also living with a disorder set within a particular context that often has cultural meanings about illness, while also being subject to other systems in the wider community (Rolland & Williams, 2005).

Adolescence is recognized as a precarious phase involving numerous adjustments, and it is further complicated when a chronic illness is present (Segal, 2008). It has long been recognized that social, relational, and psychological factors all influence medical issues (De Geest et al., 2013). Psychosocial factors have a profound effect on the subsequent health of lung transplant recipients, and researchers have embarked on psychosocial research to help identify suitable candidates for this type of procedure, which is costly and restricted by the supply of organ donations (De Geest et al., 2013).

Terms like bio-psychosocial and integration of care are frequently used in the medical field, with implementation of such models being left to the good intentions of health care workers who are left operating outside of their area of practice or education. Patient-centeredness has often been associated with the bio-psychosocial model. Scholl, Zill, Härter, and Dirmaier (2014) performed a review of five databases in an effort to characterize patient-centeredness. The authors identified 15 elements that were used most often to delineate the term patient-centeredness. Patient-centeredness encompassed characteristics of the clinician, the clinician-patient relationship, the clinician-patient communication, the patient as unique person, a bio-psychosocial perspective, patient information, patient involvement in care, involvement of family and friends, patient empowerment, physical support, emotional support, integration of medical and non-medical care, teamwork and teambuilding, access to care, and coordination for continuity of care (Scholl et al., 2014). It was observed that the definitions of patient-centeredness did not appear to be linked with health care laws or policies (Scholl et al., 2014). Although it is widely recognized that the bio-psychosocial model integrates multiple important aspects of health, it is not applied universally or with expertise in many cases (Scholl et al., 2014). Research demonstrating the applicability of this model is needed to help health professionals know what to ask and look for in vulnerable populations, and to determine how to best assist families supporting a child with chronic illness.

Attachment Theory

Another theory that provides support for this study is the theory of attachment proposed by Bowlby (1969). Although Bowlby was skilled in psychoanalysis, he found this approach was not adequate to account for all the human experiences to explain why people acted or responded to others in the manner that they did (Bowlby, 1969; Hooper et al., 2012). With the development of the theory of attachment Bowlby, was able to amalgamate ideas from the medical, cognitive, cybernetics, social, and emotional fields and present a well-rounded image concerning the way individuals interact in different environments (Hooper et al., 2012). Specifically, Bowlby asserted that communication among parents and children created an "internal working model" (IWM), or mental representation for relating to others, which in turn caused emotions to stimulate a physiological response (van Ecke, Chope, & Emmelkamp, 2006, p. 83). Bowlby asserted that the activation of a particular physiological response pattern seen in childhood could later be activated and observed in adulthood when similar circumstances or communication regarding survival materializes (van Ecke et al., 2006). Bowlby's theory encompasses some of the factors necessary for the development of confidence such as a secure attachment, which results in the cultivation of trust between parents and youth (Ditzen, Schmidt, Strauss, Nater, Ehlert, Heinrichs, 2008). This trust is significant to foster self-governance and independence in youth (Bazzazian & Besharat, 2012). Insecurely attached individuals are more likely to evaluate taxing situations such as chronic illness as intimidating, and they are unlikely to seek ways to resolve conflict compared to securely attached individuals (Bazzazian & Besharat, 2012). It is necessary to understand the emotional and social attachments within the relational dyad of parents and youth living with a chronic illness in order to identify where problems can evolve that could impinge on the health of the patient or possibly expand to other systems, such as the triad consisting of physician, patient, and parent.

Adolescence is a time of metamorphosis, and generally met with the expectation that adolescents will become independent, free thinking, self-determined individuals. By the same token, this transformation can be arduous for individuals living with chronic illness (Kreindler, & Miller, 2013).

Wong and Heriot (2008) investigated the influence that parent hopefulness and anticipation had on their chronically ill children's health. They found that parents of children with CF who had confidence in the care provided to their children also maintained a belief that the treatment would have a good outcome, tended to engage in problem solving, were more likely to mentally reconstruct ideas, and typically sought the support of others in comparison to parents who contained their emotions or viewed the illness as something they had control over, all of which contributed to healthier outcomes for their children (Wong & Heriot, 2008). Other research has confirmed a link between parents who adopt an avoidant approach of their children's illness and setbacks experienced by their children in the areas of mental and physical health (Sheehan, Hiscock, Massie, Jaffe, & Hay, 2014). Likewise, there is a strong relation between how youth appraise parental support and their report of feeling sad and lonely (Luyckx et al., 2014). In particular, it was found that when youth with CHD perceived their parents to be sympathetic towards them they reported fewer internalizing issues such as feeling lonely or feeling sad (Luyckx et al., 2014).

Psychosocial factors such as stress on the family, peer relations, and family dynamics all influence adherence, but more research is needed to establish what specific type of communication and relationship encourages adherence and the development of self-care skills (Harrop, 2007). Some research has identified the importance of independence for the development of self-care skills (Dashiff et al., 2008; Delmar et al., 2006; Withers 2012). The development of these self-care skills is expected to take place within the context of the parent/child relationship. Therefore, the quality of this relationship is a focus of this study.

Family Systems Theory

Another theory employed in this study is Murray Bowen's intergenerational family systems theory (1972). The family unit according to this theory is viewed as organic in nature, and stability is obtained by the individual when they maintain a balance between both being together as a family system and separation from that same system (van Ecke et al., 2006). When an individual is unable to establish equilibrium in the family system this will create fearfulness within the individual (van Ecke et al., 2006). In the event that an individual is exposed to worry for an extended period of time then they are likely to experience "fusion" where the individual's cognitive capacity is determined by their emotional state (van Ecke et al., 2006).

Significance of CF and CHD for the Problem under Study

CF and CHD are both chronic illnesses identified in childhood, and both disorders are lifelong and incurable, increasing the likelihood that these populations will experience a lifetime of moving between the need for others and a desire for independence. The teenage years are a typical time of evolution, but for the populations in this study, the presence of a chronic illness has the capability to generate numerous complications, and there is a need to develop a better understanding of the psychosocial issues that can impact health outcomes (Luyckx et al., 2014).

Transition from Pediatric to Adult Care

Transitions have been characterized as the intentional, calculated movement of adolescents from pediatric to adult health care, where the focal point is adult concerns (Withers, 2012). The timing of this transition has been a subject of debate (Kennedy et al., 2007). Kirk (2008) has indicated that the transition to an adult facility is not always completed in a timely manner, while Kennedy et al. (2007) has suggested that there is significant variability to the timing of this event. A number of factors (Fletcher-Johnson et al., 2011) could influence the timing of transition to adult care, such as the age of the patient (Hafetz & Miller, 2010), the hesitance of the patient, or parent, or hesitance on both parts (Guomundsdottir, Guomundsdottir, & Elklit, 2006).

Knowing when and how to transition can be complicated for a number of reasons. Specifically, there is a concern about adherence, as adolescence is the phase where good health behaviors are likely to plummet (Modi, Marciel, Slater, Drotar, & Quittner, 2008). Family conflict has a significant effect on adherence, and subsequently the quality of health of the patient (Quittner, Drotar, & Ievers-Landis, 2004). Moreover, the quality of communication, especially between parent and the adolescent or young adult, can impact the youth's perception of independence and sense of autonomy, which will likely impact the development of self-care skills (DeVito et al., 2013). Modi et al. (2008) reported that parents diminish their regulation of adolescents with a chronic illness at the age of 15 years, but were later seen to re-establish themselves as supervisors for adolescents between the ages of 16 and 17 years. More research is needed to understand the dynamics of the relationship between parents and their chronically ill children to comprehend how they handle change of responsibility both medically and psychologically.

Individuals living with chronic illness are likely to experience numerous changes, but unlike their peers, they are likely to experience a number of other transformative processes bodily, cognitively, and socially, in addition to other developments such as preparing for college, and living independently of the care of others (Withers, 2012). Hegarty, MacDonald, Watter, and Wilson (2009) point out that chronic illness is likely to ensure that the individual experiences repeated hospitalizations throughout their lifetime, which can be expected to have physical, emotional, social, and spiritual impact.

Physical Constraints Related to CF and CHD

Chronic illnesses such as CF and CHD may inhibit the lifestyle of individuals and present a reminder to adolescents about the disparity between them and their peers. Chronic illness often sets limits, resulting in poorer physical strength. For example, a reduction in muscle mass in lower appendages can present a barrier to some activities for individuals living with CF (Rogers, 2003). One technique used to assess the individuals' tolerance limits is the three-minute step test, or the treadmill (Rogers, 2003). Despite the limitations, parents of youth with CF are instructed to encourage their youth to participate in some level of physical activity, as this will influence bone mass later in life with the possibility of mitigating the development of a secondary illness such as osteoporosis (Rogers, 2003). Parents are expected to be the chief contributors to endorse healthy physical practices to their youth, and this can lead to disagreements in this triad.

Nutrition

Nutrition in individuals living with a chronic illness can be critical to the management of the illness, and following strict diets, or ensuring high or low caloric intake can create additional demands. Rogers (2003) emphasized the importance of nutrition in the prevention of secondary illnesses such as osteoporosis. Abbott et al. (2000), while investigating the opinion of parents with regard to the eating behavior of their children, found that parents of children with CF were more likely to appraise their children’s eating behaviors in an unfavorable light than the parents of a healthy peer group. The parents of children with CF in this study frequently reported that they found their children’s drawn-out pace of eating exasperating; however, the children with CF had a higher intake of calories than their cohort (Abbott et al., 2000). The perception of parents with regard to the pace of eating and their frustration with this behavior presented insight about how the demands of a chronic illness can affect the stress response of parents. With high caloric intake essential for prolonging the life of the individual with CF, parent’s annoyance may impede the health and nutritional needs of their children

(Abbott et al., 2000). Further research is needed to understand the quality of parent and youth relations when demands for the management of a chronic illness are strenuous.

Psychological Factors Related to CF and CHD

Mental Health

Studies of the psychological health of individuals living with CF and CHD frequently identify emotional disturbances such as anxiety and depression in these populations (Pilewski & Taichman, 2014). A number of inquiries have also attempted to determine the origins of body dissatisfaction frequently reported in individuals living with CF, and the possible development of eating disorders. Pilewski and Taichman (2014) reported that anxiety and depression are commonly mentioned in individuals with CF. Bregnballe, Thastum, and Schiøtz (2007) gave an account of anxiety in children with this diagnosis as young as 7 to 10 years.

Anxiety and depression also impacts individuals living with CHD, and these issues are known to affect psychosocial functioning and create complications for their physical health. Individuals living with CHD demonstrate a higher incidence of internalizing issues in comparison to controls, resulting in melancholy and feelings of isolation (Luyckx et al., 2014). Other researchers have found a connection between the Big Five personality traits, including extraversion, conscientiousness, agreeableness, emotional stability, and openness to experience, to health behaviors of adolescents with CHD (Rassart et al., 2013). Luyckx et al. (2014) reported a direct relationship between the occurrence of feelings of melancholy and the prevalence of feeling lonely in adolescents with CHD. Luyckx et al. also found that the perception of parental support by the individual living with CHD reduced the level of melancholy and loneliness reported by adolescents (Luyckx et al., 2014). How individuals with CHD perceived the quality of their lives was directly linked to their opinion of how supportive they thought their parents were of them (Luyckx et al., 2014). Future research needs to explore the influence of parental and youth relations, and the potential impact this relationship has for the health of individuals living with a chronic illness.

Body Image

Adolescents may anticipate that they will develop physically at the same rate as their peers and may look forward to their physical transformation into adults. There is, however, some delays noted among males and females living with CF, placing these populations in stark contrast to their healthy peers (Withers, 2012). Female growth rate has been reported to fall behind healthy peers by as many as two years, and they are less likely to develop mature mammary glands (Withers, 2012). Similarly, males with CF experience a growth rate behind their peers by 1.5 years, and tend to be prone to smaller figures with lower muscle mass in contrast to their peers' development (Withers, 2012).

A number of inquiries have been performed in an effort to determine if individuals living with CF are prone to eating disorders, and these have yielded mixed and inconclusive results. For example, Steiner, Rahimzadeh and Lewiston (1990), compared individuals living with CF to controls, and a group formally diagnosed with anorexia or bulimia. None of the participants living with CF were found to meet the diagnostic criteria for either eating disorder; however, the findings revealed that two of 10 CF patients met the diagnostic criteria for an anxiety disorder and one met criteria for the diagnosis of adjustment disorder with disturbed mood (Steiner et al., 1990). Walters (2001) examined the beliefs CF patients to ascertain if their evaluation of their body mass would be exhibited in some of their eating habits. Females with CF tended to inflate their size, while males had a propensity to deflate their body mass (Walters, 2001). This influenced their eating habits with the males reporting that they wished to increase their body mass and adhering to daily enzyme treatments that help promote absorption, while the females were less likely to take enzyme treatments greatly reducing the assimilation of nourishment and lowering body mass (Walters, 2001). Due to the lack of self-awareness observed in this sample, it was suggested that individuals diagnosed with CF may be in jeopardy for the development of an eating disorder (Walters, 2001). More research is needed to replicate these findings and to determine if relational issues at the family level are contributing to this phenomenon.

Conversely, it has been proposed by Bryon, Shearer, and Davies (2008) that individuals with CF might be more health conscious than their peers because their diet is rigorously monitored to ensure that their Body Mass Index (BMI) is adequate. Although individuals living with CF may appear to talk about body image and dissatisfaction with weight more in comparison to peers, much more research is needed to determine if these individuals are just more health conscious than their peers as a result of a hands-on experience and a lifetime of managing a chronic illness, or if there is an underlying psychological factor driving eating habits (Bryon et al., 2008). In a study consisting of 55 participants with CF, none were found to meet the diagnostic criteria needed for a diagnosis of bulimia or anorexia (Bryon et al., 2008).

Although a number of studies have been performed in an effort to determine if the eating behaviors of individuals living with CF might meet the diagnostic criteria for some of the listed eating disorders in the Diagnostic Statistical Manual, research reveals mostly negative findings and a need for further investigation regarding self-care. Abbott et al. (2000) state it is uncertain why mortality rates are much higher and earlier for females diagnosed with CF versus their male counterparts. Furthermore, it has been noted that males diagnosed with CF are more motivated to gain weight than females with the same condition, and males are better at adhering to enzyme treatments, which are employed to increase the absorption of nutrients (Abbott et al., 2000). It is unclear if females living with CF might be manipulating recommended therapy to control their body weight (Abbott et al., 2000). Further examination of this peril to the health and well-being of individuals diagnosed with CF is warranted.

Medical Factors Related to CF and CHD

A diagnosis of CF or CHD guarantees an ongoing relationship and interactions with members of the medical field. A variety of medical issues have raised concerns in the medical community in their encounters with some of the CF population to include incidents of non-adherence (Williams, Muhopadhyay, Dowell, & Coyle, 2007; Withers, 2012), which lessens the success of transplants (DiMatteo, Haskard-Zolnierek, & Martin, 2012; Shaw et al., 2003), or the development of secondary illnesses such as cystic fibrosis related diabetes (CFRD) (Kostakou et al., 2014). The most troublesome medical factor faced by individuals living with CHD is the need for exposure to numerous surgical procedures (Soulvie, Desai, Parker-White & Sullivan, 2012). Changes in neurological processing have been observed in some individuals diagnosed with CHD following surgical procedures making the prospect of surgical procedures frightening (Soulvie et al., 2012).

Adherence

According to Withers (2012) some of the more commonly cited obstacles concerning non-adherence in adolescents with CF are a desire for lesser input from parents, a yearning for acceptance by their social group, a loss of optimism about treatments, a failure to remember medical regimens or routines, challenges with parental management, coming to the conclusion that treatments are pointless because death is inevitable, and the clash of opinions with a primary care physician. Adherence means patients follow routines for suggested medications and stick to health activities specified by their health care provider (DiMatteo, Haskard-Zolnierek, & Martin, 2012). Non-adherence is defined as the cessation or interruption by a patient to stay on suggested medications or follow health activities specified by their health care provider (DiMatteo et al., 2012). For individuals living with CF, adherence is particularly important when it comes to taking enzyme treatments, as these are considered a necessary supplement to ensure the absorption of essential nutrients (Stark & Mulvihill, 1997).

Adherence is not only important to ensure the success of transplants, it is also necessary to carry out routine chest physiotherapy that individuals with CF need to perform as part of their daily self-care skills (Williams et al., 2007). Researchers suggest that individuals with CF are commonly non-adherent to this necessary daily course of therapy with as little as 50% of parents and patients with CF reporting that they follow the physician recommended therapies (Williams et al., 2007). Similar to previous findings by Withers (2012), Williams et al. (2007) reported that adherence is strongly influenced by the cohesion of the family unit in addition to other challenges such as behavior problems or rebellion of the youth against parental supervision. Indeed, the severity of the consequences to treatment non-adherence in individuals living with CF and CHD gives rise to major concerns among medical professionals, but also has the propensity to frustrate and provoke emotional outbursts in parents and patients. According to Williams et al. the exceptionally laborious treatments expected to be performed each day for the management of CF such as chest thumping or assisting the youth with breathing practices to clear their bronchial passages can generate an emotional quandary for the parent who must assist, and witnesses first hand their children's discomfort and irritation with many of the procedures. Some parents of CF patients report that they cultivate mental diversions in an attempt to reduce the disheartening aspect of their children's disorder; however, they and their children may modify physician recommendations in an attempt to lower their level of frustration and annoyance (Williams et al., 2007). More research is necessary to capture the intensity of the exchanges taking place between parent and child to develop a better understanding of strategies that might promote positive health behaviors and, those that endanger the health of the patient.

Transplants

Individuals with CF and CHD often face the prospect of giving serious consideration to organ transplant at some point during their somewhat shorter lifespan.

Regrettably, this major concern, which has the capacity to escalate anxiety and depression, among other psychosocial issues for individuals living with CF and CHD, receives very little deliberation prior to the transplant or prior to the grave state of organ failure (Shellmer, Brosig, & Wray, 2014). Determining whether to undergo a transplant is a crucial decision for individuals living with chronic illness and their family members to process. While illness has most frequently dictated stage of transfer to the transplantation team or center, often no specific plan or preparation to help patients, families, and their physicians is in place to assist with the decision-making process (Dellon et al., 2009). Researchers have identified this shortcoming in the process of consulting with patients about transplant procedures, risks and benefits, and have attempted to devise a “decision aid” to help physicians and patients identify concerns about the process (Stacey et al., 2015; Vandemheen, Aaron, Poirier, Tullis, & O’Connor, 2010).

The pervasiveness of non-adherence following organ transplants is proposed to be somewhere in the range of 30 and 70%, making this trend in poor health behaviors a significant concern for surgeons (Shaw, Palmer, Blasey, & Sarwal, 2003), and a significant expense for the health care system (DiMatteo, Haskard-Zolnierek, & Martin, 2012). One study found that over half the beneficiaries of renal transplants were found to be non-adherent (Shaw et al., 2003). Shaw et al. reported as many as 52% of adolescents were non-adherent as a result of some breakdown in parental management. One of the key issues related to the breakdown of parental management was conflict in the parent and child relationship (Shaw et al., 2003). The nature of the breakdown in parental management was not clearly understood and further research is warranted to explore what would lead to this collapse in health care management.

Social Factors Related to CF and CHD

The theories chosen to guide this study included the bio-psychosocial model (Engel, 1977), the theory of attachment (Bowlby, 1969), and the intergenerational family systems theory (Bowen, 1976). The remainder of this chapter presents a discussion of Bowlby's attachment theory (Hooper et al., 2012), and Bowen's intergenerational family systems theory in particular, as both are essential to assess family relations and establish how the family system impacts other social systems. A number of social issues have been observed to influence the health of individuals living with CF and CHD. For example, family relations and communication (Goldbeck & Melches, 2005), attachment styles (Soulvie et al., 2012), peer relations (Salzer-Muhar et al., 2002), dependence versus independence (Brown, Small & Palmer, 2008), development of self-care skills (Brown et al., 2008), and the exploration of alternative ways of thinking and behaving while moving away from the conventional wisdom of parents and physicians (Withers, 2012), have all been determined to have some level of influence on the health and well-being of individuals living with a chronic illness.

There is, however, a gap in the literature regarding the experience of parents and their offspring living with a chronic illness when it comes to communication about important issues. Current research suggests that little is known about the impact of the family system in the meaning of the organ transplant referral process (Shellmer et al., 2014), the exploration of life issues with peers, and how significant events and conflicts are handled by the parents and their offspring.

Family Interactions, Conflict and Communication

In the discussion about chronic illness there is much talk about the parents' role in the management of illness and adherence (Quittner et al., 2004). Parents are often defined as occupying the role of an intermediary between their child and the physician (Bryon & Wallis, 2011). This may be a difficult role for parents to sustain, particularly if the patient disapproves of treatments and decisions that were previously made by parents on behalf of their children. Even more disconcerting is when dysfunctional dyads or triads are generated as a result of rigidity of the family system or a failure to adjust to changes in the system (Shapiro, 2001). Without warning, family systems of chronically ill patients can be catapulted into new circumstances where they experience a disruption to former alliances, or the alienation of family members who previously provided care (Shapiro, 2001). Because of this, it was necessary to look at the experiences of parents and their offspring living with chronic illness to further our understanding of how they navigated transitions and communicated their needs to each other during these phases. Furthermore, it was important to recognize intergenerational family system patterns of reacting to and communicating about difficult topics.

Smetana, Yau and Hanson (1991) examined family conflict and conflict resolution, and suggested that prior research has typically focused on documenting the exchange, but not the subject matter. Specifically, they suggested that conflict resolution be investigated by looking at a specific topic that needs to be resolved, and specific family relations within the context of that problem (Smetana et al., 1991). The current study used interviews in a qualitative design to document individual descriptions of the experience while looking at the specific subject matter.

Cicognani and Zani (2010) looked at the construct validity of the When We Disagree (WWD) scale, which is an inventory designed to gauge family members conduct while they are experiencing disagreements. This instrument was designed specifically for youth between the ages of 13 and 15 years. The findings of this research revealed a greater frequency of disputes involving female adolescents and mothers compared to other dyads. Moreover, younger males were more likely to cooperate with parents and demonstrate less hostility towards them, while older males state that parents are more forceful and uncompromising in their interactions with youth (Cicognani & Zani, 2010). Parents most often viewed adolescents as less cooperative when it came to ways of thinking, attending to what others say, and yielding, while also rating adolescents as more aggressive to include cynicism, resentment, and outcry against parents (Cicognani & Zani, 2010). For their part, youth in this study also described themselves as confrontational and unwilling to negotiate, but perceived this insubordination as their effort to develop self-determination, and demonstrate to their parents that they have another way of thinking (Cicognani & Zani, 2010). Self-determination is a desired outcome for entering adulthood: in society we encourage our youth to develop this characteristic. It is, however, something that has to be learned, and it usually begins in the context of the parent/child interactions in the family.

Attachment

Individuals living with CF or CHD are susceptible to the development of an insecure attachment style as a result of an illness that makes the duration of their lives uncertain. A critical factor to prevent the development of an insecure attachment is the influence of early interactions with a care provider (Hooper et al., 2012). It was suggested by Hooper et al. (2012) that Bowlby's theory of attachment be employed to offer an explanation of why patients are non-adherent or quarrel about treatments. Incorporation of the theory of attachment is likely to assist physicians as they converse with their patients about critical issues such as the transitory processes, transplants, and the importance of being committed to therapies, while addressing any apprehensions a patient may experience within the context of a safe and trusting environment.

Peer Relations

Peers contribute to social support while family members are deemed to offer practical input (Barker, Driscoll, Modi, Light & Quittner, 2011). Even though individuals living with CF may turn to peers for support, research suggests that as many as 17% of youth with CF have elected not to divulge information to their peers about their chronic illness (Barker et al., 2011). Further research is needed to determine what aspects of peer and family relations helps adolescents with CF, or how the different type of relations might accommodate self-care skills or improve health outcomes (Barker et al., 2011).

One of the major aspirations of most adolescents is the desire to fit in with peers. The individual living with a chronic illness such as CF or CHD is likely to possess that same aspiration, but the presence of a chronic illness can often make fitting in difficult.

One of the issues that may set the adolescent with CF apart from their peers is that they need to eat a high calorie diet (Bryon, Sherer, & Davies, 2008) due to their lower ability to absorb nutrients (Stark & Mulvihill, 1997), while their friends may be more interested in dieting. Abbott et al. (2000) noted that both males and females living with CF indicate that they are continually harassed to eat more than their peers.

Independence versus Dependence

Independence is needed to develop self-management skills for successful transitions to adult health care when complex regimens, transplants (DeVito Dabbs et al., 2013), poor nutrition (Morton, 2009), chronic stress (Brown et al., 2008), and depression (Brown, et al., 2008) are all risks for youth who are learning to take care of themselves. Delmar et al. (2006) examined patients’ outlook towards health and disease to understand the experience of living with chronic illness. The authors found independence and dependence were often experienced together, but being able to choose and determine when and how to depend on or receive help from others had a significant value to individuals living with chronic illness (Delmar et al., 2006).

Autonomy

Both the intergenerational family systems theory and attachment theory describe the family unit as a system that maintains equilibrium through a balance of being together and moving away (van Ecke et al., 2006). This separation and development of self-determination is known as “differentiation” in Bowen’s intergenerational family systems theory, while this severance in Bowlby’s attachment theory is labeled “secure attachment” (van Ecke et al., 2006, p. 84). According to the intergenerational family systems theory, a failure to find equilibrium within the family system between being together and moving away may cause the individual to experience fear and apprehension, which could result in “fusion” (van Ecke et al., 2006, p. 84). When individuals experience fusion, their reasoning is more likely to become automated and directed by their emotional system and this frequently occurs without their awareness (van Ecke et al., 2006, p. 84). According to attachment theory, a failure to find stability within the family system during the development of separation is likely to arouse the attachment organism, where the individual will be observed to employ a variety of defenses in an effort to reduce their anxiety (van Ecke et al., 2006). A number of defenses may be employed to include: mentally blocking out the attachment problem, becoming engrossed with the attachment issue, or lingering on the attachment issue uncertain of how to work out a solution (van Ecke et al., 2006).

Smetana and Asquith (1994) discussed the difficulty of navigating parental influence and the development of adolescence self-governance. This study examined the opinion of parents and adolescents regarding where they perceived a margin might exist in parental control and adolescent self-government (Smetana & Asquith, 1994). The hypothetical questions used in the study incorporated ideas that focused on ethical, traditional, personal, recklessness and personal alliances (Smetana & Asquith, 1994). The reckless items discussed were poor eating habits, alcohol use, and cigarette smoking, or taking risks by going for a car ride with a non-experienced car driver (Smetana & Asquith, 1994). The findings revealed a boundary in the perception of parents and adolescents concerning who had control over which subject matter. For instance, parents were granted authority when it came to traditional or ethical issues, but adolescents endorsed the idea that they should be in control of their relationships, health issues, or issues relating to personal authority (Smetana & Asquith, 1994). On the other hand, parents in this study professed that health, relationships, and personal eating habits where subject to their authority out of a concern for youth (Smetana & Asquith, 1994). A key emphasis of the authors was that there is a greater need for future research to examine the specific nature of conflict between parents and adolescents based on the type of disagreement under review. Additionally, there is a need to develop a greater understanding of specific conflicts such as efforts to achieve autonomy while living with a chronic illness that creates a dependency on others, or conflict about transitions, transplants, treatments and times of change during the illness. Other research has looked at discord in families where chronic illness places demands on family resources, management skills, and adaptability to handle stress, particularly when most of the care provision tasks are performed by one individual (Murdock, Adams, Pears, & Ellis, 2012). In their study Murdock et al. (2012) examined parent and child tension in the management of childhood asthma. The findings revealed that care-giving load was not a good predictor of restrictions on family activity; however, family discord was (Murdock et al., 2012). As in other research looking at conflict between parents and children, the authors suggested that environmental and system attributes of discord should be examined to determine if tension in families or social systems are exacerbating each other. Further research is certainly justified to explore this reciprocal relationship.

Self-care Skills

Self-care agency is defined as the competence and motivation to carry out the activities necessary to sustain health and help manage symptoms of disease (DeVito Dabbs et al., 2013). For the individual living with CF there is a realization that extensive time and vitality will be needed to maintain health over the lifespan (Williams, Mukhopadhyay, Dowell, & Coyle, 2007). Although the adolescent may become habituated to routines for the management of the disease by the time they reach adolescence, there is often an additional complication of the development of secondary illnesses (Bazzazian & Besharat, 2012). For the individual living with CF, there is a higher likelihood of lung transplantation where self-care activities are essential and non-adherence becomes life-threatening (DeVito Dabbs et al., 2013). The purpose of the DeVito Dabbs et al. (2013) study was to determine which candidates selected for lung transplantation posed the highest risk when it came to self-care skills. The Dyadic Adjustment Scale (DAS) was employed to assess the attributes of the beneficiary of the lung transplant and the status of their relationship with their primary source of care. A significant finding was that individuals who received lung transplants and scored at a low level on self-care skills also had poorer quality bonds with their primary source of care at home, in addition to experiencing higher rates of melancholy and fearfulness about their abilities (DeVito Dabbs et al., 2013). While the findings of this study were informative, the authors recognized that the individuals were surveyed right before they were released from the hospital, when they were likely feeling upbeat about the prospect of taking care of themselves, Secondly, the authors admit a survey of self-care agency does not necessarily predict who will in reality go home and perform these critical health behaviors. Further research is warranted to look at interactions between recipients and their primary care giver and to gather greater insight about the psychological stress associated with undergoing transplants, all of which according to this study has the capacity to reduce self-care agency.

According to attachment theory, the alliance between parents and their children is the first system where children experience motivation for survival (van Ecke et al., 2006). The schema formed in these early interactions with the primary caregiver is what alerts the individual later in life that there is a need to activate an emotional response, which in turn produces a physiological response (van Ecke et al., 2006). Bowlby and Bowen hypothesized a connection between the psychosocial and emotional features of the family unit, and the presentation of physiological symptoms (Bowlby, 1969; Bowen, 1976; & van Ecke et al., 2006). Further research was necessary to examine the parent and adolescent relationship to determine how attachment behaviors might impact the health and well-being of individuals living with chronic conditions such as CF and CHD.

Communication

The decision-making process that a family will employ for the management of their children with chronic illnesses is greatly determined by the quality of their relationship, the quality of the communication, and any contextual conditions. Miller (2009), looked at the concept of collaborative decision making (CDM) using a sample of participants ages eight to 19 years who had been diagnosed with asthma, type 1 diabetes, or CF. Miller (2009) noted that while other studies have examined independent decision-making from the perspective of either the parent or children, a review of existing research did not yield any standard tool to gauge the CDM of parents and children with regard to regulation of a chronic illness. The findings of Miller's study (2009) indicated that parents were less likely to engage in CDM if they experienced pressure due to time constraints, fatigue, and other children nearby, a misbehaving child, recent disagreements between the parent and child, learning challenges in the child, or a recent hospitalization of the child. In contrast to parents, children were less likely to engage in CDM with their parents if their parent was irritated by something, if the child perceived their parents tended to be anxious and worried, when motivated to evade treatments, or when they desired to hedge being accountable for their own care. Sometimes the child tried to be tough and take action without consulting their parents, in particular when they were worried about something they would avoid CDM with parents (Miller, 2009). Both parents and children often engaged in various decision-making styles with each other. It is important to follow up on the issue of communication styles to determine how this might influence the health behaviors of patients with chronic illness, and the relationship between parents and their children with chronic illness. It is possible that both parents and children engage in different methods of communicating to prevent raising concern or placing a burden on the other. Not much is known about this aspect of life with a chronic illness. Unfortunately, if an avoidant style of communication was engaged in with greater frequency, then this could be less effective as a strategy for the management of chronic illness. More information is needed from the perspective of families who live through the experience of managing chronic illness to determine how they negotiate through times of personal development regarding management of the disease.

Current research continues to examine messages within families where chronic illnesses have been diagnosed. For example, Branstetter, Domian, Williams, Graff, and Piamjariyakul (2008) gathered information looking at messages between parents and children who were diagnosed with a chronic illness, and their healthy brothers and sisters. Drawing on a number of theories such as the family systems theory, the family stress theory, and the symbolic interaction theory the Branstetter et al. study revealed four topics concerning family messages. The first description of family messages acknowledged the obstacle that the demands of the illness often placed on all of the family members, reducing the quality of communication (Branstetter et al., 2008). In the second description of family messages healthy children described the relief of being able to express their concerns, while parents described finding solace in the receptive interactions with their healthy children following treatments with their chronically ill children (Branstetter et al., 2008). The third description of family messages described family members grabbing hold of whatever chance they got to communicate while juggling responsibilities (Branstetter et al., 2008). The fourth description of family messages illustrated the additional stress family members all experience as a result of the additional responsibilities involved in the management of a chronic illness. More importantly, the findings of this study demonstrated that family members often reduced stress by modifying their expectations about the standard of communication that could be expected as a result of having a family member with a chronic illness (Branstetter et al., 2008). It was clear that further research was needed to explore the quality of communication between parents and their children diagnosed with a chronic illness, to look at exchanges between this dyad and triad, and to examine how they negotiated in the course of discussing complex issues.

Summary and Conclusions

Lindsay-Withers (2012) opined that the quest for self-determination in the individual living with a chronic illness is to some extent a contradiction in terms. Although there have been numerous studies performed in an effort to chart the experience of both parents and their children diagnosed with a chronic illness (Berge, 2004; Bin, 2006; & Brown et al., 2008), previous research has not adequately focused on or captured the complexity of exchanges taking place between parents and their children. As a result of the findings presented by Sobel and Cowen (2003), it is possible to observe what happens to a family communication network in the first phase of what can be an unpredictable and stressful existence when a family unit first learns that a family member has been diagnosed with a chronic illness. This research also presented a minimal view of how families may select to converse about the chronic illness in the early stages of the illness within the family system. There is however a gap in the research when it comes to how families converse about the deterioration of health and treatment plans in the advanced stages of the disease.

Chapter 3 includes the introduction, research design, role of the researcher, research methodology, and a summary.

Chapter 3: Research Methodology

Introduction

The purpose of this qualitative phenomenological study was to explore how parents and adolescents transitioning from childhood health care to adult care communicated about complex issues related to health care as they progressed through this transition. This study employed a phenomenological method to form a detailed account of the participants’ lived experiences while communicating and acting together to manage a chronic illness. The phenomenological approach provided rich narrative data from parents and their adult children regarding perceptions and experiences of the transition from pediatric to adult care. Within the stories provided by parents and their children, it was anticipated that rich and textured descriptions of their experience conversing and making decisions with regard to transitions for the management of chronic illness would be revealed, in addition to disagreements and tension they may have experienced.

In this chapter, the reader was provided with a description of the current study, the research questions, a comprehensive account and justification for the research method chosen for this study, a discussion regarding the process used to recruit participants, a description of the setting and sample, a description concerning the role of the researcher, a discussion about informed consent and confidentiality, a description concerning data collection and analysis, and a discussion about ethical considerations involved with this study.

Research Questions

Research Question 1: How do parents and young adults aged 18 to 30 years with CF or CHD describe their experience of negotiating who is responsible for health care tasks during the transitory process from pediatrics to adult care?

Research Question 2: How do parents and young adults aged 18 to 30 years with CF or CHD describe their experience of negotiating when and how young adults gain responsibility for health care tasks?

Research Question 3: How do parents and young adults aged 18 to 30 years with CF or CHD describe the quality of their communication when they discuss who is responsible for health care tasks and medical decisions?

Research Question 4: How do parents and young adults aged 18 to 30 years with the diagnosis of CF or CHD describe the quality of their relationship during negotiations about health care decisions and transfer of responsibility?

Research Design and Rationale

Qualitative research consists of five different approaches for research to include: case study, narrative study, phenomenological method, grounded theory study, and ethnographic study (Creswell, 2007). A phenomenological approach was chosen to deal with the research questions under consideration in this study. Rationalization for choosing this qualitative research method over all of the others is provided below.

Case Study

Case studies are used to study a specific program, incident, group, or a single individual (Creswell, 2007). Case studies are best employed when the researcher wants to study a system that is bounded by time or an activity. The drawback of this method is that while the phenomenon may be experienced individually, the data is analyzed for the entire group (Creswell, 2007). The purpose of this study was to explore the relations between parent and children dyads during the transitory process, which can span across time. Therefore, the boundary of time was seen as a limitation set by this method. The aim was also to examine common experiences or patterns across individuals, which requires a larger sample size than a case study design.

Ethnographic Study

Ethnographic studies are performed by means of observing participants of a specific cultural group in their environment to document activities, and beliefs shared by the group (Creswell, 2007). Although this study looked at the dyad or triad of parents and children with specific diagnoses, an ethnographic study was not deemed suitable to capture the complexity of the communication style or the individual experiences of parents and their children during the transitory process. The goal was not to observe the transitory process as it occurs, but instead to engage the participants in a recall of this process, and so ethnography was not an appropriate method of study.

Narrative Study

Narrative studies invite participants to present an account of their life story, which is then organized and rewritten by the researcher, and presented as a biography, or autobiography, or memoir (Creswell, 2007). This study explored the complex relations between parent and children dyads and triads during the transitory process in order to make sense of their lived experience while communicating about complex decisions and negotiating conflict, and did not concentrate on the specific story of each individual. Furthermore, this study was not attempting to examine the chronological sequence of events (Creswell, 2007). Therefore, a narrative study was not appropriate for this research.

Grounded Theory

Grounded theory engages in a continuous evaluation of data and sampling of different groups to intensify the search for connections or distinctions in the information until a point of saturation has been reached in order to develop theory (Creswell, 2014). Grounded theory was not chosen as a research method for this particular study because the focus was to explore the lived experience of the parent and children dyads and triads while communicating about complex issues, and not to establish a theory regarding the phenomenon. Grounded theory also does not allow for the detailed examination of narratives that phenomenology does, and the research questions required this level of detail.

Phenomenology

The main research question(s), or problem, is the decisive factor for determining what research approach will be utilized (Englander, 2012). The phenomenological approach makes use of a reflexive technique, whereby participants are invited to consider their personal thoughts and feelings in an effort to understand their lived experience (Osborne, 1994). Although there is value in quantitative methods, sometimes it more prudent to simply query participants about their rationale for their actions, and trust that, to the best of their ability, they will divulge their motivation for behaving in the manner that they did (Osborne, 1994). Phenomenology moves past typical methods for inferring meaning from behavioral observations to study the individual experience (Osborne, 1994). From a traditionalist and Husserlian perspective, phenomenological research was founded on the premise of intuitive knowledge or consciousness, and what Husserl termed as “eidetic seeing” (Osborne, 1994, p. 170). According to the Husserlian viewpoint, phenomena collected during interviews may offer insight about the conscious experience of the individual with that particular phenomenon, and thereby capture their reality of the phenomenon (Osborne, 1994). Present day phenomenological research has deviated slightly from the strict Husserlian standpoint, which placed an emphasis on structures of awareness. Current day phenomenological researcher now focuses on structures of meaning (Osborne, 1994).

Two Opposing Views: Descriptive and Interpretive Phenomenology

Osborne (1994) harkens inexperienced researchers to be cognizant of a theoretical divergence within the field of phenomenological research. The first phenomenological methodology is credited to Husserl, and known as the transcendental phenomenological approach, which employs a descriptive methodology with the purpose of understanding the individual experience of reality from a subjective standpoint (Husserl, 1970; Osborne, 1994). According to the first fundamental of Husserlian phenomenology, researchers are expected to postpone their view concerning the certainty of reality (Husserl, 1970; Osborne, 1994).

According to the second fundamental of Husserlian phenomenology, researchers are expected to postpone what they know about the phenomenon under study and expect that information may transcend what the investigator knows (Brown & Kimball, 2013; Husserl, 1970; Osborne, 1994). Additionally, the emphasis of descriptive phenomenology is to ascertain the essence of an individual's lived experience of a phenomenon (Brown & Kimball, 2013). Conversely, the hermeneutic research method is based on the views of Heidegger, who set out to decipher concealed meaning without the use of Husserl's bracketing and reduction techniques (Heidegger, 1962; Osborne, 1994).

According to Englander (2012) to attain face validity, and the precision of other research methodologies, the researcher practicing Husserlian phenomenology is expected to adhere to descriptive methods for gathering and analysis of information. The information that was obtained for this study was encouraged through the use of research questions and by conducting individual interviews using a semi-structured interview technique.

Role of the Researcher

As I previously mentioned, there are considerable differences between the phenomenological methods suggested by Husserl and Heidegger (Brown & Kimball, 2013; Heidegger, 1962; Husserl, 1970; & Osborne, 1994). For this study I adhered to a Husserlian descriptive phenomenology methodology. My responsibilities included all of the following: recruiting of participants, interviewing participants, coding, analyzing data, and writing reports to summarize the findings. In addition, it was my responsibility as a researcher employing a Husserlian phenomenological approach to write a reflection to consider any issues concerning my own personal biases, beliefs, or prior assumptions I may have made about the phenomenon being studied. By adhering to Husserlian descriptive phenomenology, I refrained from the Heidegger interpretive phenomenological approach.

A Husserlian phenomenological approach was chosen for this study not only because it is the best approach to employ to explore the research questions presented, but also because this method does not objectify the participant or their experience. While the researcher invites a participant to discuss their encounter with a phenomenon, it is not the role of the researcher to make the participant the object of the study, but rather document the participant's description of the phenomenon (Englander, 2012). Essentially, the role of the researcher is to ensure that interview questions are written in such a way that they invite the participant to describe a specific circumstance where the participant actually encountered the phenomenon (Englander, 2012). The situation of interest in phenomenological research can often extend across time, whereas in other research methodologies such as quantitative research, the situational conditions are typically expected to be the same for each of the participants (Englander, 2012).

According to Heidegger (1962), researchers cannot avoid personal bias while performing phenomenological research and he suggested that Husserl's techniques of reduction and bracketing were unnecessary, as they could not diminish the preconceptions of the researcher (Osborne, 1994). Bracketing also known as epoche, is defined as the practice of suspending one's personal prior knowledge about a phenomenon, deferring certainty about the phenomenon, and being present to the participant's reality of the phenomenon (Hamill & Sinclair, 2010; Husserl, 1970; & van Deurzen, 2014). An example of bracketing is described by Davidson (2004), who suggested that therapists who wish to understand the hallucinations of their patients must suspend prior knowledge of psychosis and listen to the individual patient's description of their experience of this phenomenon. Davidson (2004) described the process of bracketing as adding an element of respect for the participant and their personal experience. Two styles of bracketing are possible: the first is intuitive and involves determining the essence of a phenomenon, while the second involves reflective consideration (Husserl, 1970; Osborne, 1994). Essence makes use of detection of themes in the descriptions of participants (Hamill & Sinclair, 2010). Having awareness is essential to the Husserlian process of bracketing (Hamill & Sinclair, 2010; Husserl, 1970) and self-reflection provided me the opportunity to consider any preconceptions, biases and judgments that I had prior to conducting this research.

Self-Reflection

My personal interest in this particular topic stemmed from my own experience with my brother's son who has lived with CF for the past nineteen years. Although my nephew was diagnosed almost immediately following his birth, his illness is never discussed by his parents with the rest of the family, which my other seven siblings find frustrating as they would like to know more about this chronic illness and genetic testing. Although my brother and his family have all been genetically tested for CF, none of the details have been discussed with the rest of the family.

More recently, my nephew living with CF unexpectedly announced that he was not going to undergo a lung transplant. Following this experience, I wondered if this wall of silence is common in families dealing with chronic illness in children, and how this type of communication impacts the preparation of the individual living with chronic illness for various transitions such as lung transplants. As I have reflected on these experiences in my own family, I am now aware that positive and destructive outcomes are possible.

It is a combination of these events that inspired me to explore the experience of individuals living with chronic illness, and there is clearly a gap in the literature concerning communication in families and how this may be a part of both the successes or risks of transitions. In this reflection I have documented my own personal experience with this topic to create awareness and set aside my own personal assumptions. I have not discussed this topic with my brother or his family. Participants selected for this study had no relation to me.

Methodology

Participants

Seven parents and six adult children diagnosed with CF, aged 18 to 30 years, who had either completed or where undergoing the transition participated in this study. It was intended that the participants included six pairs, or triads: of which three pairs included parent(s) and their adult child, aged 18 to 30 years, who had been diagnosed with CF and who had either completed the transition or were in the process of transitioning from a childhood health care facility to an adult health program; and three pairs were intended to include parent(s) and their child diagnosed with CHD who had either completed, or were in the process of transitioning from a childhood health care facility to an adult health program. None of the parents and adult children diagnosed with CHD who contacted the researcher met the inclusion criteria, and thus only patients with CF and their families were included in the research. This study utilized in-depth interviews, which were conducted confidentially with each individual participant over the phone. Parents were interviewed individually, and their adult children were interviewed separately to avoid contamination of responses. Informed consent was obtained from each participant prior to conducting the interviews. The potential risks and benefits regarding participation in this study was discussed before participants were asked to sign consent forms

Sampling Strategy

I initiated this study by purposefully pursuing participants using a criterion-based sampling technique. Participants had experienced the phenomenon of interest if they were a family unit with an adult who had the diagnosis of CF or CHD, were currently undergoing or had undergone a transition in their health care program, and were aged 18 to 30 years old. Another criterion that needed to be met was that the parent(s) of the participant with the diagnosis of CF or CHD needed to be agreeable to participate in this research. Participants were accepted regardless of sex, gender, ethnicity, or educational level.

I incorporated snowball sampling, as initial contacts were familiar with others who had the diagnosis of CF. By only soliciting participants from support groups or focus groups, I risked the possibility of the development of a homogenous sample (Fossey et al., 2002; Patton, 2002). Therefore, to increase the trustworthiness of the findings, I began with a criterion-based sampling technique (Brown & Kimball, 2013), and included snowball sampling in order to focus recruitment on the population of interest.

Recruitment leaflets and letters were distributed to specialists, physician offices and sent to online support group facilitators for CF and CHD (see Appendix: A, B, C, D). The leaflets consisted of a description of the study, the criteria for inclusion or exclusion, and contact information for the researcher. Two forms of recruitment leaflets were made available, one was placed in professional offices (see Appendix: A & B), and another recruitment leaflet was sent to online group facilitators (see Appendix: C & D). Both of these materials are available in the appendices, and describe the inclusion criteria, which stated that participants needed to be adults aged 18 to 30 years living with CF or CHD, and either both parents or their single parent. In addition, the individuals with CF or CHD must have either completed the transition from a childhood to adult health care program, or they were currently in the process of this transition at the time this study was conducted. A consent form was provided to each participant prior to gathering any information.

Participant Compensation

All participants were compensated for their time with a $15.00 gift card.

Informed Consent

Potential participants who were interested in enrolling in the study contacted me by phone or email. Those that met the inclusion criteria were provided with a consent form, which included notification of the participants’ right to withdraw from the research at any time. No interviews were conducted until I was certain that all participants concerns were addressed, and consent forms were returned to me via mail or email, and it was confirmed that the parent(s) and their adult child were all willing to participate in this research.

Confidentiality

Due to the sensitive nature of this research, all participants were assigned a letter and random number to maintain confidentiality. An e-mail account was established exclusively for this study, and all contacts were deleted after data had been collected, unless participants requested a copy of the findings, in which case contacts were deleted after this information was sent. Interview material and demographic information was stored in a locked safe box in the researcher's home office which was also locked, and no identifying information was kept with the electronic or raw data. The key associating names with code numbers was kept separately in a locked file cabinet drawer, and only I have access to this data. All electronic files and information was stored on my laptop secured with passwords known only to me, which was also stored in a locked office located in the researcher's home. This laptop was used only by me. Electronic information on this laptop related to this study was never viewed in an open access area where personal information could be compromised. Hard copies of all the data will be kept for a minimum of five years, and then destroyed.

Data Collection

After the consent forms were signed and returned to me, participants were sent a demographic survey (see Appendix F). Participants were informed that the interview would last for 45 to 75 minutes, and they were expected to fill out a consent form prior to their participation in the study. Potential participants were also informed that a follow up interview might be conducted in the event that any participant responses were unclear. Once the consent forms and demographic information was obtained from all family members, interviews were scheduled.

Interviews

Seven parents and six adult children diagnosed with CF were interviewed for this study. Participants for this study included five pairs and one triad consisting of both parents and their adult child diagnosed with CF who had either completed or was in the process of transitioning from a childhood health care facility to an adult health care program. None of the parent(s) or adult children diagnosed with CHD who contacted the researcher met all the inclusion criteria to participate in this current study.

Data were collected for this phenomenological study by means of phone calls, and featured a combination of semi-structured and open-ended questions. Participants all opted for an interview using phone calls rather than using face to face or Skype videoconferencing, and were invited to choose a specific time convenient for them when they could answer questions while maintaining confidentiality.

During the in-depth telephone interview and prior to formally introducing the interview questions, time was taken to permit the participant to chat and become familiar with the researcher. During this informal report building stage of the interview I reviewed items from the demographic questionnaire to ensure that they did meet all the requirements to participate in this study. The interview questions addressed the research questions, and all individuals were asked about their communication and relationship during the transition from pediatric care to adult care. Examples of questions that were asked included (to the parents), “How would you describe the relationship with your child while you were transferring responsibility and promoting self-management skills?” and, “Were there treatment decisions that you and your child could not agree on? If so, could you describe how you managed that situation?” (to the adult child with CF or CHD), “To what extent do you think your parent’s involvement in the management of your illness has influenced your relationship with them today?” and, “Parental involvement has often been described as being both valued and disliked by children. What was your experience during your parent’s involvement with the management of your illness?” The complete list of questions presented to both parents and adult children is available in Appendix H. All of the participants were provided with a list of mental health resources in their area before I proceed with the interview.

Debriefing Participants

Each participant was formally debriefed in a discussion with the researcher immediately following each interview as a means to check-in with the participant and deal with any issues that might have surfaced as a result of the interview. During the data collection process, the researcher performed regular check-ins with the participant. The researcher performed this same check-in with the participant at the end of the collection of data to ensure that any psychosocial issues were adequately addressed, and to determine if the participant needed to be provided with contact information for a supportive counselor in their area. Member checking was performed at the end of data collection to allow participants to review the transcripts and respond with any corrections.

Data Analysis

All qualitative data collected during interviews was transcribed verbatim by the researcher conducting this study. I ensured that no personal identifiers were accidentally included in the transcription to ensure that the confidentiality of all personal information gathered during this study was maintained. Interviews were recorded on an external digital voice recorder and transcribed verbatim by me. Data were coded and organized to find themes using NVivo. Another researcher trained and familiar with organizing information using NVivo was asked to review the techniques employed for coding information. Each participant response was separated into components through a process known as horizontalization: clustering was then used to bring the components together (Brown & Kimball, 2013). Clusters conveyed textual and structural meanings: structural relating to what the participant experienced of the phenomenon, and textural referring to how the phenomenon was experienced (Brown & Kimball, 2013). This process was repeated to identify themes for each of the research questions.

Issues of Trustworthiness

Member checking was one method that I used as a way of clarifying respondent statements after the telephone interview. Member checking allowed the informant an opportunity to appraise the final transcript and verify if any of the themes echoed the participants' sentiments (Creswell, 2003). The purpose was to ensure that I had not added any personal bias to the respondent's statements or misrepresented the respondent's personal experience and story. If participants wished to change any of their initial responses, they were also given an opportunity to do so following the interview. None of the participants opted to change their responses.

The rationale for employing transcendental phenomenology was to uncover the essence and meaning of the individual experience (Lien, Pauleen, Kuo, & Wang, 2014). Writing a self-reflection was one method that was utilized to reduce researcher bias (Brown & Kimball, 2013; Creswell, 2003). In an effort to reduce personal bias I wrote a reflection concerning my own personal interest in this area of research.

Triangulation was another method that was used to clarify narratives and to check for consistency among the participants' narratives. Triangulation is a method that is employed when information about the same event is gathered from different sources (Brown & Kimball, 2013; Creswell, 2003). In this study both parents and their adult children diagnosed with CF were all asked to share their family relational experiences in the course of major transitions while maintaining the management for a chronic illness. If there were discrepancies in the information that was gathered, participants were contacted for follow-up questions and discrepancies were then noted in the results. At no time was information about other family member's comments divulged to other participants.

Dissemination of the Findings

A number of stakeholders may want to review the findings of this study. In the event that participants wanted to know more about how their experiences contributed to this research, I agreed to send them a copy of my summary electronically. I plan to attend professional conferences to present information obtained in this research and have the results published in a scholarly journal. I believe the findings can contribute to positive social change in part by encouraging young adults with chronic illnesses to be more vocal about their personal experiences. The findings of this study will hopefully change the public discourse about how societies and families approach the sharing of information about chronic illness.

Ethical Considerations

The risk of this study was low, and was limited to issues regarding confidentiality and the potential for psychological distress. This study was conducted only after approval had been granted by the Walden University's Institutional Review Board (IRB). The approval number from Walden University's IRB was (2016.12.05 19:49:21-06'00'). Participants were instructed that their participation in this study was voluntary and that they could withdraw consent at any time, and they were made aware of the sensitive nature of the subject matter. They were informed that they were free to refuse to answer any question that they wished. If a participant reported that they had experienced any discomfort or unwanted feelings following their participation in this study, steps were taken to ensure that the participant was referred to a specialist to address their concerns immediately. The incident was also reported to the Walden IRB.

