

CONSUMERS' PERCEPTIONS ON COLLABORATIVE  
COUNSELING AND HEALTH CARE

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A Thesis  
Presented  
to the Faculty of  
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In Partial Fulfillment  
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Master of Science  
in  
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by  
Brandy Nicole Thomas  
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## DEDICATION

I would like to dedicate this work to my Mother, who is the inspiration to my life and my Father- Lost for now but loved forever. Thank you for making me the woman I am today.

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## ABSTRACT

### CONSUMERS' PERCEPTIONS ON COLLABORATIVE COUNSELING AND HEALTH CARE

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Interest in collaborative services is on the rise, yet little is known about consumers' perceptions of these services. The current research study aimed to gain further information on consumers' and their family members' perceptions on collaborative counseling and health care in the areas of personal interest, perceived benefits, and the desired structure of the services. Participants completed a measure on family functioning and a constructed perceptions measure. A series of correlations were conducted and the results indicate that current health care satisfaction had a significant positive relationship with healthy family functioning and a significant inverse relationship with perceived physical benefits of collaborative services. The findings of this research indicate that consumers believe there is a perceived benefit and interest in collaborative counseling and health care.

## CHAPTER I

### INTRODUCTION

#### Background

The aim of collaborative family counseling and health care (CCHC) is to integrate family counseling with the treatment of a medical concern using a health care team that consists of several different professionals. As this field develops, it is becoming clear that there are many benefits to the collaboration between mental and physical health treatment. A variety of factors influence physical and mental health, such as the connection between the mind and body, family and culture. Finally it is important to explore the advantageous of treating physical and mental health together.

A variety of biological and psychological empirical research has uncovered the reciprocal connection between the body and mind, for example neuropeptide involvement in emotions (Zittel, Lawrence & Wodarski, 2002). Research also indicates that stress has a negative impact on the immune system and medical outcomes (Littrell, 2008). In addition, physical illness can be linked to a decline in mental well-being (Weaver & Hadley, 2011) and an increase in the use of mental health services (Yoon & Bernell, 2013).

An individual's family system can impact and be impacted by one's physical and emotional health. Research indicates that physical concerns experienced by a person can emotionally and physically affect that individual's whole family, such as a caregiver

experiencing poor mental and physical health due to factors such as family conflict, financial burdens, and the duration and type of care provided (Schulz & Sherwood, 2008). On the other hand, family functioning can positively influence an individual's health. Appropriate family involvement can have a positive effect on a patient's outcome (Papadopoulos, 1995; Walker & Chen, 2010). Finally, there are commonalities that can be seen within the family experience of a medical concern. McDaniel, Hepworth and Doherty (1999) explored the shared experiences of individuals struggling with a medical concern and their families and found ten emotional themes related to illness, one of which was finding a balance between sharing and privacy. This indicates the importance of the shared family experience when dealing with a medical concern.

In addition to the influence of family, cultural values and beliefs can play a large role in one's lifestyle and health. Due to cultural values, some individuals may have difficulty making health care choices without the input of their family (Pillari, 2005). For example, Chinese and Pakistani cultures often put family needs above individuals' wants (Kennedy, Godlas, Gale & Parker, 2010; Simpson, 2005). Due to the priority of the family's needs it can be rationalized that important decisions, such as health care, may fall to the family (Simpson, 2005).

Cultural values and beliefs play a role in how mental health symptoms are expressed and treated. Psychosomatic expressions of mental health symptoms are often exhibited in cultures where it is more acceptable to have a physical illness than a mental illness. For example, Korean Americans are more likely to express relational stressors somatically and therefore seek physical care rather than mental care (Kim, 2005).

Furthermore, suppression of emotions can also cause psychosomatic symptoms. In Chinese society aggressive behavior in women is less socially acceptable than for males, and can lead to feelings of guilt, stressful interpersonal relationships and reduced social support causing further deterioration of health (Weng, Lin & Jiang, 2010). It is important for mental health and medical professionals to be aware of potential causes of psychosomatic symptoms and to have an understanding that treatment may need to include a consideration of both physical and mental health.

The confounding variables that contribute to one's mental and physical health are intertwined with one another. Due to the connectedness of the mind-body connection, family impact, and cultural values, it would be advantageous to integrate treatment to account for these interactions. Bischoff, Springer, Felix and Hollist (2011) explained the importance of treating the entire person, including the mind, body, and soul. Bischoff et al. reported the importance of holistic treatment because it allows the patient to feel understood and cared for. In addition to the benefits of collaborative care indicated above, integrative services can be beneficial to the members of a care team by increasing effective communication and collaboration between the providers and the consumer of the services (Bischoff et al., 2011; Papadopoulos & Bor, 1995).

The research support for collaborative services is evident. However, due to the newness of CCHC that many facets still require further investigation. Miovic et al. (2006) reported that little quantitative data exists regarding the content of psychotherapy in contemporary clinical settings, as well as what patients and clinicians think it ought to be. Moreover, little is known about consumers' perceptions on CCHC and the format or

structure they would desire for these services (Bischoff et al., 2011). Since McDaniel et al. (1999) and many others have reported the shared family experience of illness, it is also important to gain an understanding of the family's perceptions on CCHC as well as the relationship between family functioning and health concerns.

### Purpose of Study

According to a 2009 publication by the Center for Disease Control, about 133 million Americans—nearly 1 in 2 adults—live with at least one chronic illness.

Furthermore, depression is relatively common in patients of primary care, particularly if the illness is severe and chronic (Østergaard & Foldager, 2011). This staggeringly high number of people suffering from chronic illness in America suggests the imminent need for a greater understanding and utilization of collaborative services. The current research study aimed to gain further information on individuals' and their family members' perceptions on CCHC in the areas of interest, potential benefits, and ideal structure of the services. Knowledge of what these CCHC services should look like is needed in order to properly format services to maximize consumer benefit and involvement.

The present study intended to fill current gaps in the collaborative services research by posing four questions: 1. What do consumers and family members want the structure of collaborative health care and counseling to look like? 2. What are consumers and family members' interest in and perceptions on possible benefits that are associated with collaborative counseling and health care? 3. Is there a relationship between family functioning and satisfaction with health care services, use of mental health services in the past, and the perceived benefit of CCHC to mental health in the future? 4. Are there

demographic differences regarding perceptions of CCHC? Two predictions also were made for this study: 1. Healthy family functioning will be positively correlated to current health care satisfaction. 2. Individuals that are less satisfied with their current health care will be more likely to be interested in CCHC services. These questions and predictions were addressed through a combination of Likert scale questions and open-ended questions to provide a more enriched view of perceptions on CCHC. Finally, the family APGAR questionnaire was used to identify family functioning and its possible relationship to the medical concern.

#### Limitations to the study

The primary limitation in the present study is the lack of knowledