THE DEVELOPMENT AND PSYCHOMETRIC TESTING OF AN INVENTORY TO MEASURE HEALTH-FOCUSED PERCEIVED FAMILY SUPPORT AND COMMUNICATION BEHAVIORS WITH CHRONIC DISEASE PATIENTS: A THREE-PHASE STUDY

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Submitted to the faculty of the University Graduate School
in partial fulfillment of the requirements
for the degree
Doctor of Philosophy
in the Department of Communication Studies,
Indiana University

June 2019

Accepted by the Graduate Faculty of Indiana University, in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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DEDICATION

To my family: because with their love, I can do anything.

ACKNOWLEDGEMENT

To say that this dissertation would not be possible without the assistance of others would be an understatement. Frankly, I know within me that the supports I have had through my entire life are the very reasons I am drawn to study relationships, systems, and support.

First, I would like to thank my professors and research committee at IUPUI for the world-class education extended to me through the new doctoral program at the university in health communication. I have irreplaceable friendships from my time here with top-notch classmates, like Nicole Johnson who embodies the type of peer we could only hope for -- encouraging, smart, and determined, and Daniel Park that served as a content reviewer. Each class, project, professor, and experience at IUPUI made me a stronger, more thoughtful scholar because their support and passion never wavered. Dr. Jennifer Bute and Dr. Susan Rawl fed my inquisitive mind, and Dr. Katy Head provided me with invaluable opportunities of mentorship and inclusion on research, projects, and presentations. With utmost gratitude, I cannot thank Dr. Maria Brann enough for being more than just a committee chair. I extend my thanks in exchange for her dedication to weekly meetings, exploring new ideas, and supporting my visions for this project.

For the past twelve years and during my doctoral education, I have been lucky enough to be employed at Ivy Tech Community College. Through the five years of technically being full-time at both institutions, there were many colleagues and supervisors that encouraged me and supported me in my completion. More often than not, they had more confidence than I did that the finish line would come. I cannot say thank you enough to the people in this past year that said things like, “I’m not letting you sign up for anymore committees or projects until your dissertation is done. All of those opportunities will be here when you're finished." There are not many places that someone could work that would be this forthcoming with support and personal prioritization.

Through my higher education, there has always been "my one solid rock." I am deeply indebted to Dr. Barbara Garvey for her mentorship, friendship, and everlasting confidence. Without a doubt, I can say she is single-handedly responsible for my pursuit of any graduate education. My start in communication arose from the idyllic atmosphere with the entire communication department at Hanover College (Barbara, Bill, David, and Elizabeth), and they are who built the foundation that launched me into my research and careers in higher education. Barbara remains my utmost mentor, and I have to admit she is solely responsible for snowballing about 100 participants in this very study. Barbara has always and continues to build me up to what I am capable of, helps me with anything I need, and lovingly confirms when "it's about time."

Through my entire life, I have been lucky enough to be a small piece of one of the strongest and most loving families I know. Through and through, they are smart, supportive, and God-fearing. The foundations for this family and my love comes from my grandparents Clyde, Edna, Fred, and Jean. Three of these wonderful people are no longer with us to celebrate the conclusion of my education, but they were all there in the beginning through the grandparents' days, extra-curricular events, and graduations whether it be kindergarten or college. Most recently, I have been lost without my Mamaw Jean. I can still hear Mamaw Jean asking me if my "doctor book" was finished yet, and I wish she could have been here for me to tell her yes. While most are gone, I am ever so grateful to still hold time and love with Mamaw Edna. She teaches me so much about the right priorities and building a strong family. I look forward to sharing and celebrating this graduation with her this May, and I am certain her joy and love will be more than enough and on behalf of those who cannot be here.

These grandparents raised the two wonderful people I get to call my parents. I am extremely grateful to the opportunities, love, and encouragement my parents showered on me and continue to bless me with. My dad can brighten any day with his smile and friendship, and my mom has instilled in me the most beautiful kind of grit and persistence that gets me where I am today. They have taught me how to be a student, spouse, sibling, and parent, and I do not get the opportunity to tell enough people how much they mean to me and how much credit they deserve for who I am today.

The many people that surround these grandparents and parents are a beautiful part of my family's tapestry that have always been here for me and especially during this phase of my education. My siblings, in-laws, aunts, uncles, cousins, and dear friend Kami have pushed me and kept me grounded during the entire experience. I am lucky to have friends like Amy, Mell, Dawn, and Susie that helped in content review or helping me decompress after a long day's work. I look forward to the times and things we get to do together now that it is done.

I have saved my very last acknowledgment for the beautiful family I get to call my very own – Kyle, Taylor, Bodie, and Annie. Many of the people mentioned thus far pushed me and encouraged me to complete this project, but it was the four of you that had to pay the biggest price. Kyle, while I get the congratulatory cards for finishing my Ph.D., I can honestly say what you have done for me during this time was harder. So, thank you. All four of you had to give up this time and love that you honestly deserved from your wife and mom while I chased this accomplishment. You never seemed to notice or question my diverted attention, but it was hard on me because I have always wanted to give you every ounce of love and time I have. We have such a special family, and I thank you for your patience, hugs, and extras you helped with. Each one of you are considered the best things to ever happen to me, and here is to the rest of our lives!

Amanda M. Harsin

THE DEVELOPMENT AND PSYCHOMETRIC TESTING OF AN INVENTORY TO MEASURE HEALTH- FOCUSED PERCEIVED FAMILY SUPPORT AND COMMUNICATION BEHAVIORS WITH CHRONIC DISEASE PATIENTS: A THREE-PHASE STUDY

Hospitals and policymakers acknowledge the importance of the family in improved healthcare outcomes. Although there has been an increase in policies and research to bring families into planning, delivery, and evaluation of healthcare, there has not been a means to assess health-focused perceived support and communication behaviors. Without a means of assessing these factors, healthcare professionals cannot succinctly evaluate support and communication in a family system or provide recommendations for engaging family members in providing beneficial health-focused support and communication. This study involved the creation of the Inventory for Family Health-Focused Perceived Support and Communication Behaviors (Family HF-PSCB). Informed by family systems theory, social support literature, and health communication behaviors research, this three-phase study consisted of (a) generating items for the Family HF-PSCB, (b) establishing test-retest reliability, and (c) establishing a factor structure and convergent validity. Because of the increase of chronic disease in the United States, the Family HF-PSCB was created and tested with samples of individuals having chronic disease(s).

Using a mixed methods approach, in-depth interviews with 12 participants generated 91 items for psychometric analysis. These items were tested through expert content review, and in pilot testing (n = 23), the remaining 84 items demonstrated test-retest and internal reliability. Through factor analysis (*n* = 209), two factors emerged to explain 72.1% of the variance. The final Family HF-PSCB contains 13 items, which indicates an individual's perception of family health-focused support and communication behaviors. The factor explaining 63.2% of the variance has 8 items demonstrating health-focused communication behaviors, and the second factor has 5 items demonstrating health-focused instrumental support. The developed scale suggests that family health-focused communication behaviors may be a more explanatory variable in the family system for someone with chronic disease(s). The 13-item Family HF-PSCB demonstrates convergent validity through significant correlations with the Perceived Social Support Family Scale and the General Functioning Scale of the McMaster Family Assessment Device. Future studies should explore the correlation of the Family HF-PSCB with health outcomes attributed to symptom management in populations of chronic disease patients.

Maria Brann, PhD, MPH, Chair

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LIST OF ABBREVIATIONS

CVI	Content Validity Index
Family HF-PSCB	Inventory of Family Health-Focused Perceived Support and Communication Behaviors
GFS	General Functioning Scale
I-CVI	Item Content Validity Index
PSS-FA	Perceived Social Support-Family Scale
S-CVI/Ave	Scale Content Validity Index Averaged

Chapter One: Introduction

More than half of adults in the United States have at least one chronic health condition (i.e., a disease lasting three months or longer that is generally incurable and is ongoing [National Health Council, 2014]), and approximately one in four have multiple chronic conditions (U.S. Department of Health and Human Services, 2016; Ward, Schiller, & Goodman, 2014). When diagnosed with a chronic disease, the individual is likely asked by his or her health professional(s) to implement changes in the way he or she approaches health on a daily basis in an attempt to slow the progression of the disease. Some examples of these changes might include engaging in activities that promote physiological and psychological health, interacting with health care providers, adhering to treatment recommendations, or monitoring health status changes (Bayliss, Steiner, Fernald, Crane, & Main, 2003). Fortunately, studies suggest that 40-60% of these individuals have some form of family that they can rely on to provide support and assistance (Lee et. al, 2017; Rosland, Heisler, Choi, Silveira, & Piette, 2010; Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008). Studies show the importance of this family support from an extensive body of literature that correlates positive family support with a higher implementation of the recommended lifestyle changes needed for those with chronic diseases (Chisholm-Burns, Spivey, & Wilks, 2010; DiMatteo, 2004; Fallatah & Edge, 2015).

As one example of how a family might support someone in the family with chronic disease(s), family health communication behaviors (i.e., the way family members share messages about health) have been associated with improved psychological outcomes such as reduced mortality rates, improved blood pressure control, improved glycemic control, and reduced joint inflammation (Rosland, Heisler, & Piette, 2012).

Due to the associated improvement in physiological and psychological outcomes for individuals with support from family members, there is a need to examine which family support and communication behaviors are perceived to be supportive and assistive by individuals who are chronically ill. For researchers and professionals trying to understand the specific ways that family members might build the perception of support to individuals with chronic condition(s), it is important to be able to identify and measure these concepts in a family dynamic. When needing to engage the family as a support system, it would be helpful if healthcare providers had a way to identify the level of communication and support available. Then, if there is a family system that could provide support, the provider can encourage their involvement. When there is not a system for support, the provider might suggest alternative ways to engage support through support groups or other relationships such as coworkers or friends. This dissertation develops an Inventory of Family Health-Focused Perceived Support and Communication Behaviors with chronic disease patients. The first chapter describes the rationale for the study by exploring the intersection of chronic disease in the United States, family health-focused perceived support, and family health-focused communication behaviors.

State of Chronic Disease in the United States

Chronic diseases are responsible for 7 in 10 deaths in the United States each year and the majority of health care costs (National Center for Chronic Disease Prevention and Health Promotion, 2017). Some examples of chronic diseases include arthritis, cancer, chronic kidney disease, diabetes, heart failure, and hypertension (Centers for Medicare and Medicaid Services, 2017). Because of their duration, chronic diseases require long-term management, which is largely dependent upon an individual’s circumstances and motivation to manage day-to-day decisions. When a healthcare provider suggests changes, the goal of recommended management behaviors is to slow the progression of the chronic disease (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Chronic care of this nature often involves a complex combination of tasks that might include routine health visits, nutritional restrictions, medication regimens as well as a variety of other lifestyle changes (Dwarswaard, Bakker, Staa, & Boeije, 2016; Grey, Knafl, & McCorkle, 2006; Powers et al., 2017; Udlis, 2011). Fortunately, when patients have social support, they typically demonstrate greater treatment adherence and better health outcomes (Mayberry, Berg, Harper, & Osborn, 2016). In addition to physiologically slowing the progression of the disease, changes in perceived social support correlates with an overall higher quality of life psychologically (Bennett et al., 2001).

The chronic disease diagnosis affects more than just the patient; it has been found that engaged families must also recontextualize their prior way of life, relationships, and communication after a chronic disease diagnosis (Årestedt, Persson, & Benzein, 2014). The chronic disease of a family member can add stress and require adjustment for family members (Sieh, Dikkers, Visser-Meily, & Meijer, 2012). Sometimes when this occurs, the family system can affect the situation negatively in which the family provides obstructive behaviors rather than supportive behaviors (Mayberry & Osborn, 2014). Mayberry and Osborn (2014) evaluated both supportive and obstructive behaviors but recommended that future studies develop a more thorough understanding of patients’ supportive family context so that we might enhance family involvement by training them to communicate productively.

Family Defined

This study is guided by the family systems framework in which an individual’s motivations and ability to manage health must be considered within the context of the family system (Årestedt, Benzein, Persson, & Rämgård, 2016; Perrino, Coatsworth, Briones, Pantin, & Szapocznik, 2001). Different from theory that focuses on the individual’s ability to make health behavior changes, family systems sees the family as a unit and focal point of change because the social context of the person managing health lifestyle changes has been considered (Årestedt et al., 2016; Weihs, Fisher, & Baird, 2002). The family system could quite possibly be one of the most immediate and modifiable influences on disease management (Fisher, 2005, 2006; Fisher & Feldman, 1998; Vedanthan et al., 2016). In particular, the family has been shown to have a positive effect with patients in the ICU (Fumagalli et al., 2006), in pediatrics (Aronson, Yau, Helfaer, & Morrison, 2009), after a major surgery (Chisholm-Burns et al., 2010), and among those who have experienced varying types of chronic diseases (Årestedt et al., 2014; Fisher, 2005, 2006; Stanton, Revenson, & Tennen, 2007).

Family systems theory prioritizes the family as the unit of analysis, as opposed to specific family members (Bavelas & Segal, 1982). Family is defined as a group of individuals with legal, genetic, and/or emotional relationships (Bylund, Galvin, & Gaff, 2010). With the constructs of family systems theory, the family is viewed as an open system where elements of change (such as new health concerns) require the family to positively or negatively provide feedback because one person’s behavior leads to another person’s behaviors in a circular fashion (Bavelas & Segal, 1982). When supportive behaviors exist, the members showing support affect the entire family and thus provide stability to the entire system.

Perceived Support and Health-Focused Communication Behaviors Defined

Support can be communicated in the structures of everyday relationships. Family relationships are one such structure which allows individuals to build a foundation where they try to manage the problems of everyday life (Goldsmith, 2004). There are many types of general social support that have been studied in health communication including support of friends (Tang, Zhu, & Zhang, 2016), spouses (Bolger, Zuckerman, & Kessler, 2000), coworkers (Gray, 2014; LaRocco, House, & French Jr, 1980; Reifegerste, Schumacher, Hoffmann, Schwarz, & Hagen, 2015), support groups (Finlay & Elander, 2016), and online relationships (Braithwaite, Waldron, & Finn, 1999). Despite many sources of social support, family members may be one of the most well-positioned groups to provide social support because of geographical proximity, frequency of contact, and longevity of the relationships. These factors might more readily allow them to assist in health management techniques such as setting goals, providing coping techniques, and being involved in the health care process (Rosland & Piette, 2010).

The research in this study focused on both the family support and communication behaviors that an individual perceives within his or her family that are specifically related to health. The first focus is on family support, which is defined as anyone the individual considers to be a part of their family regardless of legal or biological ties (Mayberry et al., 2016) who help one another (Warren-Findlow & Prohaska, 2008). This definition of family support requires the presence of the family in an overall assistive nature (rather than disruptive or unhelpful) with the help of at least one or more caregivers (Warren-Findlow & Prohaska, 2008).

The second focus of the study is on health-focused communication behaviors. Communication behaviors that exist in a family without the presence of health concerns and without a health focus can be classified into *general* communication behaviors. Examples of ways general communication behaviors have been operationalized include family functioning, family support, cohesion, and autonomy (Rosland et al., 2012). However, family health-focused communication behaviors, which are the focus in this study, include communication about, and attentiveness to, health generally or to the individual's specific health needs.

Scholars have debated whether support should be conceptualized as actual support or the perception of hypothetical support (Goldsmith, 2004; Haber, Cohen, Lucas, & Baltes, 2007). Existing literature supports both of these positions. Received support represents the actual support where an individual can identify supports they have received from others or can be identified through observation (Helgeson, 1993), and perceived social support is the subjective judgment that family and friends would provide quality assistance with future stressors (Wills & Filer, 2001). Although it is acknowledged that the perception of being supported in the future is not necessarily the reality of being supported, perceived support has been demonstrated to buffer the effects of negative outcomes in stressful situations (Wethington & Kessler, 1986). Methodologically, perceived support can be assessed regardless of whether individuals share common experiences in their past because perceived support is the subjective judgment of whether family would provide assistance in the future. Hence, perceived social support is the focus of this study.

Statement of the Problem

Chronic diseases are the leading cause of death in the United States and the leading driver of health care costs (Centers for Disease Control, 2019). The ability to adhere to positive health care changes for those individuals with chronic disease(s) has been correlated with individuals who have family support. For this reason, the ability to assess how much an individual perceives family health-focused support and communication behaviors in any family situation is important to families, healthcare providers, and patients themselves (Glasgow, Toobert, & Gillette, 2001).

There have been several instruments developed to better understand non-health specific family support and communication behaviors in families experiencing chronic disease, such as family coherence (Anderson, 1998; Antonovsky & Sourani, 1988; Ballard-Reisch & Letner, 2003; Rena, Moshe, & Abraham, 1996), family adaptability and cohesion (Friedman et al., 1988; Phillips, West, Shen, & Zheng, 1998; Somerfield & Curbow, 2014), and family functioning (Iloh, 2017; Miller et al., 2000; Pless & Satterwhite, 1973; Zhang, Wei, Shen, & Zhang, 2015). There has not been, however, an instrument that takes into consideration the combination of both family health-focused perceived support and communication behaviors. The particularly unique features of this scale are the health-focused nature and the inclusion of communication behaviors. This is important to explore because there needs to be a reliable and valid way to measure these health-focused support and communication behaviors in families so that there can be a clearer assessment of the types of health-focused communication in the family system.

Purpose of the Study

Overall, there have been more studies about general perceived support and general family behaviors related to chronic disease (i.e., family cohesion, family adaptability) (Friedman et al., 1988; Mirzaei-Alavijeh et al., 2015; Narad et al., 2015) than family perceived support and communication behaviors specifically related to health. By focusing on general support and communication, researchers have not captured the specific health-focused support and communication behaviors that might have different effects on individuals within the family. Fisher (2006) warned that many studies related to chronic disease and family support have been too generic, and he encouraged future research to focus on well-defined behaviors. For this reason, this study sought to contribute to existing literature by providing researchers and interventionists with a tool to inventory the specific *health-focused* perceived support and communication behaviors in the family. Researchers and health care professionals need to know how to properly assess an individual for their family health-focused perceived support and communication behaviors so that individuals without an adequate level of family support and communication might be supplemented with other forms of support. Because of the identification of family as one of the most influential factors of modifiable health support (Fisher, 2005, 2006; Santos, Crespo, Silva, & Canavarro, 2012), further exploration of a psychometric assessment was warranted. The creation of this inventory intends to give a summative index of the patient's perceived family health-focused support and communication behaviors.

The purpose of this study was to develop a valid and reliable instrument with the Inventory of Family Health-Focused Perceived Support and Communication Behaviors

(Family HF-PSCB). The Family HF-PSCB specifically measures family health-focused perceived support and communication behaviors. This dissertation is organized into six chapters. Chapter one outlines the rationale and major concepts of family, perceived support, and health-focused communication behaviors for developing an instrument. The second chapter provides a review of relevant research that informed the development of the three-phase study. Then, chapters three through five outline the methods and results for each phase of the creation of the Inventory of Family Health-Focused Perceived Support and Communication Behaviors. Chapter six outlines the conclusions, implications, and directions for future research.

Chapter Two: Review of Literature

This dissertation seeks to build an instrument that provides the unique ability to assess the existence of health-focused perceived social support and communication behaviors in families that are measurable for individuals with varying or multiple chronic diseases. Fundamentally, the Family HF-PSCB is rooted in family systems theory with key variables of family social support and communication behaviors. Furthermore, the Family HF-PSCB focuses on being generalizable across multiple chronic diseases so a brief section addresses this target. At the conclusion of this chapter, a review of the instrumentation literature is reviewed to guide the creation and testing of the Family HF-PSCB.

Family Systems Theory

Framed by Family Systems Theory (Bell, 2015; Rolland, 1999), this study explored how families experience chronic disease alongside the patient. Although families can look different or individuals have different perceptions of family, most people can identify some person(s) as family. According to family systems theory, “decontexted individuals do not exist” (Galvin & Young, 2010, p. 102), meaning that almost everyone has some form of long-standing relationships that resemble family, regardless of whether they are biologically or legally tied. Because of the longstanding interdependence with familial relationships, persons in the family are a part of “of an open, ongoing, goal-seeking, self-regulating, social system” (Broderick, 1993, p. 37).

The contextualization and systemic nature of the family system becomes particularly important when an individual is presented with a stressor, such as a chronic disease that cannot be cured. When researchers investigate persons with an illness within a family systems approach, they view patients as part of a larger family system in which he or she constructs and communicates with the family's established frame of disease and health. This has led researchers to view the family as a type of ecological system in which research can be expanded from what the *individual* might do to manage chronic symptoms to a broader scope of what the *family* might do to support the management of chronic symptoms. By studying what is happening in the family around the patient, providers can recognize how the family communicates with one another and how the group and social unit affects the health situation for one or many of the individuals in the family (Galvin & Young, 2010).

Family Systems Illness Theory (Rolland, 1999) is a more specific family systems theory that is relatable to any illness, particularly chronic disease. In Family Systems Illness Theory research, participants are typically asked to respond to questions or interviews about the family unit rather than identifying any single relationship or particular caregiver. This approach allows the researcher to look at the family as a unit rather than a sum of individuals. In contrast, studies without the foundation of Family Systems Illness Theory might look at specific caregivers in the family such as spouses, children, or another person who is the most helpful in managing the individual's health needs. The Family Systems Illness Theory looks at the sum of the communication behaviors of the family unit that might assist in various ways. In practice, individuals can pool many different types of support from multiple individuals to have an overall perception of support within the entire family. This approach has been used in studies assessing the family and health behaviors (Vedanthan et al., 2016). Sample items in previous studies include questions such as, "How are family members utilizing health facilities?” (Hohashi & Honda, 2011) and “Would you say that your family is happier than most others you know, about the same, or less happy?” (Iloh, 2017; Miller et al., 2000; Zhang et al., 2015).

Family Systems Illness Theory guides the current research which is focused on the positive influences a family unit might provide, and it purposively leaves the problematic communication and relationships in the family for other theoretical investigations and scope (Rolland, 1999). Although it is acknowledged that the family system can affect the situation negatively through obstructive and unhelpful behaviors, this inventory was built to focus on only the supportive potential within families. By focusing on supportive behaviors, the theory allows the researcher or provider to consider the supportive nature of the family and the ways the family might improve health outcomes as the end goal. Alternatively, if there is a lack of a positive system, the research or provider can consider ways to improve or supplement with other potential types of support and communication.

Family Support

The supportive potential in family, or the perceived social support, has been studied extensively and found to provide many benefits to populations of chronic disease patients, such as individuals diagnosed with diabetes (Littlewood, Cummings, Lutes, & Solar, 2015), cancer (Lekka et al., 2014), and depression (Kitamura, Takauma, Tada, Yoshida, & Nakano, 2004; Whitley, Kelly, & Lamis, 2016). Barrera (1986) argued for the abandonment of the global concept of social support, and in its place, the use of more precise concepts and models of social support. In Barrera’s argument, he identified narrower concepts of social support such as perceived social support and received support. Perceived support scales assess perceived support for future needs and the expectation that family would assist when needed (Wills & Shinar, 2000). Received support scales assess prior support because they measure retrospective evaluations (Barrera, 1986).

Interestingly, perceived and received support are not always related when studied statistically. Perceived social support consistently assesses the extent to which an individual perceives to be accepted, loved, and in relationships where communication is open (Sarason, Shearin, Pierce, & Sarason, 1987). Perceived support has been associated with reduced mortality and improved physiological well-being (Wills & Shinar, 2000). In stressful situations, individuals with high levels of perceived support within the family have a significant reduction in psychological distress (Maulik, Eatonn, & Bradshaw, 2010). The availability of perceived support has been viewed to be of considerable significance for health (Wills & Shinar, 2000). One of the possible explanations for this significance may be because the perception that support is available, in itself, is supportive. On the contrary, measures of received support may not behave similarly psychometrically because received support has the opportunity to already be judged as unhelpful by the receiver (Kaniasty & Norris, 2008). This study used the construct of perceived support as an evaluation of whether the person with chronic disease(s) believes his or her family to be available in future times of need and to indicate the presence of open communication and acceptance as indicated by Sarason et al. (1987).

Perceived Social Support-Family Assessment. One instrument developed to assess perceived social support in the family is the Perceived Social Support-Family Assessment (PSS-Fa). The PSS-Fa measures perceived social support as the extent to which an individual believes that his or her needs for support, information, and feedback are fulfilled by the family (Procidano & Heller, 1983). The PSS-Fa is a 20-item scale consisting of declarative statements in which the individuals answers “Yes,” “No,” or “Don’t Know.” Responses that indicate perceived social support are scored as +1, but responses that do not indicate perceived social support by answering “No” or are answered “Don’t Know” are scored as 0. After adding all scores from all items, the sum of scores range from 0, indicating no perceived social support, to 20, indicating the maximum perceived social support (Procidano & Heller, 1983). The internal consistency reliability of the PSS-Fa is good with Cronbach’s alphas ranging from 0.88 to 0.90 (Procidano, 1992), and factor analysis reveals that the scale is only composed of a single factor (Procidano & Heller, 1983). Patients seen in clinics had means on the PSS-Fa from 7.19 to 11.34 on the 20-point scale (Procidano, 1992). The criterion validity of the PSS-Fa has been established from relationships of the PSS-Fa with the Family Environment Scale and the Inventory of Socially Supportive Behaviors (Procidano, 1992). Although the PSS-Fa has been useful in assessing perceived social support in the family, it is not health-focused with items being general in nature, such as “Members of my family share many of my interests.” Therefore, there is a need to develop a measure that specifically addresses health-focused perceived support.

Communication Behaviors

In addition to perceived social support, family health-focused communication behaviors substantially affect individual members’ positive health behaviors (Bylund & Duck, 2004), but there has been some question as to whether the influence is from general family communication or from health-focused communication. In a meta-analysis of 374 studies, Rosland et al. (2012) explored the connection between family and chronic diseases that require active self-management, and in the analysis, almost all studies could be divided into two categories: (a) those that are about general family communication characteristics that occur through all interactions or (b) those that focus on the family communication behaviors related solely to health and/or illness. Family communication behaviors such as conversation frequency have been shown to positively correlate with healthier attitudes and behaviors, but fewer studies have centered on the health-focused communication behaviors specific to health and illness (Baiocchi-Wagner & Talley, 2013; Rosland et al., 2012). This section first explores the general communication behaviors from the literature, followed by health-focused communication behaviors.

General family communication behaviors. Researchers have studied the effect of general family behaviors on chronic disease outcomes (Duijster, Verrips, & van Loveren, 2014; Edwards & Clarke, 2004; Grey et al., 2006; Heo, Lennie, Moser, & Kennedy, 2014; Narad et al., 2015; Rosland & Piette, 2010). Some general family behaviors have been associated with positive patient outcomes including family encouragement, family achievement, and family cohesion. In contrast, other general family behaviors have been associated with poor patient outcomes including family control, high family structure-organization, and family criticism (Rosland et al., 2012).

General Functioning Scale. One family systems model instrument developed to assess family functioning as a general family communication behavior is the McMaster Family Assessment Device (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). As a clinical instrument, the McMaster Family Assessment Device is a two-part assessment that includes a subjective self-report instrument as well as an objective clinical observation assessment. The subjective self-report instrument of the McMaster Family Assessment Device includes items for a General Functioning Scale (GFS) that measures the overall level of the family's functioning. Independently, the GFS has been considered to be a good summation of family functioning in a short, easy-to-use form where high levels of family functioning are an indication that the family manages problems productively, recognizing no family can be perfect in managing all problems (Ryan et al., 2005). As family functioning relates to both physical and mental illnesses, high family functioning on the GFS was more likely to correlate with good treatment adherence (Ryan et al., 2005). When studied separately, families with a psychiatrically ill individual were more likely to have lower family functioning than families with a non-psychiatric physical illness (Ryan et al., 2005).

The GFS consists of 12 items with statements such as “we are able to make decisions about how to solve problems,” “we confide in each other,” and reverse-scored items such as “we avoid discussing our fears and concerns” (Ryan et al, 2005, p. 235). Each item is a Likert-type item with response options ranging from 1 = *strongly agree* to 4 = *strongly disagree*. Reverse items are transformed by subtracting the score from 5. To calculate the final scale score for each participant, all scores are added and then divided by the number of items (12). If more than 40% of responses are missing from a participant, the score is not calculated. If the final score of a participant is 2.00 or above, the family member perceives his or her family functioning as problematic (Ryan et al., 2005). The internal consistency reliability of the GFS is good with a Cronbach's alpha of 0.92, and criterion validity of the GFS has been supported with relationships between related measurements such as Quality of Life, the Family Unit Inventory, and Family

Adaptability and Cohesion Scale (Jozefiak & Wallander, 2015; Miller, Epstein, Bishop, & Keitner, 1985).

Family health-focused communication behaviors. Family health-focused communication behaviors have similarly been used to study the relationships between behaviors and chronic disease outcomes (Chesla et al., 2004; Fisher et al., 2004; Rohrbaugh, Mehl, Shoham, Reilly, & Ewy, 2008). Some examples of health-focused communication behaviors in families that support the management of health include frequent discussions about health, ability to ask questions, emotional encouragement about the disease, and the use of plural pronouns ("we") when discussing the disease (Coyne et al., 2001; Longo et al., 2010; Rohrbaugh et al., 2008; Rosland et al., 2012). In a sample of heart failure patients, useful discussions about illness were specifically associated with higher survival expectations (Rohrbaugh et al., 2008).

Udlis (2011) identified the major behaviors of the family in health self-management to include behaviors of health-focused support and assistance. For example, a patient might use the family as a resource to gather information. In fact, one observed health-focused communication behavior is that those with low health literacy rely on family members as their preferred or sole source of health-related information (Longo et al., 2010).

Thus far in this literature review, general family communication behaviors and health-focused communication behaviors have been discussed as if they are mutually exclusive, when in reality, general family conversation is reliably associated with the frequency and influence of health-focused communication behaviors (Baiocchi-Wagner & Talley, 2013). Therefore, the more general communication there is in the family, the more health-focused communication there is also likely to be in the family, and in turn, the more influential that health-focused communication might be.

Sampling across Various Chronic Diseases

During the past decade, there has been a national initiative calling for better research and data on chronic disease and multiple chronic conditions (Ward et al., 2014). Although there has been a significant amount of research for specific diagnoses of chronic diseases (e.g., diabetes [Powers et al., 2017] or heart failure [Bennet et al., 2001]), the breadth of diagnoses and occurrence of multiple conditions in any single individual has created the need for more research and assessments that are capable of being used across samples (Fisher, 2006; Ward et al., 2014). To date, the majority of existing research has focused on cancer, particularly breast cancer, which leaves many chronic diseases understudied (Stanton et al., 2007). Throughout the literature, there is a vast amount of studies looking at singular chronic diseases.

Fisher (2006) claimed that the majority of studies focus on the general family communication characteristics that are linked to chronic disease management or family interventions with pediatric patients. Thus, Fisher (2006) called for future research to identify specific and prescriptive behaviors of family members to potentially improve chronic disease management of adults.

The attempt to build an instrument that is health-focused yet not specific to a disease is potentially problematic because of the wide variety of diseases, stages, and treatment plans. Despite the differences, a large body of research points to the consistent relationship between positive family social support and improved health outcomes, regardless of diagnosis (e.g., cancer, [Yoo et al., 2013], diabetes [Mayberry et al., 2016], heart failure [Bennett et al, 2001], kidney disease [Cohen et al., 2007]). For this reason, it might be possible to design a family health-focused support measure with utility across most chronic diseases that is not too narrowly tailored to any one population. The gap therein lies because measures only assess the key relational concepts of general communication behaviors as they relate to the well-being of the individual (Cyranowski et al., 2013), or they focus on specific communication behaviors related to only one disease (Batte et al., 2015; Bennett et al., 2001; Benson et al., 2016). To address this gap, it might be possible to have a measure that is health focused yet applicable to any, or multiple, chronic diseases (U.S. Department of Health and Human Services, 2016). The main focus of this study is to design an instrument that addresses the needs for the types of health-focused perceived social support and communication behaviors in the family for individuals with any chronic disease or multiple chronic diseases.

Instrument Design

Duncan (1984) defined measurement as the assignment of numerals to events with a defined set of rules, and more specifically, psychometric measurement is the assignment of numerals to any psychological or social phenomenon. When pursuing measurement of a social or psychological phenomenon, specific procedures are necessary to determine the strengths and weaknesses of the measurement (DeVellis, 2017). An instrument is an application of a specific set of rules to develop a measurement (Grove, Burns, & Gray, 2013). Instruments might include a specific set of rules for observations, interviews, questionnaires, or scales. Scales are a form of self-report that are more precise than questionnaires and are based on mathematical theory; scales that are most commonly used are rating scales, Likert scales, semantic differential scales, and visual analog scales

(Grove et al., 2013). A Likert scale is used to determine the opinion or attitude of the participant with a number of options after the statement provided and most often address agreement, evaluation, or frequency (Grove et al., 2013). Whether the Likert scale should provide a neutral option has been debated, and if the scale does not give participants a neutral or uncertain option, then it is called a forced-choice version (Grove et al., 2013). After the philosophical foundation for the scale is created, the purpose of the scale should be identified (Price, 2017). Scales might be designed for diagnosis, classification, selection, progress, or placement (Price, 2017). Because instruments are designed to measure what cannot be seen, the latent variable is what the researcher is trying to measure.

A latent variable is an underlying phenomenon that has two main features: first, the latent variable is not directly observable, and second, the construct is variable rather than always constant (DeVellis, 2017). To measure the latent variable, the variable must first be conceptualized and operationalized. The conceptual definition provides the theoretical meaning of the variable, and the operational definition outlines how the latent variable will be measured (Grove et al., 2013). The latent variable is expected to be the cause of any relationship between the variable and the items in the scale that reflects the items' scores (DeVellis, 2017).

Scale design. After the latent variable is defined, scale design can begin to reflect the concept as fully as possible (Grove et al., 2013). Ultimately, the scale should define the latent variable with content that is reflective of the construct for the intended population (Price, 2017). To create a scale that operationalizes the latent variable and conceptual definition, DeVellis (2017) recommends generating a pool that is 3 to 4 times larger than the final intended list of items. Interviews are a resourceful way to embed the attributes of the construct from individuals with experience in the subject being investigated (Price, 2017). After individuals are interviewed and the process continued until no new information is found, the content analysis applies a brainstorming session to generate categorical and item brainstorming (Price, 2017). With the collected information, items can then be generated with these guidelines in mind: (a) items should measure a single content, (b) items should measure a clearly defined process, (c) trivial information should be avoided, (d) items should not be distracting, (e) comprehension level should be considered, (f) statements should be under 20 words, (g) past tense should be avoided, and (h) statements that are likely to be endorsed by all participants should be avoided (Price, 2017).

Once the items are created, the test administration procedures need to be developed. These procedures might include time estimates and delivery platform (Price 2017). Factors that need to be considered include the age of target audience and fatigue of participants (Price, 2017). After the items and procedures are designed, it is important to have pilot test administrations to obtain the first set of statistical analyses and to receive feedback from the examinees after taking the instrument in actual conditions and circumstances (Price, 2017).

Reliability and validity. There are several classical measurement assumptions to take into consideration when designing a scale. First, the measurement model assumes an observed score is the result of the true score plus the error (DeVellis, 2017). Error varies randomly, does not correlate from one term to another, and will not correlate with the true score (DeVellis, 2017). When a scale is designed to measure a latent variable, it is important the scale demonstrates reliability and validity. Reliability is the level of consistency of the measure for the latent variable, any item, or any situation (Grove et al., 2013). By making sure that a scale is reliable, the measurement method has been designed to reduce random error as much as possible. Reliability testing assesses the level or error in the instrument as it relates to dependability, consistency, stability, precision, and reproducibility (Bartlett & Frost, 2008). Validity, on the other hand, is the evaluation of whether the scale actually reflects the variable it is intending to measure (Grove et al., 2013). Similar to reliability, there is no scale that will be completely valid, but instead, the scale is designed to increase the degree of such reliability and validity.

Two ways to measure a scale's reliability include internal consistency and test-retest reliability. Internal consistency is the assumption that all items should perform similarly if they accurately represent the latent variable. In a scale with many items measuring the latent variable, it is assumed that each item is as good at measuring the variable as all of the other items in the scale, which can be assessed with reliability testing. This specific type of reliability is called internal consistency. If the items have a strong relationship with the latent variable, then these items should also have a strong relationship with one another. Internal consistency is often measured with Cronbach's coefficient alpha (Cronbach, 1951). This coefficient is intended to make an assumption about the level of error in the instrument. Test-retest reliability is the consistency of scores if the same participant takes the instrument twice. For self-report tests, it is recommended that participants take the same measurement after two weeks have lapsed. The two measurement scores are correlated with a coefficient of stability (Grove et al., 2013).

To select the best items for the final version of the scale, item analysis and factor analysis allow for the detection of items that should be removed from the scale. Item analysis might reveal that an item needs to be removed because the item is too ambiguous, does not discriminate well, or does not correlate substantially with the collection of other items (Price, 2017). Different from item analysis, factor analysis is used to reveal how many latent variables underlie a set of items by grouping the items (DeVellis, 2017). Once the groups, or factors, are identified, the scale developer can decide if the latent concepts can be accounted for within a smaller number of items. Factor analysis takes one big category of items and assesses association of individual items and how many categories are sufficient to capture the bulk of the information related to the latent variable (DeVellis, 2017). Conceptually, factor analysis begins by extracting the first factor by examining the patterns of covariation with the correlations of all items, and if one category has not accounted for enough covariation among items, then it identifies a second concept that goes on to explain some more of the covariation and continues until there is a reasonably small amount of covariation not accounted for (DeVellis, 2017). The number of factors to be extracted can be debated, but ultimately a statistical criterion uses inferential methods to determine the likelihood that the results rule out chance occurrences (DeVellis, 2017). Another way to determine the number of factors uses a method of parsimony to develop the fewest, most influential factors, identifying the source of variation underlying a set of items (DeVellis, 2017). A scree test is based on the eigenvalues associated with the factors where an eigenvalue is the amount of information captured by a factor (DeVellis, 2017). Exploratory factor analysis (EFA) can be used in the early stages of instrument development, and confirmatory factor analysis (CFA) can be used to confirm the existing theory (Price, 2017).

Chapter Three: Phase One – Inventory Development and Item Generation

The review of related literature identified some of the connections between chronic disease and family, and it specifically illustrates that some families support and communicate in ways that correlate with better chronic disease management outcomes. Since identifying the need for an inventory that measures family health-focused perceived support and communication behaviors, a three-phase study was conducted. The first phase of this study included the development of items for family health-focused perceived support and communication behaviors. This chapter describes the rationale, research questions, and phases of development conducted to complete the initial inventory development and item generation followed by a summary of the results.

Rationale

The purpose of this phase of dissertation research was to create an Inventory of Family Health-Focused Perceived Support and Communication Behaviors. Based on the existing literature, the perceived items that convey family health-focused perceived support and communication behaviors to an individual might ultimately aid a patient with better physiological and psychological management of their chronic disease diagnosis. Creating a new measure aims to: (a) identify family health-focused perceived support and health-focused communication behaviors in the context of chronic disease and (b) build an instrument that can measure an individual's perception of his or her family support and health-focused communication behaviors that might support management of the patient's chronic disease(s). The creation of this instrument started with identifying what family perceived supports and health-focused communication behaviors families might exhibit if they participate in the management of the patient's chronic disease(s). Because there was no current instrument that captured both family health-focused perceived support and communication behaviors, this phase of the study captured the experiences of family support and communication behaviors from patients with chronic disease through in-depth interviews to create items that would represent such support and behaviors.

Research Questions

Based on the reviewed literature and need for items to capture experiences of individuals who have examples of family health-focused support and communication behaviors, the following research questions were explored:

> **RQ1:** What are family health-focused perceived supports and communication behaviors that chronic disease patients identify that might be included as items in the Family HF-PSCB?
>
> **RQ2:** Do items generated and compiled into the Family HF-PSCB show evidence of content validity through expert review?

Measure Development

The creation of a valid and unbiased measurement begins with rigorous design and analysis, and to begin this process, individual items must be generated. For item generation, the aim is to consider all potential items for inclusion in the questionnaire suggested by the research question(s) (Burns et al., 2008). One way to generate items is through in-depth interviews where respondents generate items until no new items emerge (Burns et al., 2008). To generate items for a measure relative to family health-focused perceived support and communication behaviors, such interviews were conducted with 12 individuals with at least one chronic condition. This specific sample was generated from a pool of individuals diagnosed with polycystic kidney disease. Some individuals had multiple conditions where they cited diagnoses of arthritis, cancer, depression, or polycystic ovarian disease. The following section describes the step-by-step process used to construct the items. After items were generated, the items were reviewed by expert content reviewers to test all items' content validity with content validity indexes (CVI).

Part one. In-depth interviews were conducted with 12 chronic kidney disease patients to obtain natural language relative to their families' health-focused perceived support and health-focused communication behaviors (Rowan & Wulff, 2007). Twelve individuals, a convenience sample from within a larger study that required patients to be at least 18 years old and diagnosed with a chronic kidney condition called polycystic kidney disease, were recruited. The interviews were conducted with individuals who received a kidney transplant; therefore, all participants had progressed through all stages of chronic kidney disease including kidney failure, which is a requirement to be eligible for transplantation (National Kidney Foundation, 2017).

Participants were contacted by email with a recruitment template (see Appendix A). Emails were sent to 21 individuals, 14 individuals returned a response, and 12 consented to participate in the interview. Because of the various geographic locations of participants, all but one of the interviews were conducted by telephone. After arranging a mutually agreeable time for the interview, participants were provided the institutional review board study information sheet as an email attachment to read in advance (see Appendix B). Participants were between the ages of 34-76 (M_{age} = 59.8, SD = 11.9), were all White-Caucasian, and an equal number of males and females.

The interviewer contacted each participant at the arranged day and time and began the conversation by confirming the interviewee had received the study information sheet and had agreed to participate in the study. The interviewer used a semi-structured interview guide (see Appendix C) to ask about the participants' experience with chronic disease, how communication occurred within his or her family about chronic disease, and ways in which the family may or may not have supported the individual with his or her chronic disease management. After the interviews were completed, all interviews were transcribed and reviewed for accuracy.

To address RQ1 as it relates to item generation, the researcher reviewed all transcripts and coded language from participants who expressed a direct or indirect action of family member(s) that was health-focused communication or family support related to the management of the individual's chronic care or overall health. Guided by the literature review, the transcripts were reviewed for forms of family health-focused support that might be emotional, instrumental, or informational support or health-focused communication behaviors. These examples were used to create statements that reflected a single description of a perceived family health-focused support or a communication behavior.

By generating items in this manner, the natural language of individuals with firsthand experience guided the creation of a pool of items until no new items emerged (DeVellis, 2017). Ninety-one items were created from the participants' language representing family health-focused perceived support and communication behaviors.

Part two. After 91 items were created, the items were assembled into a document for content validity review by a panel of experts (see Appendix D). Content validity is the determination of the content representativeness or relevance of the items to the measure (Lynn, 1986). One way to evaluate the content validity of a newly created measure is through a content validity process where both the items and the scale are evaluated by a panel of experts (Rubio, Berg-Weger, Tebb, Lee, & Rauch, 2003). Six expert content reviewers were contacted and agreed to review the items. The experts have education and experience in the following areas: two Master's prepared communication reviewers, two Master's prepared nurse reviewers, one Master's prepared social worker reviewer, and one licensed family medicine doctor reviewer.

Each reviewer received a cover letter with directions (see Appendix E) and the document including the review items. The document with the items for review included the definitions of family support and health-focused communication behaviors, an explanation of the 4-point rating scale for the relevance of each item (1= not relevant, 2 = unable to assess relevance without revision, 3 = relevant but needs minor revision, 4 = very relevant), and a space for comments under each item. All six expert reviewers completed the document and returned the survey.

To analyze data as it related to content validity, each reviewer's response on each item was dichotomized by combining values of one/two and values of three/four to represent disagreement versus agreement for each reviewer's evaluation of each item (Lynn, 1986). To evaluate each item independently, a content validity index for each item (I-CVI) was obtained by counting the number of items that experts rated three/four and calculating the proportion of agreement among the experts (Lynn, 1986; Rubio et al., 2003; Zamanzadeh et al., 2015). Following the recommendation of Polit and Beck (2006), judgments on items were made as follows: if the I-CVI is at least .83, the item was considered relevant to the content; if it is less than .83, it was eliminated. I-CVI scores ranged from .5 to 1.00. Of the 91 items, 87 items had an I-CVI greater than .83 (see Appendix F).

To assess the scale content validity, a scale content validity index average (S-CVI/Ave) was computed by averaging all I-CVIs of the remaining 87 items. To represent an acceptable scale content validity level, S-CVI/Ave with six expert reviewers should be .83 or higher (Polit, Beck, & Owen, 2007). The S-CVI/Ave for all items was .96 reflecting an acceptable S-CVI/Ave beyond the .83 threshold.

Additionally, based on the recommendations provided by the reviewers (see Appendix G), four reverse-coded items were removed and one item was removed for not being relevant to family support or communication behavior. Slight modifications were made to reflect the perceived nature of family support and to ensure consistency in item format. See Appendix H for the revised list of 84 items.

Summary

The aims of this phase generated items for an inventory and assessed content validity for the Inventory of Family Health-Focused Perceived Support and Communication Behaviors with chronic disease patients. The interview process allowed for the natural language of family health-focused perceived support and health-focused communication behaviors to emerge in 91 items from chronic kidney disease patients, and the content validity process provided direction for the reduction and revision of the measure to 84 items. Considerations of actual family support or enacted behaviors is outside of the development of the instrument.

The expert review process provides a means for considering multiple voices from various disciplines to review the newly created items with consideration for content accuracy, but it should be noted that the review process is a subjective process that is subject to bias among the involved individuals (Burns et al., 2008). At this stage of evaluation, the expert reviewers might have been used for an even greater reduction of items to decrease the overall size of the scale. After expert review, the measure consisted of 84 items, which is still too large to be helpful for clinical use or to ensure positive completion rates. Questionnaires with more than 25 items are less likely to be completed (Burns et al., 2008). Future stages of this research and analyses aimed to reduce the number of items.

Based on the review of the literature, in-depth interviews, and expert review, the first iteration of the Inventory of Family Health-Focused Perceived Support and Communication Behaviors with chronic disease patients was created. The 84 items (Appendix H) were then tested in pilot testing using a set of cognitive interviews to improve questionnaire design and a group of test-retest participants to assess reliability.

Chapter Four: Phase Two – Pilot Testing

After the items for the Inventory of Family Health-Focused Perceived Support and Communication Behaviors were created in Phase One, the instrument was developed with the online survey software Qualtrics. The online survey was created to provide participants with a web link to the survey that could easily be delivered by email or social media. The Qualtrics survey started with an opening page that included the university's institutional review board study information sheet where the participants selected "Continue" or "Do not continue" as a means of consenting or not consenting to participate in the research. Initial questions required participants to indicate they were 18 years or older and to specify which chronic disease(s) were relevant to their condition(s). If a participant indicated they were under 18 years of age or did not have a chronic disease, he or she was directed to a concluding page that thanked them for submitting a response. For participants who did indicate at least one chronic disease diagnosis, they continued to answer the 84 items generated in phase one. Each item had instructions stating, "In this section, we are interested in finding out if you believe you could communicate or get support from any family member related to your health matters. Please answer as honestly as possible." Each item included five Likert-type answers to choose from (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, and 5 = strongly agree) (see Appendix L).

In addition to the 84 items, demographic data was collected with 11 self-report questions. These data items include age, gender, marital status, number of living parents, number of living siblings, number of living children, highest level of education, race, ethnicity, employment status, and how the participant learned about the survey.

With the development of the survey in Qualtrics completed, pilot testing was conducted to improve questionnaire design and to estimate test-retest reliability. This chapter details the rationale, research questions, improvement to questionnaire design, and test-retest reliability of the pilot testing.

Rationale

As first steps of psychometric testing with the Family HF-PSCB, two phases of pilot testing occurred to test the usability by participants: (a) through cognitive interviewing and (b) through test-retest reliability. The first step of the pretesting aimed to ensure potential participants could access, complete, and progress through the instrument. The feedback from participants was revealed through a process called cognitive interviewing. Cognitive interviewing is conducted between the initial drafting of a questionnaire and administration in the larger field (Willis, 2005). Cognitive interviewing is an iterative process where the testing, review, and modification of the instrument should progress through a modest sample size of 5-15 individuals (Willis, 2005). Cognitive interviewing aims to reduce sources of error in self-report surveys and improve the overall reliability and validity of the measure.

Cognitive interviewing is one way to improve reliability, and test-retest reliability is another evaluation to demonstrate whether an item provides consistent information when repeated under similar conditions. The reliability of a measure can be described as the proportion of the true score variance to the total score variance (Yen & Lo, 2002), and test-retest reliability provides a measure of temporal stability where scores remain constant from one testing time to another (DeVellis, 2017). Test-retest reliability is often reported as an indication that if the measure accurately reflects the construct it intends to measure, the measure should assess that construct comparably on separate occasions, assuming there is no real change in the construct over the time between testings (DeVellis, 2017).

Because questionnaire improvement and the test-retest reliability require adjustments to the measure before administration to a larger sample, these two tests were conducted in a pretest phase of this research where the methods and results are reported in the following sections.

Research Questions

Based on the reviewed literature and rationale for this pilot testing phase of the study, the following research questions were explored:

> **RQ3:** What are barriers that participants encounter when completing the Family HF-PSCB that can be edited or altered to improve the questionnaire experience for future participants?
>
> **RQ4:** Which items of the Family HF-PSCB do not have significant test-retest reliability and should therefore be removed from the measure?

Improving Questionnaire Design

The cognitive interviewing process used volunteer participants to identify problems and limitations with the questionnaire design. For this phase of pretesting, 10 chronic disease participants were recruited to take the Family HF-PSCB via the online software. All participants were recruited by email or social media private message (see Appendix I), and to be eligible to participate, individuals were required to have a chronic disease, have the ability to read and write in English, and be 18 years or older. If the participant indicated a willingness to participate, then a day and time was arranged and a confirmation email was provided (see Appendix J). At the arranged time and day, the researcher used a script (see Appendix K) and called the participant at the telephone number provided by the participant. During the telephone interview, the participant took the survey at the location of his or her choice with an electronic device of his or her choice. This method of conducting the cognitive interview by phone was selected to simulate future participants that would take the survey independently without the researcher in the room. Participants were encouraged to provide observations and questions through the phone conversation, and prior to the conclusion of the call, the researcher asked if there were any further questions or problems that had not yet been noted.

The cognitive interview participants (N = 10; 5 males, 5 females; M_{age} = 47.2, SD = 17.2*;* range 33-77 years) had varying diagnoses of asthma, bronchiectasis, cancer, Type I diabetes, hypertension, hyperthyroidism, hypothyroidism, osteoarthritis, and rheumatoid arthritis. The average number of minutes to take the survey was 13.2 minutes (range 1-55 minutes). Participants provided 10 comments resulting in suggestions for five modifications to the questionnaire design (see Table 1). Most suggested changes were made to the Qualtrics survey immediately following the conclusion of the call as part of the iterative cognitive testing process. The only comments not acted upon were made about the significant repetition of items, where participants were told that the number of items would be reduced in future stages of research.

Because multiple participants suggested the need to have an understanding of what should be included as family, an additional page was added in Qualtrics after the initial intake questions but before the 84-generated items, where the survey instructed participants with the following lead-in instructions:

> “In the next several sections, you will be asked questions about your family. In this study, we define family as a group of individuals with continuing legal, genetic, and/or emotional relationships. With this definition, please take a moment to consider who you include in your family. You can consider nuclear family, extended family, blended family, or self-proclaimed family, as long as they are a part of the group of individuals with which you have continuing legal, genetic, or emotional relationships. With these people in mind, we would ask you to continue this survey and answer the upcoming questions about family.”

Table 1

Comments from Cognitive Interviews and Suggested Modifications

Comment from Participants	Modification to Instrument
Unable to select more than one chronic disease	Adapt settings to allow more than one chronic disease to be selected
Unsure what should be considered family (3)	Include definition of family
Font is hard to read	Change font color to black and increase size of font in matrix questions
Unable to understand different types of diabetes listed as possible chronic diseases	Change *Diabetes Mellitus* to two separate options reading *Type 1 diabetes* and *Type 2 diabetes*
A lot of repetition of items (3)	No modification made: future phases of research will reduce number of items
Some of the last items would have been helpful near the beginning to help me put into context how I think about family	Suggested items were moved closer to the beginning of the list of items

Note. The number in parentheses indicates the number of times the comment reoccurred.

The analysis of barriers were edited or altered to improve the questionnaire experience for the participants according to the minor issues related to question settings, some modifications to font size and color, ordering of items, and the inclusion of a description of what should be included as family while answering questions (see Appendix L). The next phase of pilot testing estimated the test-retest reliability of the items with a slightly larger sample of participants.

Test-Retest Reliability

Prior to recruiting a larger sample of chronic disease patients for the validity and factor analysis testing of the Family HF-PSCB, test-retest reliability was evaluated for the 84 items. Per the suggestion of DeVellis (2017), test-retest reliability is typically the method used to demonstrate temporal stability of how constant scores remain from one occasion to another. This pilot test measured the test-retest reliability through the examination of the differences of means for each item in paired samples and the proportional correlation between the items at two time points.

Method. Participants were recruited with a non-random convenience sample where the researcher recruited individuals via private messaging on the social media platform Facebook (see Appendix M). Thirty-six (36) private messages were sent, and 24 individuals confirmed their willingness to participate and that they met the conditions of being 18 years or older and having a chronic disease diagnosis. The private message requested these participants send an email address to receive the directions for the study. With Qualtrics, an email was generated to send directions, the web link to the survey, and a reminder to any unfinished respondents three days following the initial email (see Appendix N). The opening page of the survey included the university’s institutional review board study information sheet where the participants selected “Continue” or “Do not continue” as a means of consenting or not consenting to participate in the research (see Appendix L). Twenty-three (23) participants finished the survey at time one (*N* = 23; 7 males, 16 females; M_{age} = 49.0, *SD* = 16.5*;* range 24-87 years).

Approximately two weeks following the initial distribution of the survey, a new email was generated to the participants. Participants were once again sent directions by email, a new web link to the survey with automated reminders generated for any unfinished respondents prior to the deadline for submitting the survey for the second time (see Appendix O). Of the initial 23 respondents that completed the survey at time one, 22 respondents (Table 2) with a variety of diagnoses (Table 3) finished the survey at time two (*n* = 22; 7 males, 15 females; M_{age} = 49.2, *SD* = 16.9*;* range 2-87 years).

Table 2

Participant Characteristics for Test-Retest Pilot Testing

	N	%
Gender (*n* = 22)		
Male	7	31.8%
Female	15	68.2%
Race (*n* = 22)		
White	22	100%
Ethnicity (*n* = 20)	20	
Not Hispanic or Latino		100%
Marital Status (*n* = 22)		
Married	22	100%
Highest Level of Education (*n* = 22)		
HS/GED	2	9.1%
Some college	2	9.1%
2-year degree	2	9.1%
4-year degree	9	40.9%
Master’s degree	5	22.7%
Doctoral degree	2	9.1%
Current Employment Status (*n* = 22)		
Full Time Employment	10	45.5%

Part Time Employment	3	13.6%
Self Employed	1	4.5%
Homemaker	2	9.1%
Retired	6	27.3%

Table 3

Chronic Diseases Indicated by Test-Retest Participants

Chronic Disease	*N*
Addison’s disease	1
Asthma	4
Cancer Breast Melanoma Prostate Skin	4
Cardiac failure	2
Chronic obstructive pulmonary disorder	1
Crohn’s disease	1
Diabetes mellitus Type I	2
Diabetes mellitus Type 2	2
Hypertension	6
Hyperthyroidism	1
Hypothyroidism	6
Lupus	1
Multiple sclerosis	1
Osteoarthritis	2
Parkinson’s disease	1
Rheumatoid arthritis	1
Other Interstitial cystitis (2) Mixed connective tissue disorder (1)	3

Note. Participants could indicated more than one disease.

Analysis. To evaluate the test-retest reliability of the items in the Family HF-PSCB with a sample of chronic disease patients, individual responses to the 84 items and their means were compared from the first administration to the second administration of the survey. The statistical software SPSS 25 was used to tabulate the results.

A Pearson product moment correlation was used to calculate the test-retest reliability coefficient. For this Pearson correlation, significantly correlated items would have a significance of $p \geq .05$. If an item did not have significantly correlated responses from Time 1 to Time 2, the item was considered unreliable and removed.

In addition to the Pearson product moment correlation, paired-sample t-tests were used to compare the means of each item for time 1 and time 2. Paired sample t-tests of test-retest reliability should not have significant differences between time 1 and time 2, where a significant difference is again $p \leq .05$. If an item does have significantly different means based on the t-test from Time 1 to Time 2, the item was considered unreliable and removed.

Results. Results from analyses revealed acceptable test-retest reliability for 72 items from the 84 items generated for the Family HF-PSCB with this sample of chronic disease patients. There were no paired sample t-tests with significant differences, and therefore, no items were removed based on the paired sample t-tests. Correlation coefficients using Pearson product moment correlations should correlate in the same direction; and therefore, if there is not a significant difference ($p \leq .05$), then there is not a significant correlation across time. Correlation coefficients ranged from .23 to .96 (median $r = .60$) where there were 12 items with Pearson product moment correlations without a significant difference (Table 4). Therefore, those items did not meet this particular test of test-retest reliability and were removed.

Summary

In sum, the pilot testing for the Family HF-PSCB with chronic disease patients generated a survey that has been tested both to improve questionnaire design through cognitive interviewing and for test-retest reliability. The sample characteristics of the test-retest population revealed a predominately female, all white/Caucasian, and completely married population. The final number of items in the Family HF-PSCB with chronic disease patients was reduced to at 72. Factor analysis would be conducted next in an attempt to reduce the overall number of items for the progression to a measure with a manageable number of items.

Table 4

Pearson Correlation and T-Tests for Test-Retest Pilot Study

		Paired Sample T-Test		
Item	Pearson correlation	T1 Mean	T2 Mean	*SD*
I have at least one family member that discusses health matters at family gatherings.	.81*	4.36	4.50	*.10*
I have someone I could partner with in my family regarding health concerns.	.78*	4.55	4.68	.10
I could converse with someone in my family about my health.**	.37	4.73	4.68	.12
I have someone in my family I could to talk to about what to do with health problems.	.67*	4.71	4.67	.08
If I had children, I could share my health information with them.**	.27	4.55	4.36	.17
My family could approach my health concerns as a team.	.72*	4.33	4.33	.15
If needed, someone in my family could help me take my pulse (count my heart rate).**	.30	4.73	4.73	.11
If needed, someone in my family could help me take my blood pressure.**	.38	4.73	4.64	.15
If needed, someone in my family could help me take my temperature.	.50*	4.82	4.73	.09
If needed, someone in my family could take action when I have health problems.	.58*	4.77	4.82	.08
My family could be a team when it comes to my health issues.	.75*	4.59	4.50	.11
My family could be considerate of my health issues.**	.41	4.68	4.59	.11
My family could talk about their health experiences.	.81*	4.55	4.55	.06
Someone in my family could help me manage my diet, if needed.	.77*	4.27	4.32	.10
Someone in my family could help me plan for my nutritional needs.	.80*	4.18	4.23	.10
Someone in my family could help me research health concerns.	.55*	4.59	4.50	.11
Someone in my family could help me solve health problems.	.51*	4.18	4.36	.16
Someone in my family could help me complete health-related paperwork.	.55*	4.50	4.55	.10
Someone in my family could provide assistance in maintaining my diet.	.47*	4.32	4.36	.14
Someone in my family could provide me emotional support when I deal with health issues.	.77*	4.64	4.59	.08
Someone in my family could reassure me about my prognosis.	.65*	4.64	4.50	.10
Someone in my family could review medical documents with me.	.52*	4.73	4.59	.12
Someone in my family could share health resources with me.	.49*	4.59	4.45	.14
Someone in my family could share information about family health history.	.48*	4.57	4.43	.14
Someone in my family could share what works for them related to their health problems.	.44*	4.41	4.41	.16
I could ask a family member about my health problems.	.67*	4.50	4.55	.10
I could ask a family member about how I might deal with my health problems.	.60*	4.41	4.55	.14
I could ask a family member questions related to my health.	.63*	4.55	4.55	.09

I could communicate with someone in my family about my health.**	.32	4.59	4.73	.12
I could dialogue with someone in my family about health-related issues.	.49*	4.64	4.50	.12
I could talk to someone in my family that works as a health professional.	.96*	3.86	4.00	.08
I could discuss health matters with someone in my family at family gatherings.	.71*	4.45	4.50	.10
I could discuss my health matters with someone in my family on the phone.	.82*	4.55	4.55	.07
I could discuss treatment options with someone in my family that might not have been brought up by my doctor.	.61*	4.32	4.41	.15
If I had medications, I could discuss my medications with someone in my family.	.72*	4.32	4.45	.14
I could discuss what my doctor says with someone in my family.	.62*	4.68	4.59	.09
I could explain my health issues to family members.	.70*	4.55	4.55	.09
I could gain knowledge about health concerns from my family.	.80*	4.27	4.14	.10
I could get a lot of support from someone in my family for my health issues.**	.23	4.55	4.55	.15
I could have an ongoing discussion about health with someone in my family.	.67*	4.45	4.50	.10
I could have communication with someone in my family about my health.	.71*	4.64	4.59	.08
I could learn good health habits from others in my family.	.64*	3.86	4.05	.14
I could name a go-to person in my family for health matters.	.61*	4.43	4.57	.14
I could name someone in my family that I consider to be the medical information person.	.68*	4.00	4.14	.17
I could name someone in my family who is on “my side” with health concerns.	.62*	4.59	4.59	.09
I could relate health matters to someone in my family.	.60*	4.41	4.41	.15
I could share knowledge about health concerns with someone in my family.	.54*	4.59	4.55	.10
If I had medications, I could tell a family member where to find my medications in case of an emergency.	.60*	4.64	4.73	.09
I could talk to someone in my family that works as a health professional.	.92*	4.05	4.00	.10
I could telephone someone in my family about health matters.	.64*	4.59	4.41	.10
Someone in my family could recommend a physician for me.	.73*	4.09	4.14	.15
Someone in my family could be attentive when I am ill.**	.36	4.68	4.55	.12
Someone in my family could advocate for my health.	.62*	4.64	4.41	.11
Someone in my family could ask me questions about my health.	.55*	4.55	4.50	.10
Someone in my family could assist with housework when I have health issues.	.79*	4.45	4.45	.11
Someone in my family could attend a health appointment with me.**	.37	4.68	4.68	.13
Someone in my family could be actively involved in my health.	.45*	4.59	4.59	.12
Someone in my family could be hands-on with my health.	.76*	4.55	4.41	.10
Someone in my family could be there when I have health problems.	.50*	4.68	4.64	.11
Someone in my family could care for me after a medical procedure.**	.39	4.73	4.64	.11
Someone in my family could collaborate on my health issues when needed.	.45*	4.64	4.55	.14
Someone in my family could come and stay with me if I have a major health situation.	.56*	4.64	4.45	.16
Someone in my family could come to me with health questions.	.44*	4.59	4.41	.10

Someone in my family could cook for me if I was ill.	.82*	4.52	4.52	.09
Someone in my family could drive me to a health appointment.	.60*	4.64	4.73	.09
Someone in my family could emotionally support me if I have health issues.	.64*	4.64	4.55	.10
Someone in my family could encourage me to schedule appointments.	.83*	4.55	4.55	.09
Someone in my family could go to a doctor’s appointment with me.	.50*	4.64	4.68	.10
Someone in my family could help me be proactive about my health.	.83*	4.55	4.45	.09
Someone in my family could help me emotionally when I have health issues.	.55*	4.68	4.55	.10
Someone in my family could help me fact-check medical information I receive.**	.27	4.59	4.50	.17
Someone in my family could help me feel less anxious about my health condition.	.66*	4.55	4.45	.11
Someone in my family could help me gather information about my health.	.54*	4.64	4.55	.11
Someone in my family could stay involved in my health.	.60*	4.55	4.45	.13
Someone in my family could talk to my doctor with me.	.57*	4.73	4.55	.11
Someone in my family could telephone me about health-related issues.**	.37	4.59	4.59	.13
Someone in my family could visit me if I have health issues.	.46*	4.73	4.68	.10
Someone in my family could visit me if I was hospitalized.	.64*	4.77	4.73	.08
Someone in my family could volunteer to go with me if I needed to go to the doctor.	.60*	4.68	4.64	.10
Someone in my family could encourage me to be physically active.	.49*	4.59	4.50	.15
Someone in my family could worry about my health concerns.	.52*	4.68	4.59	.11
Someone in my family could be good at medical research and could help me if needed.	.47*	4.50	4.36	.17
Someone in my family could share what does not work for them related to their health problems.	.55*	4.41	4.50	.15
Health could be a natural topic of conversation in my family.	.72*	4.23	4.32	.15

Note. No items had significant difference of means in paired samples t-tests.*$p \leq .05$. **Indicates item removed.

Chapter Five: Phase Three – Exploratory Factorial Analysis & Validity Testing

After the test-retest reliability was examined, the instrument reflects only the remaining reliable 72 items in Qualtrics. In phase three, an extended online survey (see Appendix P) was provided to a larger sample of individuals with chronic diseases which included the 72 items from phase two, 11 demographic items, and with permission, two additional published instruments to evaluate the convergent validity with the General Functioning Scale (GFS) of the McMaster Family Assessment Device (Ryan et al., 2005) (see Appendix Q) and the Perceived Social Support Family Scale (PSS-Fa) (Procidano, 1992; Procidano & Heller, 1983) (see Appendix R). After first discussing the rationale and research questions for this phase, this chapter explains the exploratory factorial analysis and convergent validity testing conducted with the Family HF-PSCB.

Rationale

To reduce the number of items and explore factors in the Family HF-PSCB, exploratory factor analysis was conducted. Two primary reasons to conduct an exploratory factor analysis are to determine (a) how many variables underlie a set of items and (b) to condense the amount of information in the set of items to a smaller number (DeVellis, 2017). These two objectives are particularly important in a study where a significantly large number of items were created through interviews like in phase one. The factorial analysis in this phase is exploratory, rather than confirmatory, because although item creation was guided by definitions of perceived support and communication behaviors, items were not specifically constructed to match variables or constructs. For this reason, exploratory factor analysis was the appropriate analysis to understand the possible factors in the items generated from phase one and persisted through phase two. Exploratory factor analyses are important for new scales to understand the factorial structure within a scale (Yong & Pearce, 2013), like the new inventory created in this study. As a benefit, exploratory factor analysis reduces items that have variable loadings on multiple factors, and therefore, the items remaining are clear indicators of the dominant factors.

The second part of this phase of research evaluated convergent validity of the Family HF-PSCB. While test-retest reliability in phase two measured the likelihood that the same participant will answer the items on the scale in similar ways across time and the exploratory factor analysis in phase three looks for underlying constructs in the scale, convergent validity tests establish that the Family HF-PSCB measures what it is intended to measure. To demonstrate convergent validity, the new instrument should positively correlate with previously validated scales that measure similar constructs (DeVellis, 2017). For convergent validity testing, the General Functioning Scale (Ryan et al., 2005) and the Perceived Social Support-Family Scale (Procidano, 1992; Procidano & Heller, 1983) from the literature review were tested and compared to the scores of the Family HF-PSCB.

Research Question & Hypotheses

Based on the rationale for this exploratory factorial analysis and convergent validity testing phase of the study, the following research question and hypotheses were explored:

RQ5: Which items reliably create a factorial structure in the Family HF-PSCB?

H1: The Family HF-PSCB positively correlates with the General Functioning Scale.

H2: The Family HF-PSCB positively correlates with the Perceived Social Support-Family Scale.

Method

Participants. In phase three, a new group of individuals with at least one chronic disease participated (*N* = 282; 176 females, 26 males, 3 other, and 2 preferred not to say; M_{age} = 45.9, *SD* = 15.4*;* range 18-82 years). Participants reported a variety of diagnoses, with 69 different diagnoses indicated (see Table 5). The top five diagnoses represented were hypertension (12.8%), hypothyroidism (10.4%), asthma (9.8%), cancer (8.1%), and osteoarthritis (6.4%). Participants who persisted through the end of the survey and completed all demographic questions, were largely White (*n* = 192), with others identifying as other (*n* = 5), American Indian or Alaskan Native (*n* = 2), Black or African American (*n* = 1), and 6 preferred not to answer. Participants largely identified as Not Hispanic or Latino (*n* = 196) with two participants identifying as Hispanic or Latino and five preferred not to answer.

Table 5

Chronic Diseases Indicated by Phase Three Participants

Chronic Disease		*N*
Hypertension		68
Hypothyroidism		55
Asthma		52
Cancer		43
Basal cell	2	
Bladder	2	
Brain	1	
Breast	12	

Cervical	3	
Clear Cell	1	
Colon	1	
Gastric	1	
Hodgkin’s	2	
Kidney	2	
Lung	1	
Melanoma	2	
Non Hodgkin lymphoma	2	
Ocular	1	
Ovarian	1	
Prostate	2	
Skin	4	
Thyroid	2	
Uterine	1	
Osteoarthritis		34
Diabetes mellitus Type 2		33
Rheumatoid arthritis		21
Fibromyalgia		16
Crohn's disease		15
Diabetes mellitus Type 1		15
Bipolar Mood Disorder		12
Chronic obstructive pulmonary disorder		10
Lupus		10
Hyperlipidemia		8
Multiple sclerosis		8
Dysrhythmias		7
Irritable bowel disease		7
Lyme's disease		7
Endometriosis		6
Hyperthyroidism		6
Poly cystic Ovarian syndrome		6
Ulcerative colitis		6
Chronic Migraines		5
Depression		5
Epilepsy		5
Cardiac failure		4
Glaucoma		4
Psoriatic arthritis		4
Ankylosing spondylitis		3
Cardiomyopathy		3
Chronic renal disease		3
Ehlers-Danlos Syndrome		3

Celiac disease	2
Chronic Fatigue Syndrome	2
Hemophilia	2
Post-Traumatic Stress Disorder	2
Postural Orthostatic Tachycardia Syndrome	2
Psoriasis	2
Raynaud's Syndrome	2
Sjogrens syndrome	2
Spinal stenosis	2
Addison's disease	1
Borderline Personality Disorder	1
Charcot Marie Tooth Disease	1
Chiari Malformation Type 1	1
Chronic Active Epstein Barr	1
Collagenous colitis	1
Congenital Adrenal Hyperplasia	1
Coronary artery disease	1
Cyclic vomiting syndrome	1
Dermatomycosis’s	1
Dysautonomia	1
Endomyocardial fibrosis	1
Epidermolysis Bullosa	1
Grave's Disease	1
Hepatitis C	1
Huntington's Disease	1
Hyperprolactinemia	1
Idiopathic hypersomnia	1
Idiopathic neuropathy	1
Indeterminate colitis	1
Meniere's disease	1
Myasthenia Gravis	1
Myofascial pain syndrome	1
Parkinson's disease	1
Post-Concussion Syndrome	1
Primary biliary cirrhosis	1
Primary sclerosing cholangitis	1
Sarcoidosis	1
Total	530

Note. Participants could indicate more than one disease.

Procedure. Participants were recruited in two ways. Study information with a link to the web-based survey (see Appendix S) was posted on personal and organizational Facebook and Twitter social media site pages, such as the Osteo/Rheumatoid Arthritis Group, Fibromyalgia Support Group, Chronic Conditions Support Group, Lyme Disease Support, and Heart Disease and Condition Awareness and Support.

Once clicking on the survey link from the social media site or email, participants read an IRB-approved study information sheet on the opening page (see Appendix P) and clicked "Continue" to indicate their consent. To ensure only eligible participants continued, demographic questions about age and chronic disease diagnosis were asked at the start of the survey. If participants answered “no” to having a chronic disease or reported being under the age of 18, they were directed to a "thank you" page which indicated the conclusion of the survey.

For participants who indicated they had at least one chronic disease diagnosis and were 18 years or older, they began the survey. This included the 72 items that had good reliability and validity from phase two, the GFS, the PSS-Fa, 11 demographic items (i.e., age, gender, marital status, number of living parents, number of living siblings, number of living children, highest level of education, race, ethnicity, employment status), and how the participant learned about the survey. At the conclusion of the survey, participants were provided a “thank you” page that indicated the conclusion of the survey (see Appendix P).

Analysis. To answer research question 5, exploratory factor analysis was used. Using the statistical software SPSS 25, assumptions were tested with the Kaiser-Meyer-Olkin Measure of Sampling Adequacy and Bartlett’s Test of Sphericity. Once analysis confirmed sampling adequacy and normality of data, principal axis factorial analysis with Varimax rotation was used. McCroskey and Young's (1979) guidelines were followed to ensure factors had an Eigenvalue of at least 1.0 and accounted for at least 5% of the variance. Additionally, items in the exploratory factor analysis had to have had a loading of .60 on one factor but less than .40 on any other factor to prevent cross loading. Items that did not meet the criteria were removed until remaining items did not cross load and the existing factors met the Eigenvalue criteria listed. This process allowed the identification and elimination of items that either: (a) did not fit any of the factorially derived categories or (b) fit too many of the derived categories to function properly (DeVellis, 2017).

Once the final number of items and factors were determined, the final scoring method of the Family HF-PSCB measure was determined. The scale was scored as the overall mean of the included items. There were no reverse-coded items.

To determine whether the new inventory measures what it is designed to measure, concurrent validity tests were conducted. In the statistical software SPSS 25, computed scores were created for both the GFS and the PSS-Fa. The mean score of the Family HF-PSCB was analyzed with a Pearson correlation analysis in relationship to the computed GFS and PSS-Fa variables. The scales would be considered convergent if the correlation was significant, where $p < .05$.

Results

Exploratory factor analysis. Research question five investigated the factorial structure of the inventory. With the 72 items, a Kaiser-Meyer-Olkin Measure of Sampling

Adequacy indicated adequate sampling (KMO = .96) where .90 is exceptional (Kaiser, 1974). Bartlett's Test of Sphericity was significant (χ^2 (209) = 5947.68, $p < .001$).

Given these indicators, factorial analysis was deemed suitable and the process proceeded for a total of five stages of factorial analysis (see Table 6).

Table 6

Stages of Exploratory Factor Analysis Reporting Number of Items in Stage of Analysis with Items Cross-loading and Number of Factors

	Number of Items			Number of Factors with Eigenvalue >1.0
	In Analysis	Not meeting 60/40 criteria	Meeting 60/40 criteria	
Stage 1	72	43	29	6
Stage 2	29	6	23	4
Stage 3	23	8	15	2
Stage 4	15	2	13	2
Stage 5	13	0	13	2

In stage 1, there were 72 items, but 43 items cross-loaded by loading on more than one factor. There were 6 factors in stage 1. In stage 2, the 29 items that did not cross-load were used in a new exploratory factor analysis where 6 items cross-loaded with 4 factors. Therefore, in stage 3, there were 23 items used in a new exploratory factor analysis, where 8 items cross-loaded with 2 factors. The 8 items were removed, and a new exploratory factor analysis was created with the remaining 15 items. In stage 5, the principal axis factoring of 13 items emerged using Varimax rotation with two factors explaining 72.17% of the variance. All items in this analysis had loadings at or above .60, where no items had cross-loadings above .40. Factor 1 had an Eigenvalue of 8.21 explaining 63.20% of the variance, and Factor 2 had an Eigenvalue of 1.69 explaining 12.97% of the variance. The factor loading matrix for this final solution is presented in Table 7. The 13-item scale produced a high internal reliability with a Cronbach's alpha of .95.

Table 7

Factor Loading Based on Principal Axis Factoring with Varimax Rotation for 13 Items (n = 209)

	Mean	Std. Deviation	Factor 1	Factor 2
I could ask a family member about my health problems.	3.91	1.09	.84*	
I could ask a family member about how I might deal with my health problems.	3.89	1.10	.84*	
I could ask a family member questions related to my health.	3.87	1.12	.84*	
I could discuss what my doctor says with someone in my family.	4.26	.84	.80*	.38
I could dialogue with someone in my family about health-related issues.	4.11	.97	.78*	.30
I would discuss treatment options with someone in my family that might not have been brought up by my doctor.	3.74	1.20	.75*	
I could discuss my health matters with someone in my family on the phone.	4.15	.91	.74*	.34
Someone in my family could share what works for them related to their health problems.	3.90	1.11	.60*	.31
Someone in my family could cook for me if I was ill.	3.95	1.20	.31	.87*
Someone in my family could drive me to a health appointment.	4.09	1.05		.83*
Someone in my family could assist with housework when I have health issues.	3.80	1.24	.34	.80*
Someone in my family could volunteer to go with me if I need to go to the doctor.	4.03	1.12	.34	.80*
Someone in my family could come and stay with me if I have a major health situation.	3.95	1.23	.34	.74*

*Loading greater than or equal to .60

Convergent Validity. To score the Family HF-PSCB scale by individual, the scores from the items were averaged (n = 256, $M_{\text{HF-PSCB}}$ = 3.97, SD = .85). Missing cases were excluded pairwise. Subscales were calculated independently for Factor 1 (n = 256, M_1 = 3.9, SD = .88) and Factor 2 (n = 228, M_2 = 3.96, SD = 1.03).

The scores for the GFS (n = 211, M = 2.94, SD = .61) and the PSS-Fa (n = 206, M = 12.81, SD = 2.96) were computed. Separate two-tailed Pearson correlations were conducted to test H1 and H2. There was a significant, positive correlation between the Family HF-PSCB and the GFS [r = .64, $n = 211$, $p < .01$] confirming hypothesis 1. There was also a significant, although low, positive correlation between the Family HF-PSCB and the PSS-Fa [r = .38, $n = 206$, $p < .01$] confirming hypothesis 2. The Family HF-PSCB demonstrates convergent validity with significant correlations with both the GFS and the PSS-Fa.

Summary

Phase three produced several key results for the Family HF-PSCB. First, five stages of exploratory factor analysis revealed two factors with 13 items (see Appendix T). The reduction of items allows for the Family HF-PSCB to be more parsimonious and user-friendly, especially in a clinical setting. The 13 items in the two factors explained a significant amount of variance (72.17%), where factor one (63.20%) explains more variance than factor two (12.97%). Additionally, convergent validity testing confirms statistically significant correlation of the Family HF-PSCB with two like-measures i.e., (the GFS and PSS-Fa).

Chapter Six: Discussion of Findings

Family members can be a significant source of support and communication for individuals with chronic disease (Lee et al., 2017; Rosland et al., 2010; Rosland et al., 2012). The additional support may be helpful for an individual's psychological well-being and long-term management strategies as suggested by his or her health care provider(s) (Bodenheimer et al., 2002; Maulik et al., 2010). The family has the ability to reduce the odds of panic disorder and psychological distress following life events, like the diagnosis or progression of a chronic disease (Maulik et al., 2010). In fact, patients who have social support are more likely to adhere to treatment recommendations and experience better health outcomes (Mayberry et al., 2016). Working within the family systems theory framework, this study brought two important family concepts together in one assessment: perceived social support and communication behaviors. Perceived social support is the perceived availability and adequacy of support for the individual (Wills & Shinar, 2000), and communication behaviors are the ways individuals share meaning.

Because the United States has an ever-increasing number of adults with at least one chronic disease (Ward et al., 2014) and support and communication have been shown to be positive in these cases (Prazeres & Santiago, 2016), knowing whether patients with chronic disease perceive themselves to have family social support and effective communication behaviors becomes important and is the main reason for the creation and testing the Family HF-PSCB. Although there have been several published perceived social support scales and some communication behavior measures (e.g., Barrera, 1986; Rosland et al., 2012), this study explored the intersection of both the family social support and communication behaviors relating to health as perceived by the individual with a chronic disease. There are few, if any, measures that take into consideration the family *health-focused* perceived support and communication behaviors that might be used by families to discuss health-related support and communication.

Unlike the PSS-Fa (Procidano & Heller, 1983) and the GFS (Ryan et al., 2005) that only have single factors that measure perceived social support and functioning, respectively, the Family HF-PSCB developed with two distinct factors. By having two factors, the Family HF-PSCB recognizes the complexity of both family dynamics and chronic disease. The Family HF-PSCB has the ability to measure two factors of family communication in one instrument contrary to the single factor instruments currently available. The final factors that emerged from the exploratory factor analysis included 8 items on a factor of *communication behaviors* (e.g., "I could ask a family member questions related to my health," "I could discuss treatment options with someone in my family that might not have been brought up by my doctor") and 5 items on a factor of *perceived social support* (e.g., "Someone in my family could come and stay with me if I have a major health situation," "Someone in my family could drive me to a health appointment").

Family support typically is provided in one of three ways: emotional support, instrumental support, or informational support (Fallatah & Edge, 2015; Goldsmith, 2004; Tanner, 2004). Emotional support can be the expression of empathy, sympathy, encouragement, reassurance, affection, and closeness (Yoo et al., 2013). Instrumental support represents the tangible support from others in which family members can assist or do hands-on activities for each other (Heo et al., 2014; Warren-Findlow & Prohaska, 2008). Informational support is providing people with the knowledge to make needed changes related to the disease itself, how to handle situations, and access to services (Fallatah & Edge, 2015).

Interestingly, the only perceived support items that remained in the final factor analysis were ones aligned with instrumental support, where a family member might tangibly do an act of service for the individual, such as cooking, cleaning, or attending a doctor’s appointment. Although there were many items in the initial 91 items generated related to perceived emotional or informational social support, none of those items persisted through the reliability, validity, and factor analysis testing. This is contrary to the findings of Kelly, Soderlund, Albert, and McGarrahan (1999), in which emotional-cognitive supports were more predictive than instrumental supports with a sample of individuals with Chronic Fatigue Syndrome. Upon reflection, the nature of combining all chronic diseases in the creation of the Family HF-PSCB might suggest that instrumental support is a better indicator of perceived support across a variety of chronic diseases. Because this study aimed to provide a more generalizable sample of many diseases across various stages, it is possible that the perception of emotional and informational support are not consistently reliable or valid across a sample of many diseases and stages. When considering diagnoses that might be more acute, terminal, or traumatic, the emotional support might have been more explanatory or helpful than in the current population. Chronic conditions have a unique set of needs where management is required during the course of a lifetime after diagnosis. Once diagnosed, the healthcare provider may make recommendations from simple to very complex regimens to attempt to curb or stop the progression of the disease. These potential behavior changes or additions may require tangible support from others to be successful.

This chapter is divided into five sections. The first section is a summary and discussion of the findings of the study. The second section outlines the implications for the study. The third section addresses the limitations of the study, and the final sections present future research directions and a brief conclusion.

Summary of the Study

Conceptually, this study was framed around family health-focused perceived support and communication behaviors. Family, for the purposes of this research, was defined as a group of individuals with continuing legal, genetic, and/or emotional relationships as identified by the participant. Conceptually, perceived social support was defined as the subjective judgment that family and friends would provide quality assistance with future stressors (Wills & Filer, 2011). Communication behaviors are the ways family share messages and create shared meanings. To be considered health-focused, support or communication behaviors must be about health, attentive to one's health, or related to the individual's specific health needs. The combination of the concepts within this study was developed to culminate the concepts that have demonstrated positive effects on the outcomes and management of chronic disease in the family system.