I had a list of options for participants to seek support if it was determined for any reason that a support network or professional counseling was needed as a result of any distress generated by my interview questions, and debriefing was conducted in order to determine if such resources were needed. Conditions concerning the issues of confidentiality and any limits to this provision were addressed when participants were presented with a consent form, which they were required to sign, date, and return, prior to any consideration of being a participant in this study. Consent is not merely a document; rather, it is a process, and confidentiality as well as the voluntary nature of the study was discussed at each interaction with the participants.

Summary

Chapter 3 provided a historical overview of all the qualitative methodologies, and the rationale for the selection of transcendental phenomenology versus employing a case study, a narrative study, grounded theory, or an ethnographic study. A transcendental phenomenological design examined the textural and structural descriptions regarding parents' and their children's experiences while conversing about complex issues such as transplants, transitions, sexual health issues, and how they resolved challenges. The purpose of this research was to permit each member of this dyad or triad to tell their story with rich and textured descriptions about their reality of the experience.

Although there are evidence-based transition programs that have assessed many of the issues listed here: there continues to be inconsistencies about the timing of transitions, challenges in families when it comes to communicating about complex issues such as transplants, studies looking at the psychosocial impact of chronic illness, parenting, autonomy, risks and barriers of health care transitions, adherence, social isolation, coping, depression, anxiety, the role of family and friends, parental over-protection, caregiver coping, psychosocial impact of chronic illness, view of treatment decision making, collaborative decision making, communicating about genetic risks of chronic illness, caring load, patient autonomy, road to independence, or the role of support groups.

This chapter and previous chapters included a discussion about the rationale for this phenomenological study with these specific participants.

Chapter 4 will present an introduction to the results section, a description of the environment where the research was carried out, a discussion about the demographics and characteristics for the participants, a discussion about data collection, data analysis, and a discussion about the quality of the evidence, results, and a summary.

Chapter 4: Results

Introduction

The purpose of this phenomenological study was to cultivate an understanding of how individuals with the diagnosis of CF or CHD and their parents communicated as they progressed through adolescence managing a chronic illness, and moved through the challenges of transitioning from a childhood health care program to adult care. This chapter provides a description of the setting, demographics, data collection and data analysis. Several techniques were employed to demonstrate evidence of trustworthiness, which included establishing credibility, transferability, dependability and confirmability.

Demographics

Seven parents and six adult children diagnosed with CF participated in this study. All six adult children were recruited either through Facebook or other online support groups for CF. None of the potential participants diagnosed with CHD who contacted me met the inclusion criteria. All the participants resided within the United States. Demographics of the participants are presented in Table 1 and Table 2.

Table 1

Adult Child Demographics

Identifier	Age	Sex	Ethnicity	Employment	Education	Times Hospitalized
C1	29	F	Caucasian	Full time student	Graduate Degree	60
C2	28	F	Caucasian	Sales associate	4 Year Degree	14
C3	25	F	Caucasian	Customer service	Some College	27
C4	20	M	Caucasian	N/A	High School Graduate	30
C5	19	F	Caucasian	Full time student/coach gymnastics	Some College	10
C6	23	M	Caucasian	Unemployed	4 Year Degree	30 to 40

Table 2

Parent Demographics

Identifier	Age	Sex	Ethnicity	Employment	Education
P1	58	F	Caucasian	Massage Therapist	Some College
P2A	56	M	Caucasian	Engineer	Graduate degree
P2B	55	F	Caucasian	Two Year degree	Medical Assistant
P3	53	F	Caucasian	Physical Therapist Assistant	Under Graduate Degree
P4	39	F	Caucasian	Unemployed	Some College
P5	45	F	Caucasian	Pharmacy Technician	Some College
P6	46	F	Caucasian	Registered Nurse	4 Year Degree

*P2A Father of C2

*P2B Mother of C2

Data Collection

The interviews were conducted over a 12-month period. All the adult children were interviewed via telephone as were six of seven of the parents. One parent requested a paper copy of the questions be sent to her home address for her to provide written responses.

Evidence of Trustworthiness

A rigorous procedure for data collection and analysis was adhered to at all times. This included using a semistructured script to present questions in addition to recording and transcribing each participant interview. I identified codes and themes throughout the process of listening to the recordings, as well as reviewing each transcript.

Transferability is the notion that the reader should be able to contemplate the data in this study in a similar study. Rich and thick description was used to accurately and clearly convey the participant’s lived experiences. Dependability was established by maintaining an audit trail, which included twelve recorded interviews, twelve transcriptions, one written interview, and thirteen files of codes and emergent themes. Confirmability was established during the interview process, maintaining supporting documentation, providing past research, and recording and transcribing interviews verbatim. Confirmability included having another researcher review my findings.

Results

This section provides a description of how themes evolved from participant responses to the interview questions. After reviewing all the participant responses, I established a list of organized codes used for this study. This study addressed four specific research questions:

Research Question 1 reads as follows: How do parents and young adults aged 18 to 30 years with CF or CHD describe their experience of negotiating who is responsible for health care tasks during the transitory process from pediatrics to adult care? Four questions on the survey were designed to capture the essence of this experience (7, 9, 14, and 15). Themes about the dual nature of parent and child involvement in negotiations while also trying to promote independence was supported by a common dialogue throughout the interviews and evidenced by the following themes: benefits of parental involvement in negotiations, drawbacks of parental involvement in negotiations, duality of parental involvement, recommendations and advice to others on how to negotiate and advocate for self-governance, disagreements, and importance of flexibility in negotiations to promote self-efficacy.

Benefits of Parental Involvement in Negotiations

Six adult children and all seven of the parents reported that parental involvement in negotiations was a benefit. The adult children indicated the benefit of parental involvement with terms such as “great allies,” “unbiased ears,” “trust,” as well as the value of second opinions and noting the parents’ familiarity with the disease. Parents who endorsed this theme confirmed their role in providing second opinions, having familiarity with the disease, acting as allies, teaching children to advocate for themselves, and having their children’s trust or providing security. Excerpts supporting this theme are provided below:

- "One benefit she always supports me, and I know that she'll always be there for me (C1)."
- "The benefits are immense. I think that that's really helped, even as an unbiased ear, for me to just complain to or say, "This really sucks." They've also been great allies where they'll text me, "Hey, did you hear about this new med?" (C2)"
- "She can bounce off her thought process and rationales to why she's doing or not doing something, and we can offer our opinion that way. That would be an upside (P2A)."
- "The benefit is that I would go in there very prepared. We had an Excel list of all her medications. We had our bullet list of all the questions we had for the doctors. The benefit is she became her own best advocate and a good, well educated, involved patient (P2B)."

Drawback of Parental Involvement in Negotiations

Four adult children reported no drawback with parental involvement in negotiations about health decisions. Two adult children commented that there might be a drawback in their negotiations with parents if they did not agree about a treatment decision. Two parents reported some drawbacks to their involvement in negotiations about medical decisions while one parent talked about the disadvantage of not being involved in negotiations and feeling excluded from medical decisions. Although drawbacks were less commonly mentioned than benefits, concern about disagreement over end of life decisions in particular was mentioned as a possible drawback. See excerpts supporting this theme below:

- “A drawback would be when I say I'm done, or we've talked about not my will but my advanced directive or something like that. I don't want to live in a vegetative state or if my lungs quit, just they're done. That's not what I want, and I understand that I'm her daughter and she doesn't want to see that happen to me, but the drawback would be her pushing harder than I am willing to push. When I know I've had enough, I'm afraid she's not going to let me have enough if that makes sense (C1).”
- “Of course, drawbacks are that we might disagree on some decisions. He has also made the comment to me that if he ever needed to be on a ventilator, that he never wanted to be put on the ventilator. Being in the medical field, I understand that you could be on a ventilator and be very successfully weaned off the ventilator, but he has made the comment “I don’t want anyone to ever see me on the ventilator.” So, I still think it’s a self-perception thing, and hopefully that would change or improve as he gets older (P6).”
- “Sometimes I’ll say on the downside of being involved or not being involved in some of these discussions is we don’t hear it from the horse’s mouth. It’s not primary source material. It’s good that she’s taking care of it. The bad side of that is we are less involved. We don’t get to hear the same thing as she does (P2A).”

Duality of Parental Involvement

Children are often found to give an account where they both appreciate and scorn parental involvement, and this becomes especially prevalent during the years where young adults are attempting to master self-reliance and confidence in their own abilities.

In this study both parents and adult children were asked to reflect on their likes and dislikes of parental involvement. Three adult children endorsed this theme: one commented with terms like “I relied on my mom...I also have to take control,” “it’s beneficial and it’s not” or “at times quite annoying,” “we want to be independent, we can’t really be”. Another adult child commented: “It was both and advantage and a little annoying” and mentioned being “rebellious”. Another adult child commented: “We’ve had our fights, but “she’s just trying to help”. Two parents endorsed this theme: one commented “I valued the time we were doing treatments, and I disliked when she turned 18 that I would not be in charge or not be as involved”. Another parent endorsed this theme with “I’m certain he disliked it at times, but I truly think that he valued my involvement more than he disliked it”. Excerpts supporting this theme are presented below:

- “Obviously, at times it was quite annoying because when you are reaching the age of independence, you don't want them to be involved. You want them to leave you alone, you want to do it yourself. That really isn't the case for somebody who has a serious illness because I don't know everything about it. I relied on my mom to tell me things, but then I also have to take control and actually listen to the doctors and see what they're saying, and well does that make sense to me? Yeah, it is beneficial, and it's not because I think when we want to be independent, we can't really be because we kind of rely on our parents to be there for us and take care of us in a way. Especially since we do have something, a terminal disease, instead of just letting us make mistakes, they're not as willing to do that, just because I think. I mean, it's life threatening. One mistake could potentially kill us. I think it's an overbearing relationship, but I get why they are overbearing (C1)."

- "It was both an advantage, and uh, a little annoying at times just because kids are kids and even young adults or teenagers, you know, they're rebellious and I kind of think it goes back to what I've been saying, there's so many treatments we have to do, and they take so long. I think that if it was anybody else that they would be looking back on it as an adult they are, they're glad to have their parents like I am, or my mom in my life to make sure that I'm doing what I'm supposed to (C4)."
- "I will say in the beginning when she was an infant I valued the time that I was blessed to have with her while we were doing treatments. It gave me gave me more time with my child. The disliked portion was again the same subject when she was old enough to take control of her own medication, the one medication, and she chose not to take it. Just when she turned 18 my dislike was, I never really thought of when she turned 18 that I would not really be in charge or not be as involved like going in to the doctor's offices (P1)."

Recommendations to Others on how to Negotiate for Advocacy and Self-Governance

Themes related to advice that they would give to others going through the process of transitioning from pediatric to adult care were endorsed by all six adult children, with comments like: "speak up about concerns," "the negotiables and non-negotiables really do help," "have flexibility with treatments to avoid burnout," "voice your opinion," “advocate for yourself even when it is difficult,” “acknowledge your limits,” “seek assistance” and “find a support system that works for you”. Six parents presented comments to endorse this theme like: “Be open, don’t hide things,” “Develop a plan,” “keep an open line of communication,” “don’t treat your child like a patient,” “listen to your child,” “would like to see doctors have more compassion” or “realities of CF need to be discussed sooner” and “get a living will in writing if you want your wishes to be carried out”. See excerpts supporting this theme below:

- “One thing that both my parents and my pulmonologist would do is there was a hypertonic saline that I just didn't want to do. They said, "Can you do half a vial?" I was like, "Sure, I'll try half a vial." Instead of saying, "you should do this, you should do that," they're like, "Well, can you just do 15 minutes of walking?" It's always been praise and the reinforcement for doing things that I am doing right, as opposed to badgering me for things that I'm not doing. I think that really helps too. Again, even if you’re not a little kid, the negotiables and non-negotiables really do help. It still gives you a sense of control (C2).”
- “I would say ask questions. Just make sure you are at the right doctor for you, and you’re still getting the care and support that you need, because CF is more than just physical. There’s a lot of emotional stuff that goes with it, just because, to be honest, if you get told you have a life expectancy, there’s emotions that you have to deal with (C3).”

- “Um, my advice is to, regardless of how nerve-racking it may be or how stressful it is always stay communicating with your parents or with your guardians, your caregivers (C4).”
- “For our case, it was always a relationship of being open, of not hiding things. All of the folks that have a stake in this need to be involved and to understand where things are going so that when that time comes if it comes, where tough decisions need to be made, it’s not a surprise. Plan it out, think about how you, the family unit can work as a team to achieve the goals that you think are most likely to come about. You need to be involved. It’s a team sport (P2A).”
- “Listen to your child. Allow them to feel they have a voice and somewhat control of their disease before the disease takes away all control (P4).”

Importance of Flexibility in Negotiations to Promote Self-Efficacy

Three adult children discussed the importance of having flexibility in their negotiations with parents. Two parents confirmed the value of having flexibility when it came to negotiations about treatments or regimens. See excerpts supporting this theme below:

- “The negotiables and non-negotiables really do help, it still gives you a sense of control where, “Well, I don’t want to do my best right now, but I can do my best in 30 minutes or when my favorite TV show’s on” or something like that. There’s going to be things that come up along the road that you didn’t foresee, especially when taking over your own control, where I still tell my parents, I still wish that they did all the medication for me because it’s a lot to handle (C2).”

- “If I didn’t like something both the doctor and my mom would explain it and then if I didn’t like it then we would look at different alternatives or different medicines to be put on or, uh, like for example, so like Prednisone, changes my taste buds to where I can’t taste anything so I’m hungry and angry, but also not hungry because of the way it makes my taste buds feel numb. It’s just as simple as talking to my mom, “Hey look, I don’t like the way it’s making me feel. Can we talk to the doctor and check something else out?” (C4)

Research Question 2 reads as follows: How do parents and young adults aged 18 to 30 years with CF or CHD describe their experience of negotiating when and how young adults gain responsibility for health care tasks? Three questions on the survey were designed to capture the essence of this experience (10,12, and 13). A common dialogue supported themes regarding the negotiation of when and how young adults gain responsibility. One theme that emerged was the importance of coordinating with a medical team to enhance transition readiness with comments: “it was a joint effort”; and the shortcomings of not coordinating with a medical team with comments: “it was an abrupt change,” “just kind of happened,” “horrible,” “I didn’t feel ready,” “huge difference in pediatric CF clinic and adult CF clinic”. Another theme was the perception of concerns being ignored, which heightened feelings of isolation, indicated with comments: “I didn’t feel cared about” or “I didn’t matter”. A third theme was the abrupt separation from trusted team players, indicated with comments: “wasn’t prepared for that,” “culture shock,” “difficult” and “none of us wanted to leave pediatrics”. The final theme that emerged was the perception of concerns being ignored, which heightened feelings of isolation from the care team with comments: “I didn’t matter” or “I didn’t feel cared about”. See themes and excerpts supporting each theme provided below:

Coordination with and Between Medical Teams Enhances Transition Readiness

Two adult children described a coordinated experience for when and how they gained responsibility for health care with comments: “joint effort with my clinic” or transferred care with assistance of “a teen clinic”. Five parents described a coordinated experience of when and how they began to transfer responsibility for health care to their children with the help of the pediatric medical team. All of the participants who discussed this theme presented it as a positive experience. See excerpts supporting this theme below:

- “Luckily, it was a joint effort with my clinic. When I started hitting 19-ish, I was followed at both the (names a pediatric facility) pulmonologist and I also had a pulmonologist at (names an adult facility), which is the adult CF clinic. I had a very smooth transition, as far as that's concerned, where the hospital basically said, "Well you're aging out." They worked very closely. I was very lucky that they were affiliated hospitals. My two pulmonologists talked very openly and everything (C2).”
- “Um, when I turned, let's see 12 or 13, um, they had kind of like teen clinic, um, where I would go and do all my PFTs by myself and then halfway through the appointment, my mom would come in just so that way the doctor can relay to her what he found. Um, I kind of took control a little bit over the appointments and,

um, mostly the doctor. Um, so I would say the doctor helped a lot, to guide me, guide my mom into the adulthood position of the disease (C4)."

- "I'm going to give (names a facility) credit for that. They're the ones who broached it. It was tied to her school age. We were devastated. They said, "Don't worry. We don't cut you off just right away." They made it a very good transition. Again, fortunately with the proper doctors and actually some social workers, thing like that through the hospital, that transition went pretty good (P2B)."
- "I think the transition…the team did what they could to make it good. They introduced them to the adult care facility (P3)."

Shortcomings of Not Coordinating with a Medical Team

Three adult children endorsed the experience that their transition was not a coordinated event, and this clearly was not a welcome experience, with comments: "it was an abrupt change," "just kind of happened," "horrible," "I didn't feel ready," "huge difference in pediatric CF clinic and adult CF clinic," and "I didn't feel cared about". Three parents described an uncoordinated transition and endorsed this experience with comments: "You're just flabbergasted," "there was immense pressure," "It was deflating," "It was disrespectful," "It was disheartening," and one parent described being told to "back off" as part of the preparation for transfer of responsibility. See excerpts supporting this theme below:

- "There really wasn't any initiating. I was actually with my pediatric pulmonologist until I was like 22. He was like, "Yeah, I'll see you until, you know, whenever." At 22, I moved to (names state), so it was kind of an abrupt change. When I got to (names state), I was in charge of finding care and doing everything by myself. To answer the question, there really was no discussion. It was more of an abrupt change, and everybody had to deal with it the way it was (C1)."

- "I don't remember having any sort of sit-down conversations with my parents to talk about transitioning from the peds to the adults, it just kind of happened. I was not ready for it… I remember it being brought up just briefly in our appointments with our doctor and our care team, but they weren't helpful (C3)."
- "I think it snuck up on me. All of a sudden that day was here. "Okay… you're 18 now, do you want your mom to come in?" I'm like, "Wait a minute", you get to know these nurses and doctors like they're your best friends, you know them, so you can talk to them more on a personal basis. You're just flabbergasted and they're like, "I'm sorry it's the law. She's 18 now." (P1)
- "I knew he was not ready for the transition. I mean, I know my child, but she didn't quite understand our family dynamic at the time (referring to social worker). But the transition was so forced on us. I mean it's a hard transition for all parents. You know, why is she on me so much about backing off, when no one had ever given me any indication that I hovered or that I was inappropriate? They would make comments to me, "We wish more parents were like you". You know, I have been patted on the back and given accolades and so respected for my relationship, and then all of a sudden, we're going to transition and all of a

sudden, I need to back off. I was very willing to take the direction and to do what they said. Um, looking back it was the wrong thing to do (P6)."