Five research questions and two hypotheses guided the development and psychometric testing of the Family HF-PSCB. Research question 1 explored the types of family health-focused perceived support and communication behaviors that patients identify in their families. From interviews with 12 individuals with chronic kidney disease, 91 items were generated. Research question 2 evaluated the validity of these items through expert content review, of which, 84 of the items were validated. In pilot testing the Family HF-PSCB, research question 3 identified barriers for participants when completing the instrument. After 10 individuals provided feedback to edit or improve the survey, research question 4 assessed the test-retest reliability of the Family HF-PSCB with 23 individuals. Twelve (12) items did not demonstrate test-retest reliability. In phase three, a larger sample of participants ($N = 282$) was recruited to test the 72 Family HF-PSCB items. Research question 5 explored the factor structure of the Family HF-PSCB. The final exploratory factorial structure had 13 items and two factors. A Family HF-PSCB score is measured by the average of item scores where all items scores are summed and then divided by the number of items completed. Hypothesis 1 stated that the Family HF-PSCB would demonstrate convergent validity by correlation with the General Functioning Scale, and Hypothesis 2 stated that the Family HF-PSCB would demonstrate convergent validity by correlation with the Perceived Social Support- Family Scale. Both hypotheses were supported with statistically significant correlations.

Based on the review of the literature, it might be hypothesized that individuals perceiving high Family HF-PSCB will be more likely to have the types of available support and communication behaviors that occur in families that exhibit an overall assistive nature towards health, but this correlation is not assessed in the current research. This measurement may support a better understanding of how Family HF-PSCB helps an individual manage a long-term chronic disease, which has the potential to slow the progression of disease or improve psychological quality of life. In the samples for reliability and validity testing of the Family HF-PSCB, no one specific disease was studied which allows for a more generalizable scale than some of the current scales that focus on disease-specific populations (e.g., cancer, [Yoo et al., 2013], diabetes [Mayberry et al., 2016], heart failure [Bennett et al, 2001], kidney disease [Cohen et al., 2007]). In total, there were 68 self-reported chronic disease represented in phase three of the research.

Implications

This study provides evidence of the reliability and validity of the Family HF-PSCB. Theoretically, the Family HF-PSCB supports that perceived social support and communication behaviors are present in an individual's perception of their family and explained a significant part of the variance in a sample of patients with chronic disease(s). Anyone with one or more chronic conditions can take the Family HF-PSCB, which matches the current state of chronic disease in the United States where more than half of adults have at least one chronic condition and one in four have multiple chronic conditions (U.S. Department of Health and Human Services, 2016). Additionally, 40-60% of individuals in the United States have reported that they indeed have family that they can rely on for support and assistance (Lee et al., 2017; Rosland, Heisler, Choi, Silveira, & Piette, 2010; Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008). It is important then to assess if patients perceive to not only have familial communication and support at times when they are most likely to need it (i.e., when managing a potentially life-altering chronic disease) but also the types most desired during this time. The Family HF-PSCB measures two factors of specific types: health-focused perceived support and communication behaviors, which, in this study, persisted as the most reliable and valid forms of family communication across many chronic diseases.

As a research implication, the findings of this study highlight the importance and potential of communication behaviors as a valid and explanatory variable in the family system, possibly more explanatory than perceived social support. Factor 1, as outlined in the third phase of research, was the factor with family health-focused communication behaviors. It had more items than Factor 2 and explained a much larger portion of the variance. Factor 2 had 5 items aligned with perceived support that accounted for 12.97% of the variance, but more significantly, Factor 1 had 8 items aligned with communication behaviors for 63.20% of the variance. The three items on Factor 1 with the highest loadings represent communication behaviors related to asking questions (i.e., “I could ask a family member about my health problems;” “I could ask a family member about how I might deal with my health problems;” and “I could ask a family member questions related to my health”). This availability to have someone in the family system to ask questions appears to be one of the most noteworthy behaviors of health-focused communication within the family. The significance of Factor 1 suggests that communication behaviors might be a better measure for perception of a health-focused family system. The strength of the factor of communication behaviors may point to a larger conceptual implication for studying family communication behaviors. If this is the case, the concept of health-focused communication behaviors needs a more developed theoretical framework and foundation than what currently exists in the literature.

As a clinical implication, the Family HF-PSCB is an instrument that could prove to be useful in a clinical setting where providers plan to functionally involve the family in the patient’s care and where they need to assess whether the level of family health-focused support and communication is present as a modifiable factor to help improve health outcomes (Fisher, 2005, 2006; Fisher & Feldman, 1998; Vedanthan et al., 2016). The professional administering a Family HF-PSCB would have the ability to quickly assess health-focused support and communication for a specific family in order to have a better context for suggesting how to improve chronic disease management and control as a system. This assessment can be particularly helpful when professionals are introduced to a new patient in practice (Smilkstein, 1978). Additionally, individuals with low Family HF-PSCB scores might be provided resources to seek support and to more successfully manage their chronic disease(s) or might be provided guidance for asking individuals within their existing social networks to provide more a higher level of health-focused perceived communication behaviors or instrumental support.

As an implication for individuals, the Family HF-PSCB might also prove to be a helpful interpersonal tool for individuals seeking information on ways to assess and improve their disease management and relationships within their family. With the increase of individuals seeking ways to know more about how to help oneself in the understanding and management of chronic disease(s), the scale could be useful as a type of self-education material that could be made available online for ease of access. In this scenario, the Family HF-PSCB might guide one's own understanding of family health-focused behaviors and how to improve his or her management of health by including family members in all aspects of care. Such materials would need to be developed and tested prior to assessing their impact on the ability of an individual to positively engage the family's health-focused support and communication behaviors.

Limitations

One of the larger methodological limitations in the first phase of this study is that interviews were conducted with a small group of individuals living with a specific type of chronic kidney disease. Ideally, the first phase would have included a variety of diseases to be more representative of the samples used in phase two and three. Although there may be unknown consequences of having a more limited sample in the first phase, the items persisted through the reliability and validity testing with more varied disease samples in later phases.

Demographically, there are limitations in sampling across the all three phases as a result of the non-randomized convenience sampling. Recruitment was facilitated predominately by one researcher, which may demonstrate research bias in recruitment because the sample is likely reflective of the researchers' own demographics as she posted and shared on social media sites. The phase two sample included predominately white, married individuals with educational attainment that exceeds the general population. In phase three, the sample included predominately white females. More concentrated efforts to have a randomized, representative sample may be desired. Additionally, the data presented in this research is cross-sectional. Because patients' stages and needs can change as a result of the phase of illness or during episodes of increased symptoms or complications, it is recommended that future research might take into consideration longitudinal data.

Regarding sample size, the third phase of the study indicated an adequate sample size according the Kaiser-Meyer-Olkin Measure of Sampling Adequacy ($n = 209$), but more often, it is recommended to conduct exploratory factor analysis with at least 300 participants (Yong & Pearce, 2013). For this reason, future research should use larger samples to confirm the factors found in this study. A final limitation of this study includes the fact that the Family HF-PSCB is limited to the perception of the family system on behalf of the individual completing the instrument. There is no indication of whether the individual’s perception aligns with the reality of what is occurring. Although perceived support might not be an actual representation of true behaviors, it does indicate the individual’s perception of reality. Surprisingly, although the Family HF-PSCB intended to capture the perception, the actual correlation in the convergent validity testing with the PSS-Fa was low (r = .38), although statistically significant.

Future Directions for Research

The research questions and hypotheses for this study focused on the development and psychometric testing of the Family HF-PSCB, but there is potential for more research within the existing dataset. Future analyses of these data could examine variables such as age, time since diagnosis, presence of multiple chronic conditions, gender, and educational attainment and their relationships with Family HF-PSCB scores.

In this study, the investigator developed and tested the reliability of the Family HF-PSCB, but future research should compare the scores of the Family HF-PSCB to health outcomes. Previous research has correlated scales such as the PSS-Fa or the GFS with health outcomes such as quality of life (Jozefiak & Wallander, 2015) or measures like the Family Unit Inventory, and Family Adaptability and Cohesion Scale (Miller et al., 1985), but according to the literature, Family HF-PSCB scores should correlate with improved physiological or psychological health outcomes. Nothing in this study tested those assumptions. Next phases of research should explore associations between the Family HF-PSCB and measures of health outcomes such as mortality rates, blood sugar regulation, or blood pressure rates.

Theoretically, there is a significant amount of research guided by the theory of social support, but unfortunately, there is not the same conceptualization for communication behaviors. Because family health-focused communication behaviors emerged as the most explanatory and defined factor in this study, more research should be conducted to understand the conceptual framework of family health-focused communication behaviors and its relationship to the perceived instrumental support. Although perceived social support has a developed body of literature and theoretical framework, it is not as explanatory as health-focused communication behaviors in the current study. In health communication research, health-focused communication behaviors have been part of larger theoretical frameworks , but reflecting on the results presented here, a conceptualization of health-focused communication behaviors might need to be included as its own free standing theory as a parallel to the theoretical conceptualization of social support.

One somewhat similar conceptualization of family communication to the findings of the Family HF-PSCB is Family Communication Patterns Theory (FCPT) (Wittenberg-Lyles, Goldsmith, Demiris, Oliver, & Stone, 2012). According to FCPT, families develop central beliefs that determine how much the families communicate, and furthermore family members develop rules for communicating within the relationships of the family (Koerner & Fitzpatrick, 2002). Similar to the FCPT, the results here might point to the types of factors that families develop to be the central beliefs and rules for health-focused communication. Koerner and Fitzpatrick (2002) created categories in FCPT to refer to the communication beliefs of families according to orientations towards conversation, conformity, spontaneity, and harmony (Koerner & Fitzpatrick, 2002; Wittenberg-Lyles et al., 2012). Future research might explore whether different scores on the Family HF-

PSCB coordinate with the typologies of the FCPT or if there might be alterations to the typologies based on data provided in future data collections of the Family HF-PSCB.

Conclusion

Chronic disease is a significant problem for individuals, health professionals, and families. The key to understanding family assessment is to begin with further research to understand how successful families deal with the requirements of maintaining chronic disease. Establishing the reliability and the validity of the Family HF-PSCB is a first step prior to using the instrument to understand how individuals perceive their family's support and communication. Future research should continue to assess the instrument's reliability and validity in different populations to overcome some of the limitations presented here and to explore the opportunities for an expanded understanding of how families provide health-focused support and communication behaviors to lead to better outcomes for the individual and their family.

Chapter Seven: Appendices

Appendix A

Participant Recruitment Script

Hello (insert name). My name is (insert name), and I am a (faculty/student) from IUPUI. I am contacting you to invite you to participate in a research study about family communication about polycystic kidney disease. We are contacting you because we believe you or someone in your family has been diagnosed with polycystic kidney disease. I obtained your contact information from (source).

If you decide to participate in this study, we will set up a time to have a personal interview. I would like to record your interview, and then we will use your information to understand more about how families might share information about polycystic kidney disease.

This is a completely voluntary study. You can chose to participate or not. If you would like to participate or have questions, please email me at (insert email), or call me at (insert phone).

Thank you for your time,
(Insert name)

Appendix B

Pre-Interview Email Template and Study Information Sheet

(Insert Name),

Thank you for confirming your interest to participate in an interview. I look forward to talking with you, I will call you (insert date) at (insert time) EST. In your email, you provided the number (enter phone number), and I will use this number unless you tell me otherwise.

The questions can evolve as we talk, but the fundamental questions surround the following ideas:

1. Can you tell me about your PKD journey?
2. Who do you consider family?
3. Do you talk to this family about your PKD?

Interviews usually take 30- 45 minutes depending on how many details you care to share. I have attached the study's information sheet for you to review. I look forward to talking with you (insert day of week, month, date).

Sincerely,

(Insert name)

Attachment:

INDIANA UNIVERSITY STUDY INFORMATION SHEET FOR Communication in Families with Polycystic Kidney Disease

You are invited to participate in a research study of investigating communication in families with Polycystic Kidney Disease. You were selected as a possible subject because you or someone in your family has Polycystic Kidney Disease. We ask that you read this form and contact us with any questions you may have before agreeing to be in the study.

The study is being conducted by Dr. Jennifer Bute and Amanda Harsin in the Department of Communication Studies at Indiana University-Purdue University Indianapolis.

STUDY PURPOSE

The purpose of this study is to better understand how patients with PKD talk about PKD with their families.

PROCEDURES FOR THE STUDY:

You will be asked to participate in a semi-structured interview that will last approximately 60 minutes and be audio recorded. You may be asked to participate in a follow-up interview as needed. In order to protect against loss of confidentiality, your name will not be associated with your answers.

RISKS OF TAKING PART IN THIS STUDY:

To the best of our knowledge, the things you will be doing have no more risk or harm than you would experience in everyday life.

BENEFITS OF TAKING PART IN THIS STUDY:

There is no guarantee that you will get any benefit from taking part in this study. However, some people have experienced increased knowledge and understanding about their illness after participating in similar studies. Your willingness to take part, however, may in the future help society as a whole better understand this research topic.

CONFIDENTIALITY

Your name will not be attached to any of the materials that you complete during the study. Please be aware, while we make every effort to safeguard your data once recorded, given the nature of data collection, we can never guarantee the confidentiality of the information.

Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be personally identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private as it will not be linked to your responses. However, it should be noted that researchers can be forced by law to tell people who are not connected with the study, including the courts, about your participation.

Once the data is collected, the recordings, notes, and transcripts will be securely stored on a password protected computer. Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator, her research associates, or the Indiana University Institutional Review Board or its designees.

PAYMENT

You will not receive payment for taking part in this study.

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study or a research-related injury, contact the researchers Dr. Jen Bute (xxx)xxx-xxxx jjbute@iupui.edu or Amanda Harsin at (xxx)xxx-xxxx /amharsin@iupui.edu. For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (xxx)xxx-xxxx or for Indianapolis or ((xxx)xxx-xxxx for Bloomington or (xxx)xxx-xxxx by e-mail at irb@iu.edu.

VOLUNTARY NATURE OF STUDY

Taking part in this study is voluntary. You may choose not to take part or may stop the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Indiana University-Purdue University Indianapolis.

Appendix C

Semi-Structured Interview Guide

Study Focus: The experiences of families and their communication surrounding the genetic disorder Polycystic Kidney Disease (PKD). A contextual, systemic, in-depth exploration with a few families.

Interview Procedure: During the course of the research associated with this study, participants will be recruited through convenience sampling. Participants will be asked to participate in interview sessions that will be audio recorded. Following these initial interviews, selected participants may be asked to participate in follow-up interviews. Follow-up interview participants will be chosen based on generative themes identified during the original interviews, which need contextualization and more detailed information. Participants will be asked to address several topics initiated by the interviewer and those themes generated earlier in the initial interview. The interviewer will explore the following topics and/or questions:

Procedural Expectation 1:

- Student interviewer audio record entire process.
- Explain the process is expected to take 60 minutes.

Procedural Expectation 2:

- The interviewer will provide appropriate informed consent to each participant prior to the recording process. Interviewer reads consent to participants, confirms intent to continue, and collect paperwork.

Procedural Expectation 3:

- The interviewer will guide participants through recommended questions, allowing for discussion, elaboration, and additional questions as needed.
- Recommended questioning framework:
    - First, I'd like to learn a little bit more about your family. Who is all in your family?
    - Now, I'd to learn more about Polycystic Kidney Disease in your family.
        - Other than you, has anyone else been diagnosed?
        - How did the issue start?
        - How did it progress?
        - Can you share your PKD story?
    - Does your family talk about PKD?
        - If not, why do you think that is?
        - If so, what is the talk about?
            - Can you give me an example of a conversation your family has had about PKD?
    - Do you think the communication with your family directly impacts your health?
        - If so, how?

        - Can you give me a specific example?
    - What makes you feel comfortable talking to your family?
    - If you are the patient, how does communication with your family help you manage your PKD?
        - Who is the most helpful with your PKD management?
        - How do different members of your family help you in different ways?
        - How do they help you manage PKD?
        - Who has been unhelpful or a barrier?
        - Can you give an example of when someone in your family helped you with your PKD?
        - Does your family visit the doctor/healthcare provider with you?
            - Why/Why not?
            - If so, how often?
            - If so, can you share a story about visiting your health care provider together?
    - What are the primary challenges you face as a family involving this health issue?
    - What could other families learn from your experiences?

Procedural Expectation 4:

- Professionally thank them for participating.

- Revisit the language in the information sheet should the participants have continued questions or concerns now that interview is complete.

Appendix D

Instrument for Expert Reviewers Survey Item Review

Using a 4-point rating scale please rate each of the following items according to their relevance to family support and communication in chronic care by circling the appropriate number.

Supportive Family support and Health-Focused Family Communication Behaviors for Chronic Disease Management is the direct or indirect action(s) of a family member or set of family member(s) that communicates support for the management of another family member's overall health when living with a chronic disease.

Use the space provided below the rating scale to make comments or to suggest revisions. Item #4 and Item #70 reflect *reverse* items in which you would evaluate the reverse, or opposite, of the statement as it relates to the family support and communication in chronic care.

Please rate the item in terms of its relevance to the definition of family support and communication in chronic care where,

1) Not relevant
2) Unable to assess relevance without revision
3) Relevant but needs minor revision
4) Very relevant

1. Someone in my family collaborates on my health issues when needed.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
2. Someone else in my family has recommended a physician for me.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
3. I observe the health habits of my family members.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
4. No one in my family shares health information. (reverse)	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
5. In the past, someone in my family has driven me to a health appointment.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
6. I have telephoned someone in my family about health matters.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
7. When I have had hospitalization in the past, someone in my family has offered to take care of household chores.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	

8. I have a family member that helps me solve health problems.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
9. I have someone I can relate health matters to in my family.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
10. When I have health issues, someone in my family visits.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
11. I have had a health meeting in which someone in my family went with me.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
12. I have a go-to person in my family related to health matters.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
13. I have witnessed someone else in my family with similar health conditions as me.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
14. I explain to family members my health issues.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				

15. Someone in my family encourages me in physical activity.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
16. Someone in my family knows how to ask questions related to my health concerns.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
17. Someone in my family worries about my health concerns.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
18. Someone in my family helps me be proactive about my health.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
19. Are you on a special diet? If so: I have someone I can talk to in my family to help me plan my nutrition.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
20. Health is naturally a topic of conversation in my family.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
21. Someone in my family can help me gather information about my health.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	

22. Someone in my family can help me feel less anxious about my health condition.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
23. I have asked someone in my family to be my medical power of attorney.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
24. Someone in my family has asked what medications I take.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
25. I have shared with someone in my family where to find my medications in case of an emergency.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
26. If I bring materials home from the doctor, someone in my family would review them with me.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
27. Someone in my family would volunteer to go if I need accompaniment to the doctor.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
28. Someone in my family can help me fact-check medical information I receive.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				

29. I have someone in my family on "my side" with health concerns.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
30. The communication in my family related to health is robust.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
31. The communication in my family related to health moves freely.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
32. Someone in my family is there when I have health problems.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
33. I have someone in my family that works as a health professional that I can talk to.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
34. Because of shared resources, I share the same doctor with someone in my family.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
35. Someone in my family can be attentive when I am ill.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				

36. Someone in my family offers to help me manage my diet.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
37. Someone in my family can help me research health concerns.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
38. Someone in my family shares healthy recipes with me.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
39. Someone in my family helps me emotionally when I have health issues.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
40. Someone in my family provides assistance in maintaining my diet.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
41. I know of someone in my family that I consider to be the medical information person.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
42. Someone else in my family is affected when I go through an illness.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	

43. Someone in my family takes action when I have health problems.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
44. Someone in my family visits me when I am hospitalized.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
45. Someone in my family has talked to my doctor with me.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
46. Someone in my family is good at medical research.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
47. Someone in my family has shared information about my family history.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
48. I can have conversations with someone in my family about my health.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
49. I discuss health matters with someone in my family at family gatherings.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				

50. I discuss health matters with someone in my family on the phone.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
51. Someone in my family will visit me when I have health issues.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
52. I discuss what my doctor says with someone in my family.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
53. I have someone I can partner within my family regarding health concerns.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
54. Someone in my family encourages me to schedule appointments.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
55. Someone in my family reassures me about my prognosis.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
56. I can learn health habits from others in my family.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				

57. I can gain knowledge about health concerns within my family.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
58. I can share knowledge about health concerns with someone in my family.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
59. I can discuss treatment options that might not have been brought up by my doctor with someone in my family.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
60. I have a family member that advocates for my health.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
61. Someone in my family telephones me about health-related issues.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
62. I dialogue with someone in my family about health-related issues.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
63. Someone in my family can come and stay with me if I have a major health situation.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				

64. There is someone I can ask questions to in my family related to health.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
65. If I am ill, there is someone in my family that can cook for me.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
66. I have had someone in my family attend a health appointment with me before.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
67. I have a member of my family that provides strength when I deal with health issues.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
68. I have had an ongoing discussion about health with someone in my family.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
69. If I have children, I share my health information with them.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
70. I try to hide my health issues from my family.(reverse)	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				

71. I have a family member that comes to me with health questions.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
72. There is someone in my family that would care for me after a medical procedure.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
73. My family is considerate of my health issues.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
74. Someone in my family is actively involved in my health.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
75. I have someone in my family that is hands-on with my health.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
76. Someone in my family assists with housework when I have health issues.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
77. Someone in my family is an emotional support related to my health.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				

78. My family is a team when it comes to my health issues.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
79. Someone in my family has taken my vitals before.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
80. Someone in my family stays involved in my health.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
81. My family approaches my health concerns as a team.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
82. I get a lot of support from someone in my family for my health issues.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
83. I am able to ask a family member about health problems.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				
84. I am able to ask a family member about how they deal with health problems.	☐1	☐2	☐ 3	☐ 4
Optional Expert Review Comments:				

85. I have at least one family member that discusses health matters at family gatherings.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
86. My family loves to talk about their health experiences.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
87. I have someone in my family to talk to about what to do with health problems.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
88. Someone in my family shares what works for them related to their health problems.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
89. Someone in my family members shares what does not work for them related to their health problems.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
90. I receive calls from a family member about his/her health.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	
91. Someone in my family has helped me complete health-related paperwork.	☐1 ☐2 ☐ 3 ☐ 4
Optional Expert Review Comments:	

Appendix E

Expert Content Review Email

(Insert Name),

Thank you for agreeing to review the items created for a scale I am working on related to Communicated Family Support and Communication behaviors in chronic care.