An Abrupt Separation from Trusted Team Players

Three of six adult children reflected on how they gained responsibility for their health care and the effect it had on their prior relationships with their health care team and endorsed this theme with comments: "wasn't prepared for that," "don't think we were even halfway thinking about it" referring to the transfer of care to an adult facility, and "It's all about being prepared to leave people you were with for 18 years". Three parents described the disruptive effect it had on their prior relationships with their child's health care team endorsing this theme with comments: "culture shock," "difficult," "none of us wanted to leave pediatrics," and "we knew the same doctors for years" going on to say that they were closer than family members. See excerpts supporting this theme below:

- "Horrible! It was not good at all. My doctor is a great doctor for pediatrics. They were on top of it, CF-wise. The adult clinic, I think it was still fairly new. I don't think they were fully prepared or fully understood CFers beyond 18 years old, how it transitions into the adult life. They seemed very unorganized… You get attached to certain doctors and nurses, and the people that you know. I wasn't prepared for that (C3)."
- "But, you know, it's just all about being prepared to leave the people that you had been with for 18 years, to go and talk and get treated by people that you've never

met before. Um, but I really don't think that we were even halfway thinking about how big of a difference it would be from pediatrics to the adult clinic (C6)."

- "Like I said, I moved to (Names State) at 22. I think those couple of years were difficult. For me, it was like a culture shock. Driving eight hours total just to see my doctor, and I was married to a military guy. I had military care, I was in a military hospital, so all that was a huge transition. That was a huge transition for me because it was completely new on so many different levels. There wasn't that relationship or bond that I used to have (C1)."
- "None of us wanted to leave the pediatrics. The nurses and the doctor actually came to my daughter's wedding. We were closer to the hospital, the pediatric clinic, than we were to our own family. I think the transition…the team did what they could to make it good. We went from something that was fantastic to something very mediocre and I think that's where they got to work on it (P3)."
- "We had a good social worker, and she started bringing it up a lot sooner than we wanted to talk about it, but again, it was just the fact of leaving what we knew. These nurses had been in this clinic for years, we knew the same doctors for years, so to us, we could've just stayed there forever (P6)."

Perception of Concerns Being Ignored Heightens Feelings of Isolation

When adult children and parents felt their concerns were ignored by medical personnel they reported feeling excluded from the care team. One adult child endorsed this theme with "I didn't feel like I was cared about". One of seven parents endorsed this theme with the comment: "I didn't matter". See excerpts below:

- “I would say that it didn’t feel like I was cared about (C3).”
- “Me as a caregiver, I felt like I didn’t matter! I am ignored, not spoken to (P6).”

Research Question 3 reads as follows: How do parents and young adults aged 18 to 30 years with CF or CHD describe the quality of their communication when they discuss who is responsible for health care tasks and medical decisions? Five questions on the survey were designed to capture the essence of this experience (3,4,5,6 and 11). Themes about quality of communication were supported by a common dialogue throughout the interviews and verification by the following themes: parental input is valued when it is presented as a collaboration of ideas, complex medical decisions are more difficult to discuss, deterioration and consequences of not doing treatments are difficult topics to broach, transfer of care can be difficult to introduce, pressure from outside sources can impact communication, a child’s level of maturity can influence quality of communication, and a divorce of parents can impact the quality of communication. See themes below:

Parental Input is Valued When it is Presented as a Collaboration of Ideas

Five adult children described a positive exchange of ideas while communicating with their parents about medical decisions as indicated by terms such as: “We’ve generally been pretty aligned,” “Everything has been shared,” “we were all in agreement” or “we’ve always kind of made a decision together.” Only one adult child indicated a possible drawback to communicating with a parent about medical decisions describing it as “overbearing.” Five parents reported some disagreements related to their children not wanting to adhere to medical regimens when they were younger, but these were minimized by parents who either stated, “They weren’t huge ones” or “That’s your basic argument when they were younger.” Five parents who endorsed this theme confirmed the importance of communication that helps to support their child’s appraisal of treatments. See excerpts supporting this theme below:

- “Everything’s been shared. My mom, like I said, has kind of been overbearing from the start, but I can understand that as a parent. She’s always gone to my doctor’s appointments. I’m almost 30, and she still goes to my appointments with me. Not so much that I need her there, but I know that when she’s there, she feels more comfortable about the situation (C1).”
- “Early on it might be the day-to-day battles with taking her enzymes when she was a lot younger. She needs enzymes whenever she eats and sometimes we would have discussions about that although that was generally when she was much younger and didn’t understand the disease that well and didn’t understand the implication of not taking the enzymes. We really haven’t had big blowup battles or arguments and that kind of thing (P2A).”
- “No, we pretty much agree on most things. They have a new drug called Orakambi that she, first of all, didn’t really want to take; however, after looking into it and talking about it she decided that it was the best thing for her and her lung function along the way (P5).”
- “I think all of them are shared. We all make it together, the decision together. She doesn’t just take it all on her own and as even a 19-year old, she still needs that support when that’s all you have (P5).”

- "We pretty much shared...Of course; they didn't have a choice early on… We would discuss, or they knew why they had to do the chest therapy, how that helped move the mucus, why they had to do certain breathing treatments. We weren't always 100% good with that, but we tried. They made a lot of their own decisions (P3)."

Complex Medical Decisions are Difficult to Discuss

Four adult children identified that the placement of a Port-a-cath was the most difficult procedure to discuss. One of them identified needing a transplant as a difficult topic. One adult child discussed the difficulty of discussing end of life care at some point in the future. Two parents also identified the placement of a Port-a-cath as a difficult topic to discuss. See excerpts supporting this theme below:

- "One of the major surgeries I got was getting a Port-a-cath put in. I mean, and it's in my body until it stops working… I think that was a difficult conversation to have because it was like, "Okay, this is kind of like the last resort" type of thing (C1)."
- "I think the toughest one was the Port-a-cath just because that was a constant reminder that I had CF... I think that was the most difficult one, but even that one was handled, I think, fairly well (C2)."
- "The only ones in the future...I don't know if this is the question, but in the future, the only ones we may slightly differ on is end of life care, if it comes to a point where I am intubated or on a breathing machine. I don't want to be kept on respirators just so that my body's there when my mind is not. That would be

something that, in the future, I could see them wanting to do everything and keep me on a respirator and everything. Luckily, we haven't really differed on any decisions, as of yet (C2)."

- "You know, we've talked about the future, like what would happen if one day I needed a transplant. It's definitely scary to talk about, and terrifying to think about, but it's a possibility (C5)."
- "Getting a Port, I'll have to check, that might have been one of the first times, she was 18 that she signed on her own. We always supported her… Obviously, she had no choice. Her veins where blown; she couldn't use the PICC line. It was tough times there. She knew what the answer had to be, and then we would support her (P2B)."

Deterioration or Consequences of Not Doing Treatments Are Difficult Topics

During their discussion about how they handled deterioration both the parents and adult children reflected on how they communicated. Communication often took the form of weighing options or evading some conversations until it was essential. Three adult children who acknowledged experiencing deterioration in their health in recent years reflected on how they communicated during that critical time with parents. One adult child indicated "we talked generally," while two adult children indicated "I'm stubborn". Two parents endorsed this theme where one parent reflected on the difficulty of talking about deterioration or the consequences of not doing treatments indicated by terms such as "the big thing is trying to discuss it"; while the other parent reflected on "she seeks our counsel". See excerpts supporting this theme provided below:

- “You know, from the ages of about 18 to 21, or 18 to 22, it was, uh, there was a lot of deterioration. Um, I had lost weight...a whole lot. Um, my lung performance had dropped significantly, and, um, you know my mom and my family just continued to tell me, “You know, hey, you have to do your stuff. You have to do your stuff. You have to do your stuff.” You know, I was a stubborn 18-year-old, early 20’s kid. I was just like, “Yeah, yeah, yeah, you’ve all been telling me the same thing my whole life. Um, I’m kinda gonna do what I want for a little bit.” And it sure did come back to bite me in the butt. Um, that’s why these past five or six months, has really been a real awakening, um, eye opening for me, just because if I would’ve just listened and kept on doing my meds like I had for the first 18 years of my life, then, you know, maybe I wouldn’t have seen all those sick days that I did. Or, maybe I would’ve been in, uh, better shape and better health for college (C6).”
- “I’m stubborn, so I never really have been 100% compliant with all my medicine. Doctors know that, whatever. I don’t want to say recently, but probably in the past year or maybe two years, my cough has been really uncontrollable. Obviously, you can manage it if you do it the right way or take care of yourself. Realizing your limits, that’s a really hard thing for me too. I guess admitting that it is getting worse, or admitting that, “Yeah, sorry, I have to do my meds. I can’t go out or I can’t do this.” That’s kind of been a big thing. My mom just, I guess through it all, just reminding me, if I go out of town or something like that “Make sure you bring your medicine” (C1).”

- "Yes, I have experienced deterioration as far as that's concerned. My lungs just ain't what they used to be. There was a chance...My doctor treated me for Valley Fever, which is like an illness specific to this area in (Names State), where I live. Just characterized by some breathing difficulty. We just talked, in general, "Here's the deal. Here's what's going on." I just recently found out that I'm fairly resistant to a lot of the IV meds that I used to have. This isn't necessarily a deterioration. However, it's leaning toward where I'm losing some of the drugs in my arsenal, just because I'm becoming more resistant to them. Even with this most recent cold, my mom was saying, "Well, do you want to go on antibiotics? Like oral ones, to see if I can call up and get some?" I said "No, I'd rather ride out this cold because I don't want to go on more antibiotics when I'm increasing my resistance (C2)."
- "Yes, for all of them. Two of them became diabetic. One of them had to be put on oxygen. The big thing is trying to discuss it in a way that...We looked at the facts. I guess this is how we do it. Look at the facts of knowing that...One of my daughters right now, she's pretty sick. She's on oxygen. Are we going to need a transplant here in the future? Possibly! Part of it is because in my mind she's not really taking care of herself as she should, but she is an adult, so all I can do is sit back and watch. Every now and then, I will bring up, "Hey you know, you don't take care of yourself, you know what your options are," kind of thing. It's difficult. It's hard to sit...We don't come right out and say the whole death thing. It's by not taking care of themselves because that's with CF, you don't take care

of yourself, the ultimate is...The end product is death. There's no way around it. That's kind of like, "Well you know, you don't take care of yourself, your whole life is gonna change," and they're aware of it (P3)."

- "A little while back probably the last year or so, her PFT's were going down. They weren't recovering the way that they wanted them too. She was losing weight as well. We chat. I think she seeks counsel from us, but the decision is hers on whether or not it makes sense to go on a certain med or sometimes she'll tell us she went in. The PFT's weren't that well so she thinks she's going to be on IV meds. In those cases, it is more a declaration, but kind of telling us and I think she'll listen to us, wonder if we approve or not approve. Of course, we support her decisions anyway (P2A)."

Transfer of Care Can be Difficult to Introduce

Six adult children and all seven parents reported both positive and negative experiences as they broached the topic of transfer of care. Two adult children described feeling prepared, one endorsed this theme by saying it was "awesome," and the other indicated "my CF plan has been the same for as long as I can remember." Two adult children reflected that transfer of care was only minimally discussed saying "I don't think we talked much about it for me" and the other adult child stating, "we maybe communicated, just a little." One adult child described it as an "abrupt change". Parents who endorsed this theme confirmed variation expressing both positive and negative experience with the process of communicating about transfer of care with terms like "We didn't get a chance," "just happened over time," "she was prepped pretty darn good," "we would discuss it all together," "it was very smooth," "Great" or "they're pressuring you both to do things". See excerpts supporting this theme provided below:

- "There wasn't a whole lot, as far as I remember. My sisters and I are really close in age, like one year after the next, so I think that when my sisters were transitioning, everybody just assumed that I was listening, and knew what was going to happen, but I should have said something else, or they should have known better. When you're 16 and your 18-year-old sister is transitioning to a different hospital or doctors, you're not paying attention. I was focusing on graduating high school, or my senior year of high school, instead of the health care that my sisters were getting and the new doctors. I don't think it was talked about as much for me, because they just assumed, you know, "Oh, she's paying attention," and I wasn't (C3)."
- "Uh, we maybe communicated just about it just a little. You know, (Names a social worker) had offered to us to take a tour of the, uh, adult CF clinic. Um, me and my mom had just kinda talked about it just a little. But, like I said, there was really nothing we could say for us to not to go to the, to the adult clinic (C6)."
- "We had some heart to hearts. Becoming the adult, she's got to take on more things. Once again, she was prepped pretty darn good. We would try to make it like she was the one who's doing all the work, when I would hand her a list and say, "(Names adult child), these are the questions you want to ask" (P2B)."
- "We would discuss it generally, because we'd have a two-hour ride home from (Names facility), our CF appointments, we would discuss it all together, stuck in a

car with no cell phones. They would have to listen. We would discuss it. Of course, they weren't happy with it. They did not want to move onto the adults because we really hadn't heard anything great about the adults (P3)."

Level of Maturity Can Influence Communication

Three adult children identified immaturity as a barrier to communication at some point in their interactions with their parents. Three parents also endorsed the idea that maturity played a role in their communication with their children. See excerpts supporting this theme below:

- "I didn't want her to be as involved, because I was 18, thought I knew it all. Right, yeah! So, I would say that between the time of being 18, or 18, 20, 21, just dumb! So, I was like, "No mom, stay away, I don't need your help", and before then, it was like, "Yay, mom's here to help me do all this because it's hard and I don't want to." (C3)
- "There were times where me and my mom would get in screaming matches just about my medicines or, you know, about how I'm doing them, or that I needed to do them better, and I need to take better care of myself. After I, uh, graduated high school, and I was kind of on my own, things got rough, just because, you know, I was kind of in that crazy, crazy college thing. I was partying a whole lot and just not really paying attention to my health. I got distracted by partying, girls, beer, I mean, I got distracted by it all, and I saw a true drop in my health. Just because you're 18 doesn't mean you have a new life. If you weren't supposed to do things when you were a kid because you had CF, guess what? You still can't

do them. Um, so just don't take the whole adult thing too serious, and saying like you're your own man now, and you get to do what you want because you really don't. There's still guidelines and procedures that have to be done in order to stay healthy (C6)."

- "You know, he was doing his own medications, washing his own nebulizer, packing his own meds. All that happened way before a traditional change, you know, from pediatrics to adult care, and it just seemed like so second nature, it kind of almost happened organically, you know, he just kept doing what he was doing. Now low and behold, normal rebellion happened, and he stopped some of his care, but it wasn't due to a transfer of care. It was just due to, you know, a natural reaction at that age in his human development and he was just no longer going to do it anymore (P6)."

Pressure from Outside Sources Can Impact Communication

Two adult children and one parent endorsed this theme with comments like: "Don't make non-compliant another mark against him," "I had to be his supporter for other people to lay off him," "immense pressure," "he was not ready to transition" or "there is nothing you can do for you not to transition". See excerpts supporting this theme below:

- "Me and my mom both knew, there's not really anything that you can say to not go to the adult side (C6)."
- "This is what we're going to do, Mama, we want you to "back off." That was probably the only move on her (referring to social worker) part that really

disturbed me. I knew that he was not ready to transition. I mean, I know my child, but she didn't quite understand our family dynamic at the time. Then the closer we got to his 18th birthday, there was immense pressure that you should not be staying with him in the hospital anymore. You know, if he was in the trenches, I was going to be in the trenches (P6)."

- "When he went to college, he, um, was not doing his nebulizer treatment as often as he should. One of the physicians in the CF clinic made the comment, "If you're not going to do them right, there's no sense in doing them at all". You have a young person who's already feeling neglected, frustrated, mad, doesn't want to do the treatment to begin with, and you get, that comment from a physician. "Hey, Dr. so and so, he said, "I don't have to do it and I'm not going to do it". There was nothing I could do to unravel that damaging comment. For about four years, he did refuse to do that treatment and his health suffered greatly. His relationship for other visits in the clinic suffered because of that, because he was labeled noncompliant, and he was noncompliant (P6)."

Divorce of Parents Can Impact the Quality of Communication

During their discussions about the quality of their communication both adult children and their parents reflected on the family structure. Four adult children revealed that their parents had divorced, but one added that her mother had remarried and that her step-dad was a very active participant in her care. Four parents disclosed that they were divorced, and one reported that she was later remarried. Three adult children endorsed this theme with comments: "I don't speak with my father," "he pretty much shut me out" or “it is kind of difficult”. Two parents endorsed this theme with comments: “At times yes, it has gotten very stressful and heart breaking” or “some people don’t handle illnesses very well”. See excerpts supporting this theme below:

- “It is kind of difficult. I don’t speak with my father, so when I talk about anybody, it would be my mom (C1).”
- “Um, well my parents divorced whenever I was five. Um, growing up he pretty much shut me out, uh, back then, When I was born the life-expectancy wasn’t only but 10 or 12 years old so, he got in his mind, you know, why get close to his son when he could die in the next 10 to 12 years. My mom has always been there to make sure I do all my treatments right, even from a young age. I haven’t spoken to my father for probably five years now (C4).”
- “I have been raised by my mother my entire life. Um, not really a true father figure in my life, my whole life, besides my mom’s dad, my grandfather. He’s really been the only true father figure I’ve ever had (C6).”
- “Of course, as an infant the only caretaker that she had would’ve been me, her father was very busy owning his own company. Some people don’t handle chronic illnesses or fatal illnesses as well as the other parent (P1).”
- “I have been the only parent to be involved in care, treatment, ER appointments etc…At times yes, it has gotten very stressful and heart breaking to see (Names adult child) go through surgeries, endless amounts of pill taking and hours of breathing treatments (P4).”