It is attached as a word document. For each item, you should be able to check a 1-4 rating for the relevance of the item related to the definition I have provided in the document. I have multiple reviewers completing the same process.

Please let me know if you have questions. I appreciate your willingness to review, and again, I would be happy to return the favor anytime.

My gratitude,
(Insert name)

Appendix F

Item Content Validity Indexes

Item	I-CVI
1. Someone in my family collaborates on my health issues when needed.	1
2. Someone else in my family has recommended a physician for me.	1
3. I observe the health habits of my family members.	0.5
4. No one in my family shares health information. (reverse)	1
5. In the past, someone in my family has driven me to a health appointment.	1
6. I have telephoned someone in my family about health matters.	1
7. When I have had hospitalization in the past, someone in my family has offered to take care of household chores.	.833
8. I have a family member that helps me solve health problems.	1
9. I have someone I can relate health matters to in my family.	1
10. When I have health issues, someone in my family visits.	1
11. I have had a health meeting in which someone in my family went with me.	1
12. I have a go-to person in my family related to health matters.	1
13. I have witnessed someone else in my family with similar health conditions as me.	0.666667
14. I explain to family members my health issues.	.833
15. Someone in my family encourages me in physical activity.	1
16. Someone in my family knows how to ask questions related to my health concerns.	1
17. Someone in my family worries about my health concerns.	1
18. Someone in my family helps me be proactive about my health.	1
19. Are you on a special diet? If so: I have someone I can talk to in my family to help me plan my nutrition.	1

20. Health is naturally a topic of conversation in my family.	.833
21. Someone in my family can help me gather information about my health.	1
22. Someone in my family can help me feel less anxious about my health condition.	1
23. I have asked someone in my family to be my medical power of attorney.	1
24. Someone in my family has asked what medications I take.	1
25. I have shared with someone in my family where to find my medications in case of an emergency.	1
26. If I bring materials home from the doctor, someone in my family would review them with me.	1
27. Someone in my family would volunteer to go if I need accompaniment to the doctor.	1
28. Someone in my family can help me fact-check medical information I receive.	1
29. I have someone in my family on “my side” with health concerns.	1
30. The communication in my family related to health is robust.	1
31. The communication in my family related to health moves freely.	1
32. Someone in my family is there when I have health problems.	1
33. I have someone in my family that works as a health professional that I can talk to.	.833
34. Because of shared resources, I share the same doctor with someone in my family.	.833
35. Someone in my family can be attentive when I am ill.	1
36. Someone in my family offers to help me manage my diet.	1
37. Someone in my family can help me research health concerns.	1
38. Someone in my family shares healthy recipes with me.	.5
39. Someone in my family helps me emotionally when I have health issues.	1

40. Someone in my family provides assistance in maintaining my diet.	1
41. I know of someone in my family that I consider to be the medical information person.	.833
42. Someone else in my family is affected when I go through an illness.	.833
43. Someone in my family takes action when I have health problems.	1
44. Someone in my family visits me when I am hospitalized.	1
45. Someone in my family has talked to my doctor with me.	1
46. Someone in my family is good at medical research.	1
47. Someone in my family has shared information about my family history.	1
48. I can have conversations with someone in my family about my health.	1
49. I discuss health matters with someone in my family at family gatherings.	.833
50. I discuss health matters with someone in my family on the phone.	.833
51. Someone in my family will visit me when I have health issues.	1
52. I discuss what my doctor says with someone in my family.	1
53. I have someone I can partner with my family regarding health concerns.	1
54. Someone in my family encourages me to schedule appointments.	1
55. Someone in my family reassures me about my prognosis.	1
56. I can learn healthy habits from others in my family.	1
57. I can gain knowledge about health concerns within my family.	1
58. I can share knowledge about health concerns with someone in my family.	1
59. I can discuss treatment options that might not have been brought up by my doctor with someone in my family.	.833
60. I have a family member that advocates for my health.	1
61. Someone in my family telephones me about health-related issues.	.833
62. I dialogue with someone in my family about health-related issues.	.833

63. Someone in my family can come and stay with me if I have a major health situation.	1
64. There is someone I can ask questions to in my family related to health.	1
65. If I am ill, there is someone in my family that can cook for me.	1
66. I have had someone in my family attend a health appointment with me before.	1
67. I have a member of my family that provides strength when I deal with health issues.	.833
68. I have had an ongoing discussion about health with someone in my family.	1
69. If I have children, I share my health information with them.	1
70. I try to hide my health issues from my family.(reverse)	1
71. I have a family member that comes to me with health questions.	.833
72. There is someone in my family that would care for me after a medical procedure.	1
73. My family is considerate of my health issues.	.833
74. Someone in my family is actively involved in my health.	1
75. I have someone in my family that is hands-on with my health.	1
76. Someone in my family assists with housework when I have health issues.	.833
77. Someone in my family is an emotional support related to my health.	.833
78. My family is a team when it comes to my health issues.	1
79. Someone in my family has taken my vitals before.	.833
80. Someone in my family stays involved in my health.	1
81. My family approaches my health concerns as a team.	.833
82. I get a lot of support from someone in my family for my health issues.	1
83. I am able to ask a family member about health problems.	1
84. I am able to ask a family member about how they deal with health problems.	1

85. I have at least one family member that discusses health matters at family gatherings.	1
86. My family loves to talk about their health experiences.	.833
87. I have someone in my family to talk to about what to do with health problems.	1
88. Someone in my family shares what works for them related to their health problems.	.833
89. Someone in my family members shares what does not work for them related to their health problems.	.833
90. I receive calls from a family member about his/her health.	.5
91. Someone in my family has helped me complete health-related paperwork.	1

Appendix G

Expert Reviewer Comments

Item Number	Item Language	Comment(s)
3	I observe the health habits of my family members.	I would like to suggest revising this item like, “I have talked to my family members about their health habits.”
13	I have witnessed someone else in my family with similar health conditions as me.	I would like to suggest revising this item like, “I have talked to someone else in my family about his/her health conditions similar to me.”
15	Someone in my family encourages me in physical activity.	Is this related to chronic disease or just overall health?
20	Health is naturally a topic of conversation in my family.	What if it is attention seeking?
33	I have someone in my family that works as a health professional that I can talk to.	-This would hinge on whether the family member’s field was relevant or not. -Very relevant. Helps navigate the system and obtain the right info.

34	Because of shared resources, I share the same doctor with someone in my family.	I would like to suggest using this item without “Because of shared resources” (it was difficult for me to understand what this phrase means) or revising it like, “My family members share some doctors and health resources.”
40	Someone in my family provides assistance in maintaining my diet.	If diet restrictions apply.
43	Someone in my family takes action when I have health problems.	I suggest “If needed, someone in my family would take action when I have health problems.”
44	Someone in my family visits me when I am hospitalized.	In case someone has not been hospitalized, I suggest: “Someone in my family would visit me if I was hospitalized.”
45	Someone in my family has talked to my doctor with me.	“Someone in my family would talk to my doctor with me.”
46	Someone in my family is good at medical research.	-I would like to suggest revising this item like, “Someone in my family is good at medical research related to my health concerns.” - Someone in my family is good at medical research and would help me if needed.

71	I have a family member that comes to me with health questions.	About chronic illness or seeking general health information?
77	Someone in my family is an emotional support related to my health.	- I would like to suggest revising this item like, “Someone in my family emotionally supports me when I have health issues,” or “Someone in my family is empathetic and makes feel cared when I have health issues” based on Goldsmith’s (2004) definition of emotional support.
79	Someone in my family has taken my vitals before.	-This would depend upon the condition. -I suggest: “Someone in my family would help me take my vitals if needed.”
84	I am able to ask a family member about how they deal with health problems.	Relevant if said family member is experiencing similar issues.
88	Someone in my family shares what works for them related to their health problems.	If comparable.
89	Someone in my family members shares what does not work for them related to their health problems.	If comparable.

90	I receive calls from a family member about his/her health.	Relevant if similar circumstance or just shows open communication.

Appendix H

Final Items Generated

In this section, we are interested in finding out if you believe you could communicate or get support from any family member related to your health matters. Please answer as honestly as possible.

Participants respond to each statement below with:
1 = strongly disagree
2 = disagree
3 = neither agree nor disagree
4 = agree
5 = strongly agree

1. I could ask a family member about my health problems.
2. I could ask a family member about how they deal with my health problems.
3. I could ask a family member questions related to my health.
4. I could communicate with someone in my family about my health.
5. I could dialogue with someone in my family about health-related issues.
6. I could discuss health matters with someone in my family at family gatherings.
7. I could discuss my health matters with someone in my family on the phone.
8. I could discuss treatment options with someone in my family that might not have been brought up by my doctor.
9. I could discuss my medications with someone in my family.
10. I could discuss what my doctor says with someone in my family.
11. I could explain my health issues to family members.
12. I could gain knowledge about health concerns within my family.
13. I could get a lot of support from someone in my family for my health issues.
14. I could have an ongoing discussion about health with someone in my family.
15. I could have communication with someone in my family about my health.
16. I could learn good health habits from others in my family.
17. I could name a go-to person in my family for health matters.
18. I could name someone in my family that I consider to be the medical information person.
19. I could name someone in my family who is on “my side” with health concerns.
20. I could relate health matters to someone in my family.
21. I could share knowledge about health concerns with someone in my family.
22. I could tell a family member where to find my medications in case of an emergency.
23. I could talk to someone in my family that works as a health professional.
24. I could telephone someone in my family about health matters.

25. I have at least one family member that discusses health matters at family gatherings.
26. I have someone I could partner with in my family regarding health concerns.
27. I could converse with someone in my family about my health.
28. I have someone in my family I could to talk to about what to do with health problems.
29. If I had children, I could share my health information with them.
30. My family could approach my health concerns as a team.
31. If needed, someone in my family could help me take my pulse (count my heart rate).
32. If needed, someone in my family could help me take my blood pressure
33. If needed, someone in my family could help me take my temperature
34. If needed, someone in my family could take action when I have health problems.
35. My family could be a team when it comes to my health issues.
36. My family could be considerate of my health issues.
37. My family could talk about their health experiences.
38. No one in my family shares health information. (reverse)

In this section, we are interested in finding out whether or not you can identify at least one family member that might support or communicate with you about each of the following. Please answer as honestly as possible.

Participants respond to each statement below with:
1 = strongly disagree
2 = disagree
3 = neither agree nor disagree
4 = agree
5 = strongly agree

39. Someone in my family could recommend a physician for me.
40. Someone in my family can be attentive when I am ill.
41. Someone in my family could advocate for my health.
42. Someone in my family could ask me questions about my health.
43. Someone in my family could assist with housework when I have health issues.
44. Someone in my family could attend a health appointment with me.
45. Someone in my family could be actively involved in my health.
46. Someone in my family could be hands-on with my health.
47. Someone in my family could be there when I have health problems.
48. Someone in my family could care for me after a medical procedure.
49. Someone in my family could collaborate on my health issues when needed.
50. Someone in my family could come and stay with me if I have a major health situation.
51. Someone in my family could come to me with health questions.

52. Someone in my family could cook for me if I was ill.
53. Someone in my family could drive me to a health appointment.
54. Someone in my family could emotionally support me if I have health issues.
55. Someone in my family could encourage me to schedule appointments.
56. Someone in my family could go to a doctor’s appointment with me.
57. Someone in my family could help me be proactive about my health.
58. Someone in my family could help me emotionally when I have health issues.
59. Someone in my family could help me fact-check medical information I receive.
60. Someone in my family could help me feel less anxious about my health condition.
61. Someone in my family could help me gather information about my health.
62. Someone in my family could help me manage my diet, if needed.
63. Someone in my family could help me plan for my nutritional needs.
64. Someone in my family could help me research health concerns.
65. Someone in my family could help me solve health problems.
66. Someone in my family could help me complete health-related paperwork.
67. Someone in my family could provide assistance in maintaining my diet.
68. Someone in my family could provide me emotional support when I deal with health issues.
69. Someone in my family could reassure me about my prognosis.
70. Someone in my family could review medical documents with me.
71. Someone in my family could share health resources with me.
72. Someone in my family could share information about family health history.
73. Someone in my family could share what works for them related to their health problems.
74. Someone in my family could stay involved in my health.
75. Someone in my family could talk to my doctor with me.
76. Someone in my family could telephone me about health-related issues.
77. Someone in my family could visit me if I have health issues.
78. Someone in my family could visit me if I was hospitalized.
79. Someone in my family could volunteer to go with me if I needed to go to the doctor.
80. Someone in my family could encourage me to be physically active.
81. Someone in my family could worry about my health concerns.
82. Someone in my family could be good at medical research and would help me if needed.
83. Someone in my family could share what does not work for them related to their health problems.
84. Health can be a natural topic of conversation in my family.

Appendix I

Email or Social Media Message to Recruit Sample for Cognitive Interviewing

Greetings (Name)! My name is (Name), I am nearing the completion of my PhD. To complete, I have a three phase survey to complete. This message triggers the first phase. I need ten individuals to take my survey while I am on the telephone with them to make sure the survey works for you, is easy to follow, and is user friendly. The only requirements include 1) you are over 18 or 2) you have a chronic condition. Do you meet these conditions? Would you be willing to complete the survey? If so, I will arrange a time to send you the online survey and be on the phone at a convenient time for you. Thank you for considering!

Sincerely,
(Name)
(Contact)

Appendix J

Email Confirming Telephone Interview

(Name),

Thank you for agreeing to help me in a phase of my research where I ensure that the process of taking my dissertation survey makes sense to participants. The process typically lasts about 20 minutes. I will call your phone at (Day of Week, Month, Date).

At the start of our phone call, I will ask you to use the following link to begin the survey. There will be a first page that explains a little bit about the research and will confirm that you want to participate. If you decide not to participate, I understand.

(Insert Link)

While I am on the call, I will not need to know how you answer the questions or need to talk about the survey, but I will just be there to answer any questions you have about the survey in case something does not make sense or it does not work for you as the participant.

I really appreciate the time you are giving me, and I appreciate your help. I look forward to talking soon.

(Name)

Appendix K

Script for Telephone Cognitive Interviews

Hello! Is this (Name)? This is (Name) from IUPUI, Department of Communication Studies. Thank you for agreeing to help me with this stage of my research. Is now still an okay time for you to participate?

The purpose of this phase is to make sure the process works smoothly for a participant.

Did you receive the link I provided to you?

If so, then the plan for this call is for you to work through the survey on your own while I am on the other line. The purpose of me being on the phone is in case you have questions or if something doesn't make sense. You do not have to tell me how you are answering or talk to me through the survey. I will be available if you need to make a comment or have a question. Then, once you tell me you are finished, I will have a few questions for you.

Are there any questions that you have about the survey?

Did you see any problems as you worked through it?

Appendix L

Survey Instrument after Cognitive Interviewing

Inventory of Family Health-Focused Perceived Support and Communication Behaviors with Chronic Disease Patients

Thank you for considering participation in our research related to chronic disease and family communication. The following information is required to be provided to you. By selecting "Continue" you are providing your consent in participation.

INDIANA UNIVERSITY STUDY INFORMATION SHEET FOR
The Development and Testing of an Inventory to Measure Perceived Family Support and Health-Focused Communication Behaviors with Chronic Disease Patients

You are invited to participate in a research study investigating family support and communication related to your chronic disease. We ask that you read this form and contact us with any questions you may have before agreeing to be in the study. The study is being conducted by Dr. Maria Brann & Ms. Amanda Harsin in the Department of Communication Studies at Indiana University-Purdue University Indianapolis.

STUDY PURPOSE: The purpose of this study is to better understand how patients and their families communicate about chronic disease.

PROCEDURES FOR THE STUDY: If you agree to participate in the study, you will complete an online survey that will take approximately 30 minutes. In order to protect against loss of confidentiality, we do not want any identifying information associated with the survey.

RISKS OF TAKING PART IN THIS STUDY: To the best of our knowledge, the things you will be doing have no more risk or harm than you would experience in everyday life.

BENEFITS OF TAKING PART IN THIS STUDY: There is no guarantee that you will get any benefit from taking part in this study. However, some people have experienced increased knowledge and understanding about their illness after participating in similar studies. Your willingness to take part, however, may in the future help society as a whole better understand this research topic.

CONFIDENTIALITY: Your name will not be attached to any of the materials that you complete during the study. Please be aware, while we make every effort to safeguard your data once received from the online survey/data gathering company, given the nature of online surveys, as with anything involving the Internet, we can never guarantee the confidentiality of the data while still on the survey/data gathering company's servers, or while en route to either them or us.
Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be personally identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private as it will not be linked to your responses. However, it should be noted that researchers can be forced by law to tell people who are not connected with the study, including the courts, about your participation. Once the data is collected, the survey data files will be securely stored on Dr. Brann or Ms. Harsin's password protected computer at a locked office at IUPUI. Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator, her research associates, or the Indiana University Institutional Review Board or its designees.

PAYMENT: You will not receive payment for taking part in this study.

CONTACTS FOR QUESTIONS OR PROBLEMS: For questions about the study or a research-related injury, contact the researcher Maria Brann at (xxx)xxx-xxxx and/or mabrann@iupui.edu. For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (xxx)xxx-xxxx or for Indianapolis or (xxx)xxx-xxxx for Bloomington or (xxx)xxx-xxxx by e-mail at irb@iu.edu.

VOLUNTARY NATURE OF STUDY: Taking part in this study is voluntary. You may choose not to take part or may stop the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Indiana University-Purdue University Indianapolis.

SUBJECT'S CONSENT: In consideration of all of the above, you can consent to participate in this research study by selecting "Continue" below. By choosing to complete the web-based survey, you are providing implied consent to participate in the research. You may print this consent form for your records or a researcher will provide a paper copy for you at your request.

How old are you? _______________

(if 18 or older, survey will proceed. If not, send to thank you page)

Has a doctor ever told you that you had any of these conditions? Select all that apply.

- ☐ Addison's disease
- ☐ Asthma
- ☐ Bipolar Mood Disorder
- ☐ Bronchiectasis
- ☐ Cancer, please specify type: __________________
- ☐ Cardiac failure
- ☐ Cardiomyopathy
- ☐ Chronic obstructive pulmonary disorder
- ☐ Chronic renal disease
- ☐ Coronary artery disease
- ☐ Crohn's disease
- ☐ Diabetes insipidus
- ☐ Diabetes mellitus type 1
- ☐ Diabetes mellitus type 2
- ☐ Dysrhythmias
- ☐ Epilepsy
- ☐ Glaucoma
- ☐ Haemophilia
- ☐ Hyperlipidaemia

- ☐ Hypertension
- ☐ Hyperthyroidism
- ☐ Hypothyroidism
- ☐ Lyme's Disease
- ☐ Lupus
- ☐ Multiple sclerosis
- ☐ Osteoarthritis
- ☐ Parkinson's disease
- ☐ Rheumatoid arthritis
- ☐ Schizophrenia
- ☐ Ulcerative colitis
- ☐ Other: ____________________
- ☐ I have not been diagnosed with a chronic condition. (thank you page)

Are you currently under a doctor's care for any condition mentioned above? Select all that apply.

- ☐ Addison's disease
- ☐ Asthma
- ☐ Bipolar Mood Disorder
- ☐ Bronchiectasis
- ☐ Cancer, please specify type: _________________
- ☐ Cardiac failure
- ☐ Cardiomyopathy
- ☐ Chronic obstructive pulmonary disorder
- ☐ Chronic renal disease
- ☐ Coronary artery disease
- ☐ Crohn's disease
- ☐ Diabetes insipidus
- ☐ Diabetes mellitus type 1
- ☐ Diabetes mellitus type 2
- ☐ Dysrhythmias
- ☐ Epilepsy
- ☐ Glaucoma
- ☐ Haemophilia
- ☐ Hyperlipidaemia
- ☐ Hypertension
- ☐ Hyperthyroidism
- ☐ Hypothyroidism
- ☐ Lyme's Disease

- ☐ Lupus
- ☐ Multiple sclerosis
- ☐ Osteoarthritis
- ☐ Parkinson's disease
- ☐ Rheumatoid arthritis
- ☐ Schizophrenia
- ☐ Ulcerative colitis
- ☐ Other: ____________________

Please estimate how many years ago a doctor first told you that you had one of these conditions (e.g.,: 0.5, 10)__________

In the next several sections, you will be asked questions about your family. In this study, we define family as a group of individuals with continuing legal, genetic, and/or emotional relationships.