Research Question 4 reads as follows: How do parents and young adults aged 18 to 30 years with CF or CHD describe the quality of their relationship during negotiations about health care decisions and transfer of responsibility? Three questions on the survey were designed to capture the essence of this experience (1, 2 and 8). Themes about the strength and type of caregiving relationship were supported by a common dialogue throughout the interviews and verified by the following themes: a description of family bonds before and during transfer of care, description of family bonds when transfer of care was completed, and relationship adjustments to transfer of care. See themes presented below:

Description of Family Bonds Before and During Transfer of Care

Six adult children and all seven parents provided a description of their family bond. Five adult children endorsed this theme with positive terms like: "positive relationship," "very supportive," "very strong," "very tight knit family," "pretty open relationship," while one adult child endorsed this theme with a negative term describing the care giving relationship as "Difficult". Six parents endorsed this theme with positive terms like: "very much involved," "very intertwined," "very strong," "very close" or "we are stakeholders". One parent endorsed this theme with a negative term stating the care giving relationship was "very stressful" or "heart breaking". See excerpts supporting this theme below:

- "It's kind of difficult. I'm super, super independent, and my mom has severe depression so she's ... I don't want to say she's kind of been in her own world. She very much supports me and cystic fibrosis. She always goes to my appointments, but the transition was not, I guess, based on what she wanted. It was more of, "I'm gonna do this. I'm gonna do that," and she just went along with it. There was really no, I don't want to say no communication about it, but that's pretty much what happened (C1)."

- "I have a very positive relationship with my parents actually. They've been definitely strict. As a young kid, my mom always said, relating to the CF, there were negotiables and non-negotiables… I still had that control over my life, if you will, despite the fact that many of my healthcare decisions I didn't necessarily have control over. I still talk to them about most things, where it's good to get their point of view and talk things out. I don't hide much from them. We have a pretty open relationship. I still look to them for advice and I'm thankful that they've raised me the way they have, where I'm independent yet I can seek others for advice (C2)."
- "We've always had a very strong, close bond (C4)."
- "So, we have a very tight-knit family, we have a very strong family (C6)."
- "From day one, very strong, I have been the only parent to be involved in care, treatment, ER appointments etc... At times yes, it has gotten very stressful and heart breaking to see (names adult child) go through surgeries, endless amounts of pill taking and hours of breathing treatments. He without a second guess has always known I am not going to take his care lightly (P4)."

Relationship Adjustments to Transfer of Care

Six adult children provided a description about how their parents adjusted to the transfer of care to them. Three adult children endorsed this theme with positive terms like: “always there behind me,” “gave me some control,” “came to a mutual ground” or “taught me very good medicine management”. One adult child endorsed this theme stating it was “a mix of supportive and not supportive”. Another adult child endorsed this theme stating, “my mom is a little bit overbearing”. Six of seven parents endorsed this theme with positive terms like: “we would talk about it,” “helped her understand all aspects of managing her disease,” “made it pleasant as possible,” “I began to promote self-management” or “best friends” and “very close”. One of seven parents endorsed this theme with negative terms like: “I tend to be a little bit of a worrier,” “felt cutoff” and one parent endorsed this theme with “You’re out” and “Transition, that was a shock”. See excerpts supporting this theme below:

- “My mom is a little bit overbearing, so taking over the roles ... Just making sure that I do everything on time, how I'm supposed to. I was like, "I got this. I can do this." Let me mess up, I guess, in a sense instead of her having to watch over me. Just kind of like I said, I've kind of always been independent, so as soon as I could learn something or as soon as I knew something about taking care of myself, I've wanted to know everything about it. Instead of if I saw my mom getting my medicine together or my enzymes, I wanted to know why, how, and how can I do this? I guess from an early age, I was always involved in the care (C1).”

- “That goes off where they did give me some control, in areas where they could. I remember when I was pretty young, I had hospital stays, the doctors would tell my parents that this is something that I’m going to have to deal with for the rest of my life. Obviously, they’ll still be impacted by it, since they’re my parents, but as I grow up, this is something that I’m going to need to take ownership of or I’m going to need to be responsible managing my meds, making sure I don’t miss doses, getting doctor’s appointments and actually going to them (C2).”
- “We would talk about it. I always liked to tell her what was ahead of her. I don’t think that she wanted to hear or “Let’s take it day-by-day mom, we’re not there yet, let me get through each of these days”. I love information so as I’m reading all the information that things that could possibly happen in the future I was kind of...my mind was in the future when thinking of CF, but of course when dealing with her we went day by day (P1).”
- “For (Names spouse) and I, this transference was less an event and more of a process. It started early on. Our role was and my role specifically as a partner with my wife was to help her understand all aspects of managing her disease, what that meant and giving her more and more responsibility as time went on until such a point where she took it on. I don’t think it was a surprise to her. It wasn’t a surprise to us. We knew this is the way we were going to do things (P2A).”
- “We had to trust her. At a young age she was taking on ownership, but of course we would help out cleaning her nebulizers, encouraging her to do her best. She’s

the one that had to go through it. I would often try and stay with her and all that, to make it as pleasant as possible again (P2B)."

Description of Family Bonds When Transfer of Care was Completed

Adult children and parents described how parental involvement in the management of CF had impacted their current relationship. Three adult children endorsed a positive influence with terms like "CF has definitely influenced that a lot," or "Influenced the way I do things as far as being organized" or "it's been a good influence" or "it's made it stronger". One adult child described a mixed emotions family attachment which was explained using terms like "she coddles me a little" or "she monitors what I do" while also reflecting "I feel like we've connected more". Three parents endorsed this theme with terms like: "just made us much closer," "more closeness than some families," "closeness," "she appreciates the fact that we are here for her" or "I keep him motivated and positive". See excerpts supporting this theme below:

- "I am the second child, so I'm the baby. I definitely feel like she coddles me a little bit more because of the CF, or she monitors what I do a little bit more because of the CF. I get that, I get that that's a mom's role. She's definitely more involved. Like I said, she goes to my appointments, when I'm in the hospital, she's there. I feel like we've connected more or we're around each other more than maybe we normally would be if I didn't have CF. I guess our relationship is probably stronger than it is if I didn't have CF (C1)."

- “I think CF has definitely influenced that a lot. I call my mom almost every day and tell her about you know, what my snot looked like, or my sputum, what I coughed up looks like, or how a doctor’s appointment went (C3).”
- “Um, honestly if it wasn’t for my mom I don’t think I would be here today. Um, I think the relationship that we have today we wouldn’t have that if she wasn’t so strict on me and she didn’t stay on me for my treatments (C4).”
- “We had our disagreements as far as, “Take that medication,” “No, I don’t want to.” Now the benefits are again I can trust her, I know she’s doing the right thing by taking care of herself and it’s made us so much closer. Being so involved in her life when she was younger that I think she just got used to telling me everything. I adore her and I adore our relationship (P1).”
- “We started early. I have mentioned this was a process and not an event. I think the way she does it now is a direct result of what (Names spouse) and I had tried to teach her (P2A).”
- “I think we would have been close if Cystic Fibrosis had never even entered our lives, but I think with the CF all three of us are actually very close (P2B).”
- “I think we’re closer than most, and I know a lot of people with a lot of kiddos, and I feel like him and I are extremely close. Um, and even though I’m no longer involved in the day-to-day management as I was when he lived with me all of his life, I know that my influence is still there and I know he relies on me, and where I felt like our transition, or um, advice from our physicians were you have to be uninvolved, uninvolved, uninvolved...I never should have left him. I never should

> have withdrawn. This closeness that had come from us being so involved, it never should have wavered once you went to the transition, um, it's just created an extreme closeness (P6)."

Summary

This chapter has explained a transcendental phenomenological analysis that was intended to learn more about family relational experiences during the major transition from pediatric to adult healthcare with a chronic illness. Four primary research questions were posed. The first question explored parent and adult child experience of negotiating who is responsible for health care tasks during the transition from pediatrics to adult care. The participants related their experience of negotiating responsibility with benefits of parental involvement, but also recounted times when they experienced drawbacks of parental involvement. Participants recollected times when they both appreciated and resented parental involvement, but how the nature of their chronic illnesses often enforces this duality for parents and adult children. As participants reflected on how they negotiated who is responsible for health care tasks they also provided advice to others going through the process of transitioning from pediatrics to adult care. The importance of flexibility in negotiations was critical for the promotion of self-efficacy.

The second question focused on individual accounts of their experience of gaining self-care responsibility and negotiations on how they gained responsibility. Coordination with and between medical teams improved negotiations and increased transition readiness. Shortcomings of not having a coordinated plan for moving from the pediatric to adult health care system were also identified. Participants reflected on how they gained responsibility for their health care while also experiencing an abrupt separation from trusted team players. In the process of negotiating when and how young adults gained responsibility, parents often reflected on how their concerns were ignored and how this resulted in feelings of isolation from the care team. Parents frequently described themselves as team players or stakeholders in the disease.

The third question was designed to focus on the quality of communication between parents and adult children, but as participants reflected on their experiences they also included in their responses their sentiments concerning the quality of communication with all the team players involved with management of the disease. A variety of themes emerged about factors that enhance the quality of communication, but some factors that impede the quality of communication were also part of the participants' reflection with this experience. Positive factors such as collaboration helped to build self-efficacy. Factors impeding the quality of communication were often presented when complex medical decisions where under consideration. Certain topics were difficult to broach such as deterioration and the discussion of consequences and what would happen when participants are non-adherent to medical regimens. Transfer of care was a difficult topic to advance and was often avoided until the time of transition had arrived. Maturity of participants was presented as an obstacle influencing the quality of communication. An unforeseen theme was how the divorce of parents impacted the quality of communication for some participants.

The final question focused on the quality of the relationship between participants, which resulted in reflections about the quality of the family bond before and during the transfer of care and the family bond that they had following the transfer of care. Participants reflected on how their relationship went through adjustments, but the majority of them described a closeness that was linked to the experience of having a chronic illness that placed high demands on all the team players, particularly the parent and child relationship.

In Chapter 5, the findings from this study will be related to the current body of literature. The limitations of the study will be discussed, and recommendations for future research made in addition to the implications for positive social change.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this qualitative, phenomenological study was to explore the lived experience of how individuals with the diagnosis of CF or CHD and their parents communicated as they progressed through adolescence managing a chronic illness and navigated the challenges of transitioning from childhood health care to adult health care. Several themes emerged from each of the four primary research questions, as discussed in Chapter 4. There were commonalities among many of these themes, including:

- Parental involvement in medical care during the transition to adult care is perceived in both a positive and negative manner; however, overall the adult children and parents who experienced this transition with some degree of parental involvement were satisfied with their communication, especially in retrospect.
- The type of parental involvement that was most appreciated was flexible, and highlighted the role of choice on the part of the transitioning patient.
- The medical team plays a significant role in the transition process as it relates to parent/child relationships. Smooth and coordinated transitions that involve parents are perceived as positive experiences.
- Complex medical decisions as well as non-compliance issues are highly emotionally charged and are the most difficult for children to discuss with their parents before and after the transition to adult care.
- Individual level of maturity needs to be considered with respect to both the introduction and process of the transition to adult care.

- Family bonds between parents and children in transition may change during the transition, but strong relationships tend to stay strong through the transition process.

In this chapter, the findings presented in Chapter 4 will be related to the current body of peer-reviewed literature as presented in Chapter 2. Additionally, I will describe the findings in the context of the conceptual framework of the bio-psychosocial model, theory of attachment and the family systems theory.

Interpretation of Findings

The current study echoes to a large extent the findings of previous research looking at transfer of care issues in individuals living with a chronic illness. There were several findings that are summarized below in the context of the published literature as well as the family systems and bio-psychosocial models. The results of the current study build on past research and can also be used to suggest topics for future study.

Parental Involvement in Medical Care During the Transition

Researchers have reported that individuals living with a chronic illness are not only influenced by the biological or physiological impact of their illness, but also by interactions in their immediate family context and quite frequently their wider social network (De Geest et al., 2013; Rolland & Williams, 2005). This approach is consistent with the biopsychosocial model, which incorporates multiple internal and external influences in the way some individual copes with illness. The family system is especially relevant to consider in the transition from pediatric to adult health care. In Bowen’s Family Systems Theory, “differentiation of self” apart from the family unit refers to an individual’s ability to remain in sync with the emotions of the family unit while at the same time express individual emotions (Krycak & Murdock, 2011, p.1). One of the ways that differentiation is achieved is by way of emotional support from parents or other family members (Krycak & Murdock, 2011).

Parental involvement in medical care during the transition and transfer of responsibility is often perceived as both positive and negative; however, with the benefit of hindsight many of the adult children in this study were satisfied with their relationships and communication with their parents. Luyckx et al. (2014) similarly reported that the perception of parental support reduced loneliness and depressive symptoms in individuals with congenital heart disorders. Most of the adult children in the sample reflected on how their parents provided emotional support and functioned as allies in managing their illness. Many reported an advantage in having a safe place to complain, with parents who are familiar with their disease and suffering.

Peeters et al. (2014) reported that parents of chronically ill children were sometimes perceived as overbearing by their children, and the children were sometimes perceived to be overly confident while minimizing the consequences of having a chronic illness by their parents. The current study supported this finding as well, as some of the adult child participants described parental involvement as overbearing. A few adult children in this study also acknowledged that they had minimized the magnitude of their illness and abandoned some treatments as an act of rebellion. Others stated they were simply tired of all the treatments, while others wanted to be able to make mistakes. The findings of DeVito-Dabbs et al. (2013) support the taxing impact of complex regimens on family relationships.

The current study documented accounts where the duality of parental involvement and nature of a chronic illness placed individuals living with a chronic illness in a position where the reliance on others was an inescapable part of their lives, and this was also similar to previous reports. Foster et al. (2001) noted that parental involvement was often construed as helpful while being simultaneously reproached by adolescents. Previous research by Dashiff et al. (2008) recommended that future inquiries should look at the impact of separation anxiety on young people living with a chronic illness such as diabetes, and see how this influences the development of self-sufficiency. The current study builds on this previous work in adding that some parents may experience anxiety during the transfer of care and emphasizing the need for parents to be involved in care during the transition in a way that addresses the anxiety of both parties. Parental anxiety seemed to be related to fear about deterioration in the health of their children if they did not perform recommended treatment. Research conducted by Lindsay-Withers (2012) references the difficulty of this dichotomy for both parents and their child living with a chronic illness, where the pursuit of independence can be challenging, as CF often makes it compulsory for the individual living with the disease to have some level of dependence on others.

The current findings, along with the work of Peeters et al. (2014), support the importance of educating and preparing youth with chronic medical illnesses to advocate for themselves within the medical environment. However, it is not yet clear what provisions need to be made to assist them in this process. One thing that was identified in the current research that has not frequently been identified in other literature is the need to address parental anxiety in the transition of their children to adult care. Parents of chronically ill children continue to be involved in care during and after the transition to adult programs, and need to be considered in proportion to that involvement.

Other researchers have confirmed that some parents worry about what would happen to their children's health if they were not around to assist them, and that some individuals living with a chronic illness often report apprehension about their competence to handle the demands of their illness (Fernandes et al., 2014; Lindsey-Withers, 2012; Moola & Norman, 2011). It is essential to gauge the apprehension of individuals living with a chronic illness so that early interventions can be put in place to improve self-governance and evaluate the need for continued parental involvement into adulthood (Kennedy et al., 2007; Moola & Norman, 2011). For instance, Devito-Dabbs et al. (2013) note that self-care is strongly impacted by social factors such as family relations and the individual's locus of control. If the individual does not feel competent to take over the full responsibilities for self-care, then it seems imprudent to give him/her this responsibility.

Some of how parents and adult children in this study interacted can be understood within the context of the theory of attachment (Bassazian & Besharat, 2012). The findings in this study support other studies such as Hooper et al. (2012) by drawing attention to the impact that attachment styles have on individuals' tendency to either seek and accept or mistrust and reject help. An insecure dismissing attachment style is associated with more inhibition and a tendency to shun assistance, be self-reliant, and possibly fail to follow health care recommendations (Hooper et al., 2012). Some of the participants in this current study were put into a position of being self-reliant before they were ready, and reported feeling overwhelmed with treatments or noncompliant in an attempt to be autonomous and in control or their own health care regimens. Many of the adult children in this study also described early childhood rejection of a father figure, and this may have impacted their beliefs about the competency of others to care for them after they underwent the transfer to the adult care units.

Likewise, parental anxiety can be addressed to avoid it being transferred to their children and obstructing relations with the healthcare team. Hooper et al. (2012) pointed out that securely attached individuals are much more likely to trust that others are interested in their well-being and believe they are worthy of the care they are being provided. For some families, early attachments with primary care providers can impede parent/child relations as well as interactions in the health care system.

Collaboration, Flexibility, and Giving Choices Helps to Promote Self-Efficacy

Lindsey-Withers (2012) opined that adolescent opinions should be pursued without condemnation or personal bias, as cooperation has been found to increase adherence to treatment. Being able to voice their objections without judgment was a very important component that some of the participants in this study reported gave them some sense of control in the management of their disease. In the current study, trust, which is important in the development of self-efficacy (Ditzen & Heinrichs, 2014), was formed as parents collaborated with their children on decisions, were flexible and permitted modifications with medical regimens, and used choices to give their children a sense of being in charge of their health. These findings provide support for the use of collaboration, which can be used as a platform to foster independence and self-governance provided the children are given choices and permitted to interject their opinions.

The use of flexibility may be interpreted by medical professionals as non-adherence, but to parents who are there for the day-to-day management of the disease, allowing flexibility with treatments may help them convince their children to adhere to some aspect of their treatment versus refusing treatment entirely. This is a topic that needs further attention, as labeling someone non-adherent can immediately eliminate that individual from the list as a possible transplant recipient. CF is a complicated and a time-consuming disease to manage, and families need to be supported as they attempt to navigate what can be altered without doing harm to the child.