With this definition, please take a moment to consider who you include in your family. You can consider nuclear family, extended family, blended family, or self-proclaimed family, as long as they are a part of the group of individuals with which you have continuing legal, genetic, or emotional relationships with.

With these people in mind, we would ask you to continue this survey and answer the upcoming questions about family.

In this section, we are interested in finding out if you believe you could communicate or get support from any family member related to your health matters. Please answer as honestly as possible. Participants respond to each statement below with: 1 = strongly disagree 2 = disagree 3 = neither agree nor disagree 4 = agree 5 = strongly agree
I have at least one family member that discusses health matters at family gatherings.
I have someone I could partner with in my family regarding health concerns.
I could converse with someone in my family about my health.
I have someone in my family I could to talk to about what to do with health problems.
If I had children, I could share my health information with them.

My family could approach my health concerns as a team.
If needed, someone in my family could help me take my pulse (count my heart rate).
If needed, someone in my family could help me take my blood pressure
If needed, someone in my family could help me take my temperature
If needed, someone in my family could take action when I have health problems.
My family could be a team when it comes to my health issues.
My family could be considerate of my health issues.
My family could talk about their health experiences.
Someone in my family could help me manage my diet, if needed.
Someone in my family could help me plan for my nutritional needs.
Someone in my family could help me research health concerns.
Someone in my family could help me solve health problems.
Someone in my family could help me complete health-related paperwork.
Someone in my family could provide assistance in maintaining my diet.
Someone in my family could provide me emotional support when I deal with health issues.
Someone in my family could reassure me about my prognosis.
Someone in my family could review medical documents with me.
Someone in my family could share health resources with me.
Someone in my family could share information about family health history.
Someone in my family could share what works for them related to their health problems.
I could ask a family member about my health problems.
I could ask a family member about how they deal with my health problems.
I could ask a family member questions related to my health.
I could communicate with someone in my family about my health.
I could dialogue with someone in my family about health-related issues.
I could discuss health matters with someone in my family at family gatherings.
I could discuss my health matters with someone in my family on the phone.
I could discuss treatment options with someone in my family that might not have been brought up by my doctor.
I could discuss my medications with someone in my family.
I could discuss what my doctor says with someone in my family.
I could explain my health issues to family members.
I could gain knowledge about health concerns within my family.
I could get a lot of support from someone in my family for my health issues.
I could have an ongoing discussion about health with someone in my family.
I could have communication with someone in my family about my health.
I could learn good health habits from others in my family.
I could name a go-to person in my family for health matters.

I could name someone in my family that I consider to be the medical information person.
I could name someone in my family who is on “my side” with health concerns.
I could relate health matters to someone in my family.
I could share knowledge about health concerns with someone in my family.
I could tell a family member where to find my medications in case of an emergency.
I could talk to someone in my family that works as a health professional.
I could telephone someone in my family about health matters.
Someone in my family could recommend a physician for me.
Someone in my family can be attentive when I am ill.
Someone in my family could advocate for my health.
Someone in my family could ask me questions about my health.
Someone in my family could assist with housework when I have health issues.
Someone in my family could attend a health appointment with me.
Someone in my family could be actively involved in my health.
Someone in my family could be hands-on with my health.
Someone in my family could be there when I have health problems.
Someone in my family could care for me after a medical procedure.
Someone in my family could collaborate on my health issues when needed.
Someone in my family could come and stay with me if I have a major health situation.
Someone in my family could come to me with health questions.
Someone in my family could cook for me if I was ill.
Someone in my family could drive me to a health appointment.
Someone in my family could emotionally support me if I have health issues.
Someone in my family could encourage me to schedule appointments.
Someone in my family could go to a doctor’s appointment with me.
Someone in my family could help me be proactive about my health.
Someone in my family could help me emotionally when I have health issues.
Someone in my family could help me fact-check medical information I receive.
Someone in my family could help me feel less anxious about my health condition.
Someone in my family could help me gather information about my health.
Someone in my family could stay involved in my health.
Someone in my family could talk to my doctor with me.
Someone in my family could telephone me about health-related issues.
Someone in my family could visit me if I have health issues.
Someone in my family could visit me if I was hospitalized.
Someone in my family could volunteer to go with me if I needed to go to the doctor.
Someone in my family could encourage me to be physically active.

	Someone in my family could worry about my health concerns.
	Someone in my family could be good at medical research and would help me if needed.
	Someone in my family could share what does not work for them related to their health problems.
	Health could be a natural topic of conversation in my family.

In this final section, we want to understand a little bit more about you.

What is your gender?

Male Female Prefer not to answer

What is your marital status?

- ○ Married
- ○ Divorced
- ○ Separated
- ○ Widowed
- ○ Unmarried

How many living parents or stepparents do you have? ___________________

How many living siblings or stepsiblings do you have? ___________________

How many living children or stepchildren do you have? ___________________

What is the highest level of education you have completed?

- ○ Less than HS
- ○ HS/GED
- ○ Some college
- ○ 2-year college degree
- ○ 4-year college degree
- ○ Master’s degree
- ○ Doctoral degree
- ○ Professional degree (JD, MD)
- ○ Prefer not to say

What is your race? Select all that apply

- ○ American Indian or Alaskan Native
- ○ Asian

- ○ Black or African American
- ○ Native Hawaiian or Other Pacific Islander
- ○ White
- ○ Other
- ○ Prefer not to answer

What is your ethnicity?

- ○ Hispanic or Latino
- ○ Not Hispanic or Latino
- ○ Prefer not to say

What is your current employment status?

- ○ Full-time employment
- ○ Part-time employment
- ○ Unemployed
- ○ Self-employed
- ○ Home-maker
- ○ Student
- ○ Retired

Where did you learn about this survey opportunity?

- ○ Email
- ○ Social Media
- ○ Personal Referral
- ○ Other ___________________

THANK YOU SECTION

Your survey is now complete.

Thank you for participating in this survey. We truly value the information you have provided.

If you have questions or concerns related to this survey, contact the researcher Maria Brann at (xxx)xxx-xxxx and/or mabrann@iupui.edu. For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (xxx)xxx-xxxx or for Indianapolis or (xxx)xxx-xxxx for Bloomington or (xxx)xxx-xxxx by e-mail at irb@iu.edu

Appendix M

Recruitment message for Test-Retest Sample

Greetings! I am trying to collect a group of individuals to take a survey that I have created for my PhD dissertation project at two different time points, 2 weeks apart. This means, in the next week, I would send you the link to a survey that takes less than 20 minutes to complete, and then two weeks later, I would sent you the survey again.

The only requirements include: 1) you are 18 years or older and 2) you have a chronic condition. I have included a sample list of chronic conditions below. Do you meet these conditions? Would you be willing to complete the survey? If so, would you send me your email, and I will send you the survey when it is ready. Thank you for considering!

Sincerely,

Amanda Harsin

amharsin@iu.edu

- Addison's disease
- Asthma
- Bipolar Mood Disorder
- Bronchiectasis
- Cancer, please specify type:
- Cardiac failure
- Cardiomyopathy
- Chronic obstructive pulmonary disorder
- Chronic kidney disease
- Coronary artery disease
- Crohn's disease
- Diabetes insipidus
- Diabetes mellitus Type I
- Diabetes mellitus Type 2
- Dysrhythmias
- Epilepsy

- Glaucoma
- Haemophilia
- Hyperlipidaemia
- Hypertension
- Hypothyroidism
- Lyme’s Disease
- Multiple sclerosis
- Osteoarthritis
- Parkinson's disease
- Rheumatoid arthritis
- Schizophrenia
- Systemic lupus erythematosus
- Ulcerative colitis
- Other:

Appendix N

Time 1 Email and Reminder to Test-Retest Participants

Dear {First Name},

Thank you for agreeing to participate in an important part of my research study related to chronic conditions and family communication. This phase is very important because it requires participants like you to take my survey twice, 14 days apart. Please know that only participants who complete the survey both now and again in 14 days will provide the data required for the necessary statistics. To make it easy, I will send another email and another link in 14 days.

Below, you will find the link to the survey. This link will expire on Monday, November 12th at 6 PM EST. I appreciate the time you are giving me, and I appreciate your help.

Please do not hesitate to call, text, or email me if you have problems or need assistance.

Sincerely,

Amanda Harsin

amharsin@iu.edu

(xxx)xxx-xxxx

Follow this link to the Survey:
{ SurveyLink }
Or copy and paste the URL below into your internet browser:
{ SurveyLink }Follow the link to opt out of future emails:
{ SurveyLink }

Dear {First Name},

Thank you for agreeing to participate in an important part of my research study related to chronic conditions and family communication. This is a system-generated email to remind you to complete the survey before 6 PM EST on Monday, November 12th.

Below, you will find the link to the survey. I appreciate the time you are giving me, and I appreciate your help.

Please do not hesitate to call, text, or email me if you have problems or need assistance.

Sincerely,

Amanda Harsin

amharsin@iu.edu

(xxx)xxx-xxxx

Appendix O

Time 2 Email and Reminder to Test-Retest Participants

Dear {First Name},

Thank you for agreeing to participate in an important part of my research study related to chronic conditions and family communication. This phase is very important because it requires participants like you to take my survey **twice**, 14 days apart. You were so incredibly helpful by taking it the first time, but please know that only participants who complete the survey now for a second time provide the data required for the necessary statistics. Please know, it is indeed the exact same survey that you took previously.

Below, you will find the link to the survey. This link will expire on Monday, November 26th at 11 PM EST. I appreciate the time you are giving me, and I appreciate your help. I also apologize that this is coming out near the Thanksgiving holiday, that wasn't great planning on my part.

Please do not hesitate to call, text, or email me if you have problems or need assistance.
Sincerely,
Amanda Harsin
amharsin@iu.edu
(xxx)xxx-xxxx

Follow this link to the Survey:

{ SurveyLink }

Or copy and paste the URL below into your internet browser:

{ SurveyLink }

Follow the link to opt out of future emails:

{ SurveyLink }

Dear {First Name},

Thank you for agreeing to participate in an important part of my research study related to chronic conditions and family communication. This phase is very important because it requires participants like you to take my survey twice, 14 days apart. You were so incredibly helpful by taking it the first time, but please know that only participants who complete the survey now for a second time provide the data required for the necessary statistics. Please know, it is indeed the exact same survey that you took previously. Below, you will find the link to the survey. This link will expire on Monday, November 26th at 11 PM EST. I appreciate the time you are giving me, and I appreciate your help. Please do not hesitate to call, text, or email me if you have problems or need assistance.

Sincerely,

Amanda Harsin

Appendix P

Phase Three Survey in Qualtrics

Thank you for considering participation in our research related to chronic disease and family communication. The following information is required to be provided to you. By selecting "Continue" you are providing your consent in participation.

INDIANA UNIVERSITY STUDY INFORMATION SHEET FOR The Development and Testing of an Inventory to Measure Perceived Family Support and Health-Focused Communication Behaviors with Chronic Disease Patients

You are invited to participate in a research study investigating family support and communication related to your chronic disease. We ask that you read this form and contact us with any questions you may have before agreeing to be in the study. The study is being conducted by Dr. Maria Brann & Ms. Amanda Harsin in the Department of Communication Studies at Indiana University-Purdue University Indianapolis.

STUDY PURPOSE: The purpose of this study is to better understand how patients and their families communicate about chronic disease.

PROCEDURES FOR THE STUDY: If you agree to participate in the study, you will complete an online survey that will take approximately 30 minutes. In order to protect against loss of confidentiality, we do not want any identifying information associated with the survey.

RISKS OF TAKING PART IN THIS STUDY: To the best of our knowledge, the things you will be doing have no more risk or harm than you would experience in everyday life.

BENEFITS OF TAKING PART IN THIS STUDY: There is no guarantee that you will get any benefit from taking part in this study. However, some people have experienced increased knowledge and understanding about their illness after participating in similar studies. Your willingness to take part, however, may in the future help society as a whole better understand this research topic.

CONFIDENTIALITY: Your name will not be attached to any of the materials that you complete during the study. Please be aware, while we make every effort to safeguard your data once received from the online survey/data gathering company, given the nature of online surveys, as with anything involving the Internet, we can never guarantee the confidentiality of the data while still on the survey/data gathering company's servers, or while en route to either them or us.

Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be personally identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private as it will not be linked to your responses. However, it should be noted that researchers can be forced by law to tell people who are not connected with the study, including the courts, about your participation. Once the data is collected, the survey data files will be securely stored on Dr. Brann or Ms. Harsin's password protected computer at a locked office at IUPUI. Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator, her research associates, or the Indiana University Institutional Review Board or its designees.

PAYMENT: You will not receive payment for taking part in this study.

CONTACTS FOR QUESTIONS OR PROBLEMS: For questions about the study or a research-related injury, contact the researcher Maria Brann at (xxx)xxx-xxxx and/or mabrann@iupui.edu. For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (xxx)xxx-xxxx or for Indianapolis or (xxx)xxx-xxxx for Bloomington or (xxx)xxx-xxxx by e-mail at irb@iu.edu.

VOLUNTARY NATURE OF STUDY: Taking part in this study is voluntary. You may choose not to take part or may stop the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Indiana University-Purdue University Indianapolis.

SUBJECT'S CONSENT: In consideration of all of the above, you can consent to participate in this research study by selecting "Continue" below. By choosing to complete the web-based survey, you are providing implied consent to participate in the research. You may print this consent form for your records or a researcher will provide a paper copy for you at your request.

Do you wish to continue?

○ I wish to continue.

○ I do not wish to continue.

Which age group are you currently in?

○ Under 18

○ 18 or older

Please enter your age.

____

Has a doctor ever told you that you had any of these conditions? Select all that apply.

☐ Addison's disease

☐ Asthma

☐ Bipolar Mood Disorder

☐ Bronchiectasis

☐ Cancer, please specify type:

____

☐ Cardiac failure

☐ Cardiomyopathy

☐ Chronic obstructive pulmonary disorder

☐ Chronic renal disease

☐ Coronary artery disease

☐ Crohn's disease

☐ Diabetes insipidus

☐ Diabetes mellitus Type I

☐ Diabetes mellitus Type 2

☐ Dysrhythmias

☐ Epilepsy

☐ Glaucoma

☐ Haemophilia

☐ Hyperlipidaemia

☐ Hypertension

☐ Hyperthyroidism

☐ Hypothyroidism

☐ Lyme’s Disease

☐ Lupus

☐ Multiple sclerosis

☐ Osteoarthritis

☐ Parkinson's disease

☐ Rheumatoid arthritis

☐ Schizophrenia

☐ Ulcerative colitis

☐ Other: ____

☐ I have not been diagnosed with a chronic condition.

Please estimate how many years ago a doctor first told you that you had one of these conditions. Please only enter the number of years. You do not need to add a label. For example, 0.5, 10, etc.

____

Are you currently under a doctor’s care for any condition mentioned previously? Select all that apply.

☐ Addison's disease

☐ Asthma

☐ Bipolar Mood Disorder

☐ Bronchiectasis

☐ Cancer, please specify type:

____

☐ Cardiac failure

☐ Cardiomyopathy

☐ Chronic obstructive pulmonary disorder

☐ Chronic renal disease

☐ Coronary artery disease

☐ Crohn's disease

☐ Diabetes insipidus

☐ Diabetes mellitus Type I

☐ Diabetes mellitus Type 2

☐ Dysrhythmias

☐ Epilepsy

☐ Glaucoma

☐ Haemophilia

☐ Hyperlipidaemia

☐ Hypertension

☐ Hyperthyroidism

☐ Hypothyroidism

☐ Lyme’s Disease

☐ Lupus

☐ Multiple sclerosis

☐ Osteoarthritis

☐ Parkinson's disease

☐ Rheumatoid arthritis

☐ Schizophrenia

☐ Ulcerative colitis

☐ Other: ____

☐ I am not currently under a doctor's care for any of chronic condition.

In the next several sections, you will be asked questions about your family. In this study, we define family as a group of individuals with continuing legal, genetic, and/or emotional relationships.

With this definition, please take a moment to consider who you include in your family. You can consider nuclear family, extended family, blended family, or self-proclaimed family, as long as they are a part of the group of individuals with which you have continuing legal, genetic, or emotional relationships with.

With these people in mind, we would ask you to continue this survey and answer the upcoming questions about family.

	In this section, we are interested in finding out if you believe you could communicate or get support from any family member related to your health matters. Some statements may seem very similar; please read each question carefully and answer honestly how you agree or disagree with each individual statement. Please notice that statements do not say that you do, but they say that you could.				
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I have at least one family member that discusses health matters at family gatherings.	○	○	○	○	○
I have someone I could partner with in my family regarding health concerns.	○	○	○	○	○
I have someone in my family I could to talk to about what to do with health problems.	○	○	○	○	○
My family could approach my health concerns as a team.	○	○	○	○	○

If needed, someone in my family could help me take my temperature.	○	○	○	○	○
If needed, someone in my family could take action when I have health problems.	○	○	○	○	○
My family could be a team when it comes to my health issues.	○	○	○	○	○
My family could talk about their health experiences.	○	○	○	○	○

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Someone in my family could help me manage my diet, if needed.	○	○	○	○	○
Someone in my family could help me plan for my nutritional needs.	○	○	○	○	○
Someone in my family could help me research health concerns.	○	○	○	○	○
Someone in my family could help me solve health problems.	○	○	○	○	○
Someone in my family could help me complete health-related paperwork.	○	○	○	○	○

Someone in my family could provide assistance in maintaining my diet.	○	○	○	○	○
Someone in my family could provide me emotional support when I deal with health issues.	○	○	○	○	○
Someone in my family could reassure me about my prognosis.	○	○	○	○	○
Someone in my family could review medical documents with me.	○	○	○	○	○
Someone in my family could share health resources with me.	○	○	○	○	○
Someone in my family could share information about family health history.	○	○	○	○	○

Someone in my family could share what works for them related to their health problems.	○	○	○	○	○

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I could ask a family member about my health problems.	○	○	○	○	○
I could ask a family member about how I might deal with my health problems.	○	○	○	○	○
I could ask a family member questions related to my health.	○	○	○	○	○
I could dialogue with someone in my family about health-related issues.	○	○	○	○	○
I could talk to someone in my family that works as a health professional.	○	○	○	○	○

I could discuss health matters with someone in my family at family gatherings.	○	○	○	○	○
I could discuss my health matters with someone in my family on the phone.	○	○	○	○	○
I could discuss treatment options with someone in my family that might not have been brought up by my doctor.	○	○	○	○	○
If I had medications, I could discuss my medications with someone in my family.	○	○	○	○	○
I could discuss what my doctor says with someone in my family.	○	○	○	○	○

I could explain my health issues to family members.	○	○	○	○	○
I could gain knowledge about health concerns from my family.	○	○	○	○	○

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I could have an ongoing discussion about health with someone in my family.	○	○	○	○	○
I could have communication with someone in my family about my health.	○	○	○	○	○
I could learn good health habits from others in my family.	○	○	○	○	○
I could name a go-to person in my family for health matters.	○	○	○	○	○
I could name someone in my family that I consider to be the medical information person.	○	○	○	○	○
I could name someone in my family who is on “my side” with health concerns.	○	○	○	○	○

I could relate health matters to someone in my family.	○	○	○	○	○
I could share knowledge about health concerns with someone in my family.	○	○	○	○	○
If I had medications, I could tell a family member where to find my medications in case of an emergency.	○	○	○	○	○
I could talk to someone in my family that works as a health professional.	○	○	○	○	○
I could telephone someone in my family about health matters.	○	○	○	○	○

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Someone in my family could recommend a physician for me.	○	○	○	○	○
Someone in my family could advocate for my health.	○	○	○	○	○
Someone in my family could ask me questions about my health.	○	○	○	○	○
Someone in my family could assist with housework when I have health issues.	○	○	○	○	○
Someone in my family could be actively involved in my health.	○	○	○	○	○
Someone in my family could be hands-on with my health.	○	○	○	○	○

Someone in my family could be there when I have health problems.	○	○	○	○	○
Someone in my family could collaborate on my health issues when needed.	○	○	○	○	○
Someone in my family could come and stay with me if I have a major health situation.	○	○	○	○	○

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Someone in my family could come to me with health questions.	○	○	○	○	○
Someone in my family could cook for me if I was ill.	○	○	○	○	○
Someone in my family could drive me to a health appointment.	○	○	○	○	○

Someone in my family could emotionally support me if I have health issues.	○	○	○	○	○
Someone in my family could encourage me to schedule appointments.	○	○	○	○	○
Someone in my family could go to a doctor’s appointment with me.	○	○	○	○	○
Someone in my family could help me be proactive about my health.	○	○	○	○	○
Someone in my family could help me emotionally when I have health issues.	○	○	○	○	○
Someone in my family could help me feel less anxious about my health condition.	○	○	○	○	○

Someone in my family could help me gather information about my health.	○	○	○	○	○

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Someone in my family could stay involved in my health.	○	○	○	○	○
Someone in my family could talk to my doctor with me.	○	○	○	○	○
Someone in my family could visit me if I have health issues.	○	○	○	○	○
Someone in my family could visit me if I was hospitalized.	○	○	○	○	○
Someone in my family could volunteer to go with me if I needed to go to the doctor.	○	○	○	○	○

Someone in my family could encourage me to be physically active.	○	○	○	○	○
Someone in my family could worry about my health concerns.	○	○	○	○	○
Someone in my family could be good at medical research and could help me if needed.	○	○	○	○	○
Someone in my family could share what does not work for them related to their health problems.	○	○	○	○	○
Health could be a natural topic of conversation in my family.	○	○	○	○	○

	The next part of this survey contains a number of statement about families in general. Read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family.			
	Strongly Disagree if you feel the statement does not describe your family at all	**Disagree** if you feel the statement does not describe your family for the most part	**Agree** if you feel the statement describes your family for the most part	**Strongly Agree** if you feel the statement describes your family very accurately
Planning family activities is difficult because we misunderstand each other.	○	○	○	○
In times of crisis we can turn to each other for support.	○	○	○	○
We cannot talk to each other about the sadness we feel.	○	○	○	○
Individuals are accepted for what they are.	○	○	○	○
We avoid discussing our fears and concerns.	○	○	○	○
We can express feelings to each other.	○	○	○	○

There are lots of bad feelings in the family.	○	○	○	○
We feel accepted for what we are.	○	○	○	○
Making decisions is a problem for our family.	○	○	○	○
We are able to make decisions about how to solve problems.	○	○	○	○
We don't get along well together.	○	○	○	○
We confide in each other.	○	○	○	○

	The following statements refer to feelings and experiences that occur to most people at one time or another in their relationships with their families. For each statement there are three possible answers: Yes, No, Don’t know. Please select the answer you choose for each item.		
	Yes	No	Don't Know
My family gives me the moral support I need.	○	○	○
I get good ideas about how to do things or make things from my family.	○	○	○
Most other people are closer to their family than I am.	○	○	○
When I confide in the members of my family who are closest to me, I get the idea that it makes them uncomfortable.	○	○	○
My family enjoys hearing about what I think.	○	○	○
Members of my family share many of my interests.	○	○	○
Certain members of my family come to me when they have problems or need advice.	○	○	○

I rely on my family for emotional support.	○	○	○
There is a member of my family I could go to if I were just feeling down, without feeling funny about it later.	○	○	○
My family and I are very open about what we think about things.	○	○	○
My family is sensitive to my personal needs.	○	○	○
Members of my family come to me for emotional support.	○	○	○
Members of my family are good at helping me solve problems.	○	○	○
I have a deep sharing relationship with a number of members of my family.	○	○	○
Members of my family get good ideas about how to do things or make things from me.	○	○	○
When I confide in members of my family, it makes me uncomfortable.	○	○	○

Members of my family seek me out for companionship.	○	○	○
I think that my family feels that I'm good at helping them solve problems.	○	○	○
Other people's family relationships are more intimate than mine.	○	○	○
I wish my family were much different.	○	○	○

In this final section, we want to understand a little bit more about you.

What is your gender?

- ○ Male
- ○ Female
- ○ Other
- ○ Prefer Not to Say

What is your marital status?

○ Married

○ Widowed

○ Divorced

○ Separated

○ Never married

*

How many living parents or stepparents do you have? Please enter in number form.

____

*

How many living siblings or step-siblings do you have? Please enter in number form.

____

*

How many living children, custodians, or stepchildren do you have? Please enter in number form.

____

What is the highest level of education you have completed?

- ○ Less than HS
- ○ HS/GED
- ○ Some college
- ○ 2-year college degree
- ○ 4-year college degree
- ○ Master’s degree
- ○ Doctoral degree
- ○ Professional degree (JD, MD)
- ○ Prefer not to answer

What is your race? Select all that apply

- ○ American Indian or Alaskan Native
- ○ Asian
- ○ Black or African American
- ○ Native Hawaiian or Other Pacific Islander
- ○ White
- ○ Other
- ○ Prefer not to answer

What is your ethnicity?

○ Hispanic or Latino

○ Not Hispanic or Latino

○ Prefer not to answer

What is your current employment status?

○ Full-time employment

○ Part-time employment

○ Unemployed

○ Self-employed

○ Home-maker

○ Student

○ Retired

Where did you learn about this survey opportunity?

○ Email

○ Social Media

○ Personal Referral

○ Other ____

Your survey is now complete.

Thank you for participating in this survey. We truly value the information you have provided.

If you have questions or concerns related to this survey, contact the researcher Maria Brann at (xxx)xxx-xxxx and/or mabrann@iupui.edu. For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (xxx)xxx-xxxx or for Indianapolis or (xxx)xxx-xxxx for Bloomington or (xxx)xxx-xxxx by e-mail at irb@iu.edu.

Appendix Q

Request to Use McMaster Family Assessment Device

Amanda Harsin amharsin@iu.edu Tue, Nov 20, 2018, 9:32 AM to amansfieldmarcaccio,

Dear Dr. Mansfield Marcaccio,

I am a doctoral student at Indiana University-Purdue University Indianapolis completing a dissertation in health communication. I am writing to ask written permission to use the McMaster Family Assessment Device, specifically the general functioning scale in my research study. My research is being supervised by my chair, Dr. Maria Brann.

In my project, I have created an Inventory to Measure Perceived Family Support and Health-Focused Communication Behaviors with Chronic Disease Patients, and I would like to use your McMaster Family Assessment Device General Functioning Scale to assess the criterion-related validity of my inventory. I will be administering my inventory via the online survey software Qualtrics. I do not plan to modify the general functioning scale, it would be included after the participant completes the items in my inventory.

If it is also agreeable, I also ask your permission to reproduce it in my dissertation appendix. The dissertation will be published in the IUPUI Institutional Repository and deposited in the ProQuest Dissertations & Theses database. If you would still allow me to use it but wish for me not reproduce it, I will respect your wishes.

I would like to use your McMaster Family Assessment Device General Functioning Scale under the following conditions:

- I will use the FAD-GFS only for my research study and will not sell or use it for any other purposes
- I will include a statement of attribution and copyright on all copies of the instrument. If you have a specific statement of attribution that you would like for me to include, please provide it in your response.
- At your request, I will send a copy of my completed research study to you upon completion of the study and/or provide a hyperlink to the final manuscript

If you do not control the copyright for these materials, I would appreciate any information you can provide concerning the proper person or organization I should contact.

If these are acceptable terms and conditions, please indicate so by replying to me through e-mail at amharsin@iupui.edu.

Sincerely,
Amanda Harsin

Mansfield Marcaccio, Abigail K amansfieldmarcaccio@lifespan.org

Nov 20, 2018, 11:52 AM

Hello.

I handle requests for the FAD, and I am pleased to hear of your interest in the FAD. We generally grant permission to use the FAD as long as you do not publish it online, and agree to send us references for anything you publish about your work with the FAD. We recommend that you obtain a copy of the book, *Evaluating and Treating Families: The McMaster Approach* by Ryan e tal, 2005. It's available from major vendors such as Amazon.com. The book contains the measure, scoring instructions, and information about psychometric properties, as well as cut-off scores for each dimension. Please note that the cut-off score for the general functioning scale of the FAD is 2.0 and scores higher than 2.0 indicate distress. We also have an electronic scoring package available which includes the measure and software to score it. Please let me know if you are interested in purchasing the electronic scoring package.

Please let me know if I can be of further help,

Abigail K. Mansfield Marcaccio, PhD

Psychologist, Family Research and Family Therapy

Department of Psychiatry, Lifespan Physician Group

General Functioning Scale (GFS) of Family Assessment Device (FAD)

Directions: The next part of this survey contains a number of statement about families in general. Read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family.

Items not published per permission request.

	○	○	○	○
	○	○	○	○
	○	○	○	○
	○	○	○	○
	○	○	○	○
	○	○	○	○
	○	○	○	○
	○	○	○	○

	○	○	○	○
	○	○	○	○
	○	○	○	○
	○	○	○	○

Appendix R

Request to Use Perceived Social Support – Family Scale

Amanda Harsin amharsin@iu.edu Wed, Nov 14, 2018, 9:14 AM to Procidano, Maria

Dear Dr. Procidano,

I am a doctoral student at Indiana University-Purdue University Indianapolis completing a dissertation in health communication. I am writing to ask written permission to use the Perceived Social Support-Family Scale (PSS-FA) in my research study. My research is being supervised by my chair, Dr. Maria Brann.

In my project, I have created an Inventory to Measure Perceived Family Support and Health-Focused communication Behaviors with Chronic Disease Patients, and I would like to use your PSS-FA to assess the construct validity of my inventory. I will be administering my inventory via the online survey software Qualtrics. I do not plan to modify the instrument, it would be included after the participant completes the items in my inventory.

If it is also agreeable, I also ask your permission to reproduce it in my dissertation appendix. The dissertation will be published in the IUPUI Institutional Repository and deposited in the ProQuest Dissertations & Theses database. If you would allow me to use it but wish for me not reproduce it, I will respect your wishes.

I would like to use your PSS-FA under the following conditions:

- I will use the PSS-FA only for my research study and will not sell or use it for any other purposes

·   I will include a statement of attribution and copyright on all copies of the instrument. If you have a specific statement of attribution that you would like for me to include, please provide it in your response.

·   At your request, I will send a copy of my completed research study to you upon completion of the study and/or provide a hyperlink to the final manuscript

If you do not control the copyright for these materials, I would appreciate any information you can provide concerning the proper person or organization I should contact.

If these are acceptable terms and conditions, please indicate so by replying to me through e-mail at amharsin@iupui.edu.

Sincerely,

Amanda Harsin

Mary Procidano <procidano@fordham.edu>

Fri, Nov 16, 2018, 11:49 AM

Yes, this is fine. The attachments may be of use.

Best wishes,

Mary Procidano

~~~~~~~~~~~~~~~~~~~~~~~~~~

Mary E. Procidano, Ph.D., ABPP

Associate Professor

Psychology Department
~~~~~~~~~~~~~~~~~~~~~~~~~~

Dealy Hall 240

Fordham University

Bronx, NY 10583

718-817-0925

www.fordham.edu/psychology/procidano

Perceived Social Support-Family Scale (PSS-Fa)

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with their families. For each statement there are three possible answers: Yes, No, Don't know. Please circle the answer you choose for each item.

Yes, No, Don't know	My family gives me the moral support I need.
Yes, No, Don't know	I get good ideas about how to do things or make things from my family.
Yes, No, Don't know	Most other people are closer to their family than I am.
Yes, No, Don't know	When I confide in the members of my family who are closest to me, I get the idea that it makes them uncomfortable.
Yes, No, Don't know	My family enjoys hearing about what I think.
Yes, No, Don't know	Members of my family share many of my interests.
Yes, No, Don't know	Certain members of my family come to me when they have problems or need advice.
Yes, No, Don't know	I rely on my family for emotional support.
Yes, No, Don't know	There is a member of my family I could go to if I were just feeling down, without feeling funny about it later.
Yes, No, Don't know	My family and I are very open about what we think about things.
Yes, No, Don't know	My family is sensitive to my personal needs.
Yes, No, Don't know	Members of my family come to me for emotional support.
Yes, No, Don't know	Members of my family are good at helping me solve problems.
Yes, No, Don't know	I have a deep sharing relationship with a number of members of my family.

Yes, No, Don't know	Members of my family get good ideas about how to do things or make things from me.
Yes, No, Don't know	When I confide in members of my family, it makes me uncomfortable.
Yes, No, Don't know	Members of my family seek me out for companionship.
Yes, No, Don't know	I think that my family feels that I’m good at helping them solve problems.
Yes, No, Don't know	Other people’s family relationships are more intimate than mine.
Yes, No, Don't know	I wish my family were much different.

Appendix S

Phase Three Recruitment Email

Dear (Name),

I am recruiting potential participants for a doctoral dissertation to develop a scale on perceived family support and health-focused communication behaviors for patients with chronic disease(s). Participants must be at least 18 years of age and have a chronic disease or have had a chronic disease diagnosis in the past.

If you or anyone that you know meet the criteria to participate, I would greatly appreciate if you would complete the online survey or pass the survey link onto people that you may know. The survey can be accessed at this link: (Insert Link)

Please know the survey takes approximately 10 minutes. It can be taken from any computer, phone, or tablet. Only surveys **completed in their entirety** are going to be helpful for statistics. If you have any questions, please contact (email).

Potential chronic diseases (but please do not exclude yourself if your diagnosis is not listed- you will have opportunity to add it to the options):

Addison's disease, Asthma, Bipolar Mood Disorder, Bronchiectasis, Cancer (specify type), Cardiac failure, Cardiomyopathy, Chronic obstructive pulmonary disorder, Chronic renal disease, Coronary artery disease, Crohn's disease, Diabetes insipidus, Diabetes mellitus Type I, Diabetes mellitus Type2, Dysrhythmias, Epilepsy, Glaucoma, Haemophilia, Hyperlipidaemia, Hypertension, Hyperthyroidism, Hypothyroidism, Lyme’s Disease, Lupus, Multiple sclerosis, Osteoarthritis, Parkinson's disease, Rheumatoid arthritis, Schizophrenia, Ulcerative colitis, or any other diagnosed chronic disease.

Sincerely,
(Name)

Appendix T

Family HF-PSCB

These questions are about your family. For these questions, we define family as a group of individuals with continuing legal, genetic, and/or emotional relationships.

With this definition, please take a moment to consider who you include in your family. You can consider nuclear family, extended family, blended family, or self-proclaimed family, as long as they are a part of the group of individuals with which you have continuing legal, genetic, or emotional relationships with.

With these people in mind, we would ask you to continue this survey and answer the upcoming questions about family.

In this section, we are interested in finding out if you believe you could communicate or get support from any family member related to your health matters. Please answer as honestly as possible.

Participants respond to each statement below with:

1 = strongly disagree
2 = disagree
3 = neither agree nor disagree
4 = agree
5 = strongly agree

I could ask a family member about my health problems.

I could ask a family member about how I might deal with my health problems.

I could ask a family member questions related to my health.

I could discuss what my doctor says with someone in my family.

I could dialogue with someone in my family about health-related issues.

I would discuss treatment options with someone in my family that might not have been brought up by my doctor.

I could discuss my health matters with someone in my family on the phone.

Someone in my family could share what works for them related to their health problems.

Someone in my family could cook for me if I was ill.

Someone in my family could drive me to a health appointment.

Someone in my family could assist with housework when I have health issues.

Someone in my family could volunteer to go with me if I need to go to the doctor.

Someone in my family could come and stay with me if I have a major health situation.

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Zamanzadeh, V., Ghahramanian, A., Rassouli, M., Abbaszadeh, A., Alavi-Majd, H., & Nikanfar, A. R. (2015). Design and implementation content validity study: Development of an instrument for measuring patient-centered communication. *Journal of Caring Sciences, 4*, 165-178. https://doi.org/10.15171/jcs.2015.017

Zhang, Y., Wei, M., Shen, N., & Zhang, Y. (2015). Identifying factors related to family management during the coping process of families with childhood chronic conditions: A multi-site study. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, *30*, 160-173. https://doi.org/10.1016/j.pedn.2014.10.002

Curriculum Vitae

Amanda M. Harsin

Education

Ph.D., Indiana University, 2019

Indiana University-Purdue University Indianapolis

Major: Health Communication, Minor: Nursing

M.A., University of Kentucky, 2007

University of Kentucky, Lexington, Kentucky

Major: Communication, Emphasis: Health Communication

B.A., Hanover College, 2006

Hanover College, Hanover, Indiana

Major: Communication

Publications

Bell, L. G., & Harsin, A. (2018). A prospective longitudinal study of marriage from midlife to laterlife. *Couple and Family Psychology: Research and Practice*, *7*, 12-21.

Head, K. J., & Harsin, A.M. (2016). Mother knows best: Valenced subjective normative influences on young women's HPV vaccination intentions. *Florida Communication Journal*, 44, 15-24.

Conferences

Head, K. J., Harsin, A. M., & Ellis, R. J. (2017, June). *Identifying sources of patient dissatisfaction when seeking care for a chronic and complex disease: A content analysis*. Paper presented at Communication, Medicine & Ethics Interdisciplinary

Conference, Indianapolis, IN.

Harsin, A. (2016, November). *The relationship of family and patient activation to maintenance behaviors for polycystic kidney disease*. Paper presented at the annual meeting of the National Communication Association, Philadelphia, PA.

Johnson, N., Harsin, A., Zajac, R., & Parrish-Sprowl, J. (2016, November). *How Polish smokers decide to quit: An examination of the relationship between health literacy and health information seeking behaviors*. Poster presented at the annual meeting of the National Communication Association, Philadelphia, PA.

Harsin, A. (2016, November). *Accessing family communication and activation: The sharing of knowledge, beliefs, and confidence in families with genetic kidney disease and a post-transplant patient*. Research in progress presented at the annual meeting of the National Communication Association, Philadelphia, PA.

Johnson, N., Harsin, A., Zajac, R., & Parrish-Sprowl, J. (2016, May). *How Polish smokers decide to quit: An examination of the relationship between health literacy and health information seeking behaviors*. Poster presented at the annual meeting for the Society for Prevention research, San Francisco, CA.

Harsin, A. M, & Head, K. J. (April, 2016). *The effect of physician endorsement on patients' perceived importance and necessity in disclosing genetic disease to family.* Poster presented at Kentucky Conference on Health Communication, Lexington, KY.

Shin, Y., Breidenbach, M., Amarsinghe, U., Harsin, A. M., & Parrish-Sprowl, J. (April, 2016). *Investigating under-reporting of adolescent sexual assault: Preliminary* *analysis of focus group interviews with teachers.* Poster accepted to the Kentucky Conference on Health Communication, Lexington, KY.

Head, K. J., & Harsin, A. M (November, 2015). *Mother knows best: Subjective normative influence on young women's HPV vaccination intentions.* Paper presented at National Communication Association conference, Las Vegas, NV.

Shin, Y., Amarsinghe, U., Harsin, A. M, Breidenbach, M., & Parrish-Sprowl, J. (November, 2015). *Preliminary analysis of Indiana adults' adverse childhood experience report on sexual assault*. Poster presented to the American Public Health Association conference, Chicago, IL.

Harsin, A. M. (April, 2015). *An evaluation of individualism and collectivism in the United States' Centers for Disease Control and Preventions' health communication campaigns*. Paper presented at the Central States Communication Conference, Madison, WI.

Harsin, A. M. (April 2006). *Using personal construct theory to understand patient perceptions of health care providers' communication.* Paper presented at the Butler University Research Conference, Indianapolis, IN.

Harsin, A. M (April 2006). *Superior-subordinate relationships: Research study of the multiple authorities in medical organizations*. Paper presented at the Butler University Research Conference, Indianapolis,IN.

Harsin, A. M. (March, 2006). *Areté, Addams, and American democracy*. Paper presented at the Honors Conference in Communication at DePauw University, Greencastle, IN.

Invited Presentations at Educational and Professional Organizations

Head, K. J., & Harsin, A. M. (June, 2016). *Polycystic kidney disease patients' dissatisfaction with care: An analysis of poor care recall*. Invited presentation at the Polycystic Kidney Foundation's National Conference, Orlando, FL.

Harsin, A. (May, 2015). *Student success in community college coursework within traditional, hybrid, and online learning environments*. Paper presented at University of Wroclaw Conference, Wroclaw, Poland.

Brann, M., Coderre, P., Deason, A., DiBacco, A, Harsin, A. M., Johnson, N., Lara, P., & Rosenberger, S. *Reducing injury in Indiana: Promoting Indiana's injury prevention resource guide*. Indianapolis, IN: Department of Communication Studies, Indiana University-Purdue University Indianapolis, 2015.

Harsin, A. (February, 2015). *Information management strategies of families coping with a health crisis: In depth interview study*. Paper presented at Purdue University Research Conference, Lafayette, IN.

Harsin, A. (May, 2014). *Internationalizing interpersonal communication*. Poster presented at International Center for Intercultural Communication Conference. Bloomington, IN.

Baker, R., Cooney, J., & Harsin, A. *Internationalizing Ivy Tech curriculum*. Panel presented at Ivy Tech Community College Annual Chair Summit, French Lick, IN.

Harsin, A. (April 2009). *Jefferson County needs assessment*. Jefferson County United Way. Madison, IN.

Awards

President’s Award for Excellence in Instruction, Ivy Tech Community College, May 2016

Gail M. & William M. Plater International Scholarship for Community Engagement, Summer 2015

IUPUI International Experience Scholarship, Summer 2015

Department of Communication Studies Travel Grant, IUPUI, Spring 2015

Statewide Master Teacher, Ivy Tech Community College, April 2011

University of Kentucky Graduate Scholarship, August 2006

Philip R. Taylor Award for Student Publishing, April 2006

Distinguished Award for Communication, April 2006

Student Travel Award for Research, February 2006

Crow Long Merit Scholarship, Hanover College, September 2002