In the current study, parental input was valued when it was represented as a joint course of action with the child rather than for the child. All the participants in this study noted the importance of having their voice being heard. Delmar et al. (2006) opined that self-governance is achieved by granting individuals the right to choose or reject help from others. Another factor in the development of autonomy is the competence to know when and how to ask for assistance from others (Delmar et al., 2006). Campbell (2003) notes that family involvement can be advantageous or destructive for individuals living with physical disorders. The current study found that parents who adopted a supportive role where they collaborated with their children rather than directed them ended up with a much closer relationship after the transition to adult care. Parents who did not force their opinion, but instead acted as sounding boards gave their children a safe place to express concerns and form a plan of action together. Campbell describes four levels of support often provided by families including: instrumental support, consisting of driving children to appointments or helping them perform treatments; informational support by offering advice; emotional support consisting of listening with compassion; and a sense of belonging, or allowing the individual to feel accepted and loved. Emotional support is often reported as the strongest form of support provided by families. Campbell notes that individuals who have sound family and social relations are also more likely to experience greater physical health, heal easier, and survive longer. Many health behaviors or regimens are established within families. Standardized educational programs could coach families for success on how to broach difficult topics and prepare for possible role changes in the future and assess family attachment and coping styles earlier to determine if family therapy might alleviate some of the stress.

Coordination with and Between Medical Teams Enhances Transition Readiness

The medical team performs a fundamental function in the transition in preparing the family. Both the parents and adult children in this study confirmed that smooth and coordinated transitions that involve parents are perceived as positive experiences. In keeping with the bio-psychosocial model, it is recommended that healthcare professionals consider both internal and external factors while considering transition readiness, such as personal beliefs, family system, and availability of resources within the health care system (Rolland & Williams, 2005). Additionally, it should be recognized that economic status, family economic stress, and limited access to resources also contribute to psychological distress (Ennis & Bunting, 2013).

Moreover, family burden and caring for a family member are two different concepts (Ennis & Bunting, 2013). Family members providing care can sometimes experience unfavorable social consequences such as economic challenges or social seclusion, anxiety or depression (Ennis & Bunting, 2013). Several individuals in this study reported social seclusion, as individuals with CF are instructed to avoid physical contact with others diagnosed with the disease. This limits access to social support groups. It is imperative for future research to document individual family burdens and from there begin to make recommendations. For instance, prior research by Ennis and Bunting (2013) revealed that family burden is linked to a greater likelihood of caregivers to report some type of mental health issue.

The health care team fits into the bio-psychosocial model as an external factor that also influences the relations between other parts of the system. Medical care is an important part of the model for any individual living with a chronic illness. Researchers have chronicled successful transitions in the context of programs that employ a formal plan and synchronize the transfer between child and adult health programs (Gorter, et al., 2011; Kennedy et al, 2007; Kirk, 2008). Unfortunately, collaboration between providers does not always take place at each facility, and irregular practices in the transfer of care disrupts its stability (Kennedy et al., 2007; van Staa et al., 2011). Some individuals in the current study reported experiencing inconsistencies during their transition, and in some cases a failure to synchronize their movement between facilities.

In the current study some participants recounted the experience of feeling pressured to transition before they felt ready, which in turn encumbered parent and child communications. Other researchers have also reported that both parents and youth may feel ill-prepared for the transition and take exception to the experience of being informed “now you’re 16, you have to go” (van Staa et al., 2011, p. 827). It is important that health professionals be mindful of the indirect influence that their comments can have on already apprehensive parents and children who are facing the transition process. It is best to promote early education and preparation to build confidence, and steer clear of eliminating parental participation (Reed-Knight et al., 2014; van Staa et al., 2011).

If parents and children are already having issues accommodating promotion of autonomy in the child, then it is likely that these same issues will be transferred to the triad to include the parent, child and health care provider (Bazzazian & Besharat, 2012). Some of the parents in the current study portrayed their parent/child relationship as “a unit” or “a team”. It seems contrary to recommendations from prior researchers for health professionals to exclude parents and not incorporate them as team players.

The findings of van Staa et al. (2011) revealed that parents and youth expressed a preference in receiving information well in advance of the transition to the adult program. Van Staa et al, also noted that all the parents and youth agreed that the transition process needed to be improved, as health care workers were the only ones who were pleased with the model of transition. The current study did not include seeking the opinions of health care workers; however, the findings supported previous research indicating that the adult programs need to focus on enhancing the transition experience for their patients. In the current study, two adult children reflected about the benefit of their pediatric provider introducing the topic of transition in a timely manner and then proceeding to educate the family about the transfer of care. Others unfortunately described an abrupt transition with no time to deliberate or contemplate the changes taking place.

Further research is warranted to look at what exactly can be done to improve the patient and family's satisfaction with transfer to an adult program. van Staa et al. (2011) reported that parents and young adults ages 15 to 22 years desired parental engagement in the course of the transition, and this was supported by the current findings. One parent in the study emphasized the difference between the physical transition and the promotion of autonomy, and opined that these concepts are misrepresented by the medical community.

Further research is warranted to examine methods to prevent triangulation when the topic of transition is being introduced to families. There is some evidence in the current study to suggest that mishandling the transition may contribute to triangulation, where the parent and child will team up and work in opposition to the medical team if they feel their concerns are not being heard or addressed. Triangulation is more likely to occur when one actor in the triad feels ostracized by the other two. Shapiro (2001) indicated that triangulation occurs in family medicine practice when either the parent or patient feels neglected in the communication about health care issues. Family systems theory also describes the concept of enmeshment, which is when two individuals develop an excessive reliance on each other or are too entangled, preventing the individuals from acting or thinking independently (Shapiro, 2001). It is believed that when dyads are heavily enmeshed these individuals will form "illicit coalitions" where they display oppositional behaviors such as arguments with the ostracized third party (Shapiro, 2001, p. 206). The family systems theory is relevant to the practice of coordinating events for families who are managing a chronic illness and the prevention of negative triangulation among patient, family and physicians.

Manderson et al. (2012) noted disintegration in healthcare services for older adults living with a chronic illness and made the recommendation for the provision of a navigator. The role of the "navigator" is to coordinate transitions based on treatment objectives and an individual health care plan (Manderson et al., 2012, p.113). This seems relevant as transitions are a notorious time of vulnerability for individuals with a chronic illness, and some of the burden may fall to family members, as it was for some of the participants in this study. A navigator who can address potential issues in advance and reduce obstructions to timely treatments would be advantageous (Manderson et al., 2012). This concept fits well with the needs of the individuals from the current study, and also with the bio-psychosocial model, as the work of the navigator involves recognizing the need to address multiple aspects of a complex situation.

Only one adult child in this study reported an excellent experience with her transition team, which was the result of outstanding teamwork and coordination between her pediatric and adult programs. Both the parents and adult child described early education and input from their providers. The transition included discussions with family members and was well-coordinated between pediatric and adult health centers. This was, however, the only family in the study that reported a pleasant experience in the transition. This suggests that despite prior research by Lattimer (2011) and others (e.g., Fernandes et al., 2014; Fletcher-Johnston et al., 2011; Reed-Knight et al., 2014; van Staa et al., 2011) who offered recommendations about the necessary components for a successful transition, there remains a gap between research and the practice of how patients are transitioned. All the participants in the current study were satisfied with their pediatric providers services and felt prepared for the transition. It was in the adult health care system that most of the participants reported negative experiences.

Three obstacles appeared to impact satisfaction about the transition experience. These included not feeling properly coached about the transition, perceiving an abrupt separation from a care team they had a strong attachment to, and feeling that there was a lack of preparation on the part of the adult health care team. Fernandes et al. (2014) reported that many participants in their study found it difficult to transition to adult programs after developing a strong bond with the pediatric health care team. Almost half of the youth and parents in the Fernandes et al. study described an emotional bond with the pediatric team reporting the disruption of this relationship as a negative experience. The authors also mentioned that the bond with the health care team had less relevance at the age of 25 years. Many of the participants in the current study also indicated that the transition would be less harrowing if it were delayed. Further research concerning the best age to transition individuals is warranted to see if the age of transition might have an impact on the health of the patient. According to Moola and Norman (2011), discussions about transitions are typically avoided until just prior to the transition or when the individual is 17 years old. Earlier education about the process and communication between transition teams is likely to ease trepidation concerning the change in care programs.

In the current study, some participants felt that their fears were not listened to or addressed by their adult care providers. The National Transitions of Care Coalition (2010) recommends that transitions include the patient and the primary care provider in the education process to guarantee its success. Moola and Norman (2011) noted that negative interactions between health care providers and youth might pave the way for an unfavorable view of the adult health care programs. All the participants in the current study emphasized the importance of having their concerns addressed. Many of the respondents validated the findings of Moola and Norman by reporting a less than satisfactory experience in their transition to the adult program. In the bio-psychosocial model, readiness for the transition process would be considered to be related to multiple internal psychological factors that in turn interact with external factors such as parental factors and how the transition itself is managed.

Complex Medical Decisions are Difficult to Discuss

Complex medical decisions and the consequences of non-adherence are often highly emotionally charged issues before and after the transfer of care. In the current study, some participants reported difficulty discussing specific medical procedures and end of life issues. For instance, many individuals in this study mentioned that the placement of a port-a-cath was a constant reminder to the individual that they had CF. Another individual mentioned the difficulty of discussing a transplant. Pregnancy and end of life care were areas that were especially difficult to broach. A few of the participants in this study employed avoidance coping such as not discussing the possibility of transplant, and some parents simply avoided what they called “the elephant in the room” when talking about pregnancy and how it would impact their child’s health.

While looking at how caregivers deal with the problematic behaviors of their children with CF, researchers found that parents tended to either engage in what they called “active coping” or in “avoidance coping” (Sheehan et al., 2014, p. 212-213). Active coping involves making inquiries, censoring changes in health, recognizing when and how to ask for help, and performing cognitive restructuring to create a more positive mindset (Sheehan et al., 2014). Avoidance coping involves turning attention away from health concerns and engaging in fantasy or self-defeating dialogue or blame, and these coping mechanisms are related to an expression of melancholy and fear in youth diagnosed with a chronic illness (Sheehan et al., 2014). Further research is needed to look at how to address topics that are difficult to discuss in the management of CF. Researchers have previously discussed the need for timely discussion about transplants (Anbar & Murthy, 2010; Dellon et al., 2009; Shellmer et al., 2014; Vandemheen et al., 2010).

Two parents in this study mentioned the strain that they experienced in not knowing how to explain why adherence to treatments is beneficial. Some reported trying to avoid discussing the consequences of not following treatments responsibly. This type of avoidant coping is related to parental anxiety (Sheehan et al., 2014). Many parents in this study avoided the topic until it was necessary to consider the next step in treatment.

In contrast, Anbar and Murthy (2010) reported that patients who are well-informed and engaged in problem focused coping strategies were more likely to stick with treatments.

Looking at communication within the context of the bio-psychosocial model, it becomes evident that families learn and promote various styles of communication within their family unit. Some families are rather open with communication, while others resort to concealment of some issues. This can be especially true in families dealing with chronic illness. Parents and children have a “reciprocal influence” on each other’s behaviors, and this can impact how parent/child decisions are discussed (Miller, 2009, p. 261). For instance, parents who avoid talking about issues might find that their children are not able to converse in a factual manner with their parents (Miller, 2009). Miller (2009) confirms that both parents and children reported monitoring what was talked about to manage the outcome for themselves and the other individual. The current research findings and the findings of Miller confirmed that a collaborative communication process promotes autonomy in children while providing parents security that they are still granted access to what is going on.

Given the finding in the current study that topics such as pregnancy, non-adherence, placement of a port-a-cath, and transplants are all difficult to discuss, it might be important to consider how medical, psychological and social interactions with these families could promote early discussions to reduce the emotional burden of some of these discussions. Finding the balance in this collaborative process is necessary and can be aided by the assistance and education of a medical, psychological and social team.

Level of Maturity Can Influence Communication

Phase of development is a construct that can be demarcated by changes in the body and cognitive functioning, or socially defined using chronological age, and can influence communication. Reed-Knight et al. (2014) reported an increase in non-adherence during the adolescent years. Peeters et al. (2014) notes that parental help might be perceived as over-protective or helpful depending on the self-reliance of the child and his/her readiness for self-care. It is clear that level of maturity needs to be considered on a case-by-case basis and certainly before transferring health care responsibility.

Researchers have reported that parental attachment can be influenced by apprehension about adolescent self-care abilities, which in turn reduces the promotion of autonomy (Dashiff et al., 2008; Peeters et al., 2014). Some of the parents in the current study felt hesitant about transferring health care responsibilities to their children because they believed that their child was not ready. The adult children also reported that development influenced how they communicated with their parents. The adolescent years are a normal phase of questioning the benefit of treatments and rebellious behaviors such as not adhering to treatment regimens. Most of the adult children in this current study noted they became cognizant of the consequences of not performing health regimens with regularity by their early or mid-twenties.

Hafetz and Miller (2010) observed that parents moderate their supervision when they know that their children are consistently adhering to self-care skills. Both parents and adult children in this study opined that transfer of care should be a gradual process to ensure the competence of the child to manage the demands of navigating the health care system and insurance companies. Transitioning too soon may result in feeling overwhelmed or admitting defeat, which could result in gaps in adherence to treatments. It would be erroneous to assume maturity is defined by chronological age, when each individual may vary in how he/she learn and like to handle health care responsibility. Family members often need time to adjust to changing roles (Branstetter et al., 2008). Moreover, a "permissive parenting style" where children make their own decisions without a learning phase guided by parents may result in immature or risky decision making (Miller, 2009, p. 262). Parents in this study confirmed that they provided the necessary safety net for their children to form and practice health regimens in those early years. Adolescent years posed some risk for non-adherence, and finding ways to support families through this phase should receive a lot more attention in research and evidence based practice. Numerous researchers (e.g., Grier & Bradley-Klug, 2011; McCluskey, de Vries, Reneman, Brooks & Brouwer, 2015; Rolland, Emmanuel & Torke, 2017) have confirmed the importance of working with a systems model to help families of individuals living with chronic illness. The current research supports this conclusion that using a bio-psychoeducational approach that incorporates the family systems theory may promote the best outcome for the individual, family and society.

Divorce of Parents Can Impact the Quality of Communication

Murdock et al. (2012) examined discord in families where a chronic illness placed additional demands when much of the care was completed by one parent. One theme that was discovered was that parental divorce impacted the quality of communication for some of the participants in this study. Previous research by Moola and Norman (2011) reported similar findings, where as many as 50% of their sample were either divorced, separated, or remarried. They were careful to point out that other research would need to determine if families of children living with chronic illnesses were at greater risk of experiencing marital discord. The current study was not intended to address this issue, but it is recommended that future studies explore this topic in greater detail to determine if these families would benefit from services to address factors that might affect communication in the family. There is a demonstrated relation between an increase in oppositional behaviors in children and tension between parents (Emery and Leary, 1992).

Parental dedication was undeniable, with evidence that mothers may take on the bulk of the responsibilities caring for their child with CF, which could in turn impact their capacity to manage other complex relationships. Marital relationships require considerable effort, but families with additional stress such as managing the health care of children diagnosed with a chronic illness require more assistance and empathy. Stress on one part of the system impacts the entire system, which is why using a model such as a bio-psychosocial framework is necessary when considering complex issues such as transition from pediatric to adult health care. Branstetter et al. (2008) found that a problem of one family member has the capacity to impact the entire family unit. Quantitative research may be used to examine the role and impact of both marital stresses and divorced parenting on transitions and health outcomes. This may in turn lead to an enhancement of services to assist families who may be in greater need of assistance.

Limitations of the Study

The purpose of this phenomenological study was to cultivate an understanding of how individuals with the diagnosis of CF or CHD and their parents communicated as they moved through the challenges of transitioning from pediatric to adult health care. Numerous limitations were noted for this study. The first limitation is the small number of participants. The experiences of seven parents and six adult children are not likely to reflect the opinions of everyone dealing with a chronic illness such as CF. However, the current study contributed to the literature by identifying themes that may be used to develop tools to be used to assess larger samples of individuals in quantitative studies to determine if these themes are prevalent in the population.

Second, none of the participants had CHD or a child with CHD; therefore, the original scope of the study was limited by the fact that all the children had CF. The findings cannot be used to generalize about other chronic illnesses, and are limited both diagnostically and geographically (as all the participants were located in the Central and Southeast regions of the U.S.). This study was also limited to medical management issues, and was not directed at identifying other difficulties in communication between parents and their adult children with chronic illness.

Recommendations

The findings of this study were consistent with previous research and advance current understanding regarding the connectivity between not only parents and their children with CF, but between pediatric and adult health care facilities. Several themes were identified that may be further investigated in future research incorporating quantitative measures to examine relations between variables. One example of this is the finding that two thirds of the parents who participated in this study were divorced, separated or remarried. While a number of studies have looked at the impact of a child’s death on divorce rates (Schwab, 1998), family conflict and the impact on the autonomic nervous system (El-Sheikh & Erath, 2011), the impact of marital conflict on the different phases of development (Nasreen & Neelam, 2016) or the impact of parenting stress for parents of children with autism (Hayes & Watson, 2013), further investigation is needed to help address family conflict while raising a child with CF.

Further research is also warranted to look at what can be done to improve patient and parent satisfaction with the transition to adult programs. Additional research opportunities may include the development of a measure to assess the transition process and incorporate the findings into educational programs for providers. In addition, research examining methods to prevent triangulation during transitions may be useful. The current findings suggest that mishandling the introduction of transitions to family members may contribute to triangulation, which may further disrupt care.

Implications for Social Change

Individuals who are living with a chronic illness may be able to identify with the challenges and accomplishments that the parents and adult children described in this study as they navigated changes in responsibilities. It is possible that other families who are traversing some of the same challenges in the transition from pediatric to adult health care will feel encouraged by the current study to find ways to communicate their concerns about future treatments and transitions to their health care professionals.

The results of this study can also help inform both pediatric and adult health care providers about some of the preferences families have for learning about the transition, such as a gradual transfer of care to the adult program and early education and introductions to the adult program team. Health care providers might also learn how important their role is in reducing fears and coaching parents on when and how to have children take on some health care responsibilities while continuing to provide a safety net for their children. Pediatricians might see the benefit of providing an appraisal of the system they have employed with families to the adult health curriculums so that adult programs can incorporate some of the same procedures.

Health care institutions serving individuals with chronic illnesses are continually performing research to determine best practice. Institutions can benefit from the findings in this study by incorporating evidence-based practice based on the feedback from family members concerning some of the difficulties they experienced navigating the transition between pediatric and adult programs. The findings of this research call into question the procedures of many programs that care for young adults with CF, and hopefully these findings may inspire health care providers to consider changes in those procedures. Individuals in this study tended to describe variance in the service they received at the adult health care facilities compared to their experience at the pediatric programs.

At the macro level, this study can contribute to positive social change for any individual, group or society who is willing to challenge the conventional way of transitioning patients and creating collaborative programs that recognize the importance of supporting families of individuals with CF. Gradual transitions that include follow up programs and connectivity between pediatric and adult health care programs should incorporate advocacy programs to promote early participation of patients and their families. Teaching youth with chronic illness to self-advocate may help them voice concerns that impact family services, health care policies and financial assistance.

Conclusions

The experiences of parents and adult children in this study produced themes that both corroborated previous findings and contributed to the literature by identifying issues that may be useful to families, health care providers, and researchers. Some of the concepts discussed in the findings would benefit from additional investigation using quantitative methodology.

The adults with CF who were interviewed for this study appreciated parental involvement more than might have been anticipated. Parental involvement appeared to be more constructive if it accommodated the growth of the child into an autonomous individual. Pressuring families to go through the process of transitioning to adult care before they are ready can create complications with direct consequences for the health of the patient with CF. Parents are instrumental in ensuring the maintenance of treatments, which is a role that should not be minimized during the fragile phase of moving between health care programs. Healthy parent and child relations were reflected in families that used collaboration as a normal part of making decisions. Additionally, health care providers who were perceived to ignore concerns of their patients or refused to be flexible with regimens risked jeopardizing the provider/patient relationship. It is important that family counselors and health care providers continue to look for ways to improve communication with individual patients with chronic illnesses and their families. The stress that these families undergo should not be underestimated. It was evident in the current study that both the parents and adult children appreciated the collaborative process where their individual voices and concerns were identified. Since adult children identified the emotional support they received from family members as teamwork, it should be concluded that families entering the health care system will act as team players unless there is evidence to prove otherwise.

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Appendix A: Recruitment Leaflet for Individuals Living with Cystic Fibrosis (CF)

If you are the ***parent*** of an adult child aged ***18 to 30 years*** living with ***Cystic fibrosis***, or individual aged 18 to 30 years with ***Cystic Fibrosis***, both parent and adult child are invited to participate in a research study involving telling your story about treatment decisions that were made for the management of the disease, and also your experience with the transition process from child to adult health care.

Juanita Sibayan, who is a doctoral candidate at Walden University, is conducting this study for her dissertation. This study has been approved by the Human Subjects Review Committee at Walden University. **This study is not associated with the offices/organizations/groups where these flyers are posted.**

If you agree to participate, you will be asked to fill in a form with information about yourself, and will be interviewed for 45 to 75 minutes. The information you share will be kept confidential, meaning no one but the researcher will have access to it. Your participation is completely voluntary, and you are free to stop at any time. You and your family members will be interviewed separately and privately either in-person or via Skype Professional Videoconferencing. In a 15 to 20-minute follow-up interview you will be offered the opportunity to examine your responses to questions for accuracy.

Participants living in the states of Georgia or Alabama will have the option to participate either in-person, via a private interview at a time and location convenient for them, or via Skype Professional Videoconferencing. Participants living outside of Georgia or Alabama will be interviewed via Skype Professional Videoconferencing. Participants who are interviewed using Skype will be directed to a webpage that was established exclusively for this study.

Anyone interested in participating in this research is encouraged to contact Juanita Sibayan by e-mail: eirejuan@aol.com, or call her at (706)-405-9481. ***All participants will be compensated for their time with a $15.00 Amazon.com gift card.***

Appendix B: Recruitment Leaflet for Individuals Living with CHD

Stories from the Heart

If you are the ***parent*** of an adult child aged ***18 to 30 years*** living with ***Congenital Heart Disease***, or individual aged 18 to 30 years with ***Congenital Heart Disease***, both parent and adult child are invited to participate in a research study involving telling your story about treatment decisions that were made for the management of the disease, and also your experience with the transition process from child to adult health care.

Juanita Sibayan, who is a doctoral candidate at Walden University, is conducting this study for her dissertation. This study has been approved by the Human Subjects Review Committee at Walden University. **This study is not associated with the offices/organizations/groups where these flyers are posted.**

If you agree to participate, you will be asked to fill in a form with information about yourself, and will be interviewed for 45 to 75 minutes. The information you share will be kept confidential, meaning no one but the researcher will have access to it. Your participation is completely voluntary, and you are free to stop at any time. You and your family members will be interviewed separately and privately either in-person or via Skype Professional Videoconferencing. In a 15 to 20-minute follow-up interview you will be offered the opportunity to examine your responses to questions for accuracy.

Participants living in the states of Georgia or Alabama will have the option to participate either in-person, via a private interview at a time and location convenient for them, or via Skype Professional Videoconferencing. Participants living outside of Georgia or Alabama will be interviewed via Skype Professional Videoconferencing. Participants who are interviewed using Skype will be directed to a webpage that was established exclusively for this study.

Anyone interested in participating in this research is encouraged to contact Juanita Sibayan by e-mail: eirejuan@aol.com, or call her at (706)-405-9481. ***All participants will be compensated for their time with a $15.00 Amazon.com gift card.*** Appendix C: Recruitment Letter Sent to **CF** Online Support Group Facilitators

Appendix C: Recruitment Letter Sent to **CF** Online Support Group Facilitators

To Whom It May Concern,

My name is Juanita Sibayan, and I am a doctoral student at Walden University where I am conducting my dissertation research to find out how parents and their adult children with ***Cystic Fibrosis (CF)*** communicated about complex medical decisions, and conferred about management of chronic illness while transitioning from pediatric to adult health care. I am writing to request permission to post the attached recruitment leaflet in your online forum.

I am recruiting participants who are adults aged ***18 to 30 years*** living with ***Cystic Fibrosis (CF)*** and either both parents or their single parent. They must have either completed the transition from childhood to adult health care, or be currently in the process of this transition.

Each potential participant will be asked to contact the researcher via email or phone. Participants (including patients and their parent(s)) will be asked to complete consent forms and return them to the researcher. Each participant will fill in an informational questionnaire, and will either log into Skype for a confidential interview, or may opt for an in-person interview if they live in Georgia or Alabama. Each individual will be interviewed separately, and individual interviews will be recorded. The video recording will only be accessible to the researcher. Interviews will include questions such as, (to parents) “Could you tell me about your care giving relationship with your child? How would you describe the relationship with your child while you were transferring responsibility and promoting self-management skills? Were any medical decisions for the management of your child’s illness difficult to discuss? If so, could you describe that specific situation and the outcome?” or, (to patients) “How would you describe the relationship between you and your parents while you were taking on responsibilities and learning self-management skills? Were there treatment decisions that you and your parents could not agree on? If so, could you describe how you managed that situation?” Interviews will take approximately 45 to 75 minutes, and will be followed with a second 15 to 20-minute interview to clarify information and make sure that my data is an accurate reflection of the participants’ experiences.

Participants will be assigned a random number to ensure confidentiality. They will be compensated for their time with a $15.00 Amazon.com gift card.

If you have any questions about this study, please contact me by e-mail: eirejuan@aol.com; or by telephone (706)-405-9481. Thank you in advance for your assistance.

Sincerely,
Juanita M. Sibayan, MS., Walden University Doctoral Candidate

Appendix D: Recruitment Letter Sent to **CHD** Online Support Group Facilitators

To Whom It May Concern,

My name is Juanita Sibayan, and I am a doctoral student at Walden University where I am conducting my dissertation research to find out how parents and their adult children with ***Congenital Heart Disease (CHD)*** communicated about complex medical decisions, and conferred about management of chronic illness while transitioning from pediatric to adult health care. I am writing to request permission to post the attached recruitment leaflet in your online forum.

I am recruiting participants who are adults aged ***18 to 30 years*** living with ***CHD*** and either both parents or their single parent. They must have either completed the transition from childhood to adult health care, or be currently in the process of this transition.

Each potential participant will be asked to contact the researcher via email or phone. Participants (including patients and their parent(s)) will be asked to complete consent forms and return them to the researcher. Each participant will fill in an informational questionnaire, and will either log into Skype for a confidential interview, or may opt for an in-person interview if they live in Georgia or Alabama. Each individual will be interviewed separately, and individual interviews will be recorded. The video recording will only be accessible to the researcher. Interviews will include questions such as, (to parents) "Could you tell me about your care giving relationship with your child? How would you describe the relationship with your child while you were transferring responsibility and promoting self-management skills? Were any medical decisions for the management of your child's illness difficult to discuss? If so, could you describe that specific situation and the outcome?" or, (to patients) "How would you describe the relationship between you and your parents while you were taking on responsibilities and learning self-management skills? Were there treatment decisions that you and your parents could not agree on? If so, could you describe how you managed that situation?" Interviews will take approximately 45 to 75 minutes, and will be followed with a second 15 to 20-minute interview to clarify information and make sure that my data is an accurate reflection of the participants' experiences.

Participants will be assigned a random number to ensure confidentiality. They will be compensated for their time with a $15.00 Amazon.com gift card.

If you have any questions about this study, please contact me by e-mail: eirejuan@aol.com; or by telephone (706)-405-9481.

Thank you in advance for your assistance.

Sincerely,
Juanita M. Sibayan, MS, Walden University Doctoral Candidate

Appendix E: Script & Screening Questions for Phone Calls with Potential Participants

Hello (name of the respondent), this is Juanita Sibayan. I am calling you back to talk about the study I am conducting looking at family experiences in the course of the change from childhood to adult care in chronic illness. The purpose of this study is to explore and understand the personal experiences of parents and their children who have had to communicate about complex medical issues while also learning how to manage an illness that can be difficult to manage.

Have you read the information about the study? (If not, request email address to send that information and clarify the nature of the research). Do you have any questions about the study?
The research will consist of completing a questionnaire about yourself, including your age, diagnosis, ethnic background, education and employment status. That will take approximately 2 to 5 minutes to complete. The first interview will take approximately 45 to 75 minutes, and will be followed with a second 15 to 20-minute interview to clarify information and make sure that my data is an accurate reflection of the participants' experiences.

What is your diagnosis, or your adult child's diagnosis?

Individuals diagnosed with (Cystic Fibrosis (CF) or Congenital Heart Disease (CHD) are also expected to meet an age requirement of being between the ages of 18 to 30 years. Does this describe you? (If speaking to the patient) or Does this describe your child? (If speaking to the parent)

Any individuals diagnosed with (CF or CHD) are also expected to have completed, or currently in the process of the transition from childhood health care program to an adult health care program. Does this describe you? (If speaking to the patient) or Does this describe your child? (If speaking to the parent)

Where in the transition process from childhood to adult health care are you, or your adult child?

I am seeking both parents, or a single parent, and their adult child with (CF or CHD), who are willing to be interviewed. Both of the parents, or the single parent and their adult child will be interviewed separately. Please keep in mind that I cannot contact anyone to recruit for my study, and your family member needs to contact me first. You can share my contact information: eirejuan@aol.com; or by telephone (706)-405-9481, and your relative may contact me by whatever method they wish. If the individual does not meet criteria for the study, inform them of this and thank them for their interest. If they do meet criteria, inform them and ask: What is the best method for me to contact you in the future?

Appendix F: Demographic Survey

1. Are you:

○ A parent of an individual diagnosed with CF?
○ A parent of an individual diagnosed with CHD?
○ An individual diagnosed with CF?
○ An individual diagnosed with CHD?

2. How old are you?

____

3. What is your sex?

○ Male
○ Female

4. Are you Hispanic or Latino?

○ Yes
○ No

5. Select one or more of the following races that you use to describe yourself:

○ American Indian or Alaska Native
○ Asian
○ Black or African American
○ Native Hawaiian or Other Pacific Islander
○ White

6. What is the highest level of education you have achieved?

○ Less than high school degree

○ High School graduate or equivalent

○ Some college

○ Two year degree

○ Four year degree

○ Under Graduate Degree

○ Graduate Degree

7. What is the name of the disease you are living with? Does it have a specific name or type of identifier?____
____
____
____
____

8. Do you have any other diseases that you are managing? Please describe:
____
____
____
____
____
____
____

9. Have you undergone surgery in the past? Please include number and type of surgeries:
____
____
____
____
____
____

10. How many times have you been hospitalized?

____
______
____
____
____
____
____

11. Have others in your family been diagnosed with the same disease?

○ Yes

○ No

○ If yes, specify who? ____

12. Have you,

○ Completed the transition process to an adult health care facility?

○ Yes

○ No

13. Are you in the process of transitioning to an adult health care facility?

○ Yes

○ No

14. Employment status:

○ Unemployed

○ Full Time Student

○ Part Time Student

○ Part time work

- ○ Full Time work

15. If employed, what kind of work do you do? ____

____

____

____

Appendix G: Interview Questions

Parents

1. Tell me about your care giving relationship with your child.
2. How would you describe the relationship with your child while you were transferring responsibility and promoting self-management skills?
3. Were there treatment decisions that you and your child could not agree on? If so, could you describe how you managed that situation?
4. What medical decisions for the management of your child's illness were shared between you and your child?
5. Were any medical decisions in the management of your child's illness difficult to discuss? If so, could you describe that specific situation and the outcome?
6. Did your child experience any deterioration in their health in recent years? If so, how did you and your child discuss possible treatments for moving forward with the management of the disease?
7. What are the benefits or drawbacks to being involved in your child's medical decisions?
8. To what extent do you think your involvement in the management of your child's health has influenced the relationship you have today?
9. Parental involvement has often been described as being both valued and disliked by children. What was your experience during your involvement with the management of your child's illness?
10. How did you initiate discussions about transitions with your child?
11. What was your experience while communicating about transfer of care issues with your child?
12. How do you feel the transition process went for you?
13. Were there times when you felt others were not aware of your concerns about transfer of care or medical decisions? If so, could you provide some examples and the outcome for you?
14. What advice would you give to others coming after you in this type of situation?

15. Is there anything that I have not asked you about your experience with the transition process or communication with your child that you would like me or others to know at this time?

Children

1. Tell me about the care giving relationship between you and your parents.
2. How would you describe the relationship between you and your parents while you were taking on responsibilities and learning self-management skills?
3. Were there treatment decisions that you and your parents could not agree on? If so, could you describe how you managed that situation?
4. What medical decisions for management of your illness were shared between you and your parents?
5. Were any medical decisions in the management of your illness difficult to discuss? If so, could you describe that specific situation and the outcome?
6. Did you experience any deterioration in your health in recent years? If so, how did you and your parents discuss possible treatments for moving forward in the management of the disease?
7. What are the benefits or drawbacks to having your parents involved with medical decisions with regard to your health?
8. To what extent do you think your parent’s involvement in the management of your illness has influenced your relationship with them today?
9. Parental involvement has often been described as being both valued and disliked by children. What was your experience during your parent’s involvement with the management of your illness?
10. How did you initiate discussions about transitions with your parent?
11. What was your experience while communicating about transfer of care issues with your parent(s)?
12. How do you feel the transition process went for you?
13. Were there times when you felt others were not aware of your concerns about transfer of care or medical decisions? If so, could you provide some examples and the outcome for you?
14. What advice would you give to others coming after you in this type of situation?
15. Is there anything that I have not asked you about your experience with the transition process or communication with your parent(s) that you would like me or others to know at this time?

Appendix H: Debriefing Form

Some of the information you shared with me may help others to voice their concerns about the transitional process, and what aspects of the transition are difficult to discuss. It is important for others to be aware that you may experience a breakdown in communication and could possibly learn from your approach on how you reconciled differences while maintaining support.

I anticipate that individuals with your illness will share some common experiences as a result of having the same chronic condition, but I also look forward to gaining insight from your personal account and hearing your voice. I also expect that parents of children living with a chronic illness will share some common experiences, but it is also important to attain each parent's individual story and capture it in their own words.

I would like to extend to each participant my deepest gratitude for your time and dedication to furthering our understanding of what it must be like to go through the transitory process, negotiate the transfer of care, and manage relational issues with others during times of personal growth and development.

Is there anything about your participation in the study that you would like to discuss with me? Was there anything negative about your experience?

Without your willingness to participate a study like this would not be possible. If you have further questions or would like additional information about your participation in this study, please, do not hesitate to contact me Juanita Sibayan at 706-405-9481 or e-mail me at eirejuan@aol.com. Once again, I would like to extend to you my gratitude for your time and contribution.

Appendix I: Resources Provided to Parent(s) & Individuals with CF & CHD

Numbers for Those Living Inside of Georgia & Alabama

CRISIS SERVICES OF NORTH ALABAMA
Confidential Address
Huntsville, AL 35804
(256) 716-1000 Confidential Help Line
(256) 716-4052 Administrative
(256) 716-0663 FAX
http://www.csna.org
csna@csna.org
Madison County
CRISIS SERVICES

WINGS ACROSS ALABAMA
400 Eastern Boulevard Suite 201
Montgomery, AL 36117
(800) 639-3000 Warm-Line
Montgomery County
CRISIS SERVICES

CRISIS HOTLINE GEORGIA
@ www.***crisis****textline.org/*

Text our trained Crisis Counselors about anything that is on your mind, simply Text “GO” to 741-741. The call is “Free” and is 24/7 and is confidential.

Numbers for Those Living Outside of Georgia & Alabama will be Provided When Respondents have Provided their Location to the Researcher during the Initial Screening Phone Conference

**For individuals who reside outside of the states of Georgia and Alabama hotline numbers and supportive counselors in the respondent’s area need to be arranged during the screening call when respondents initially contact the researcher.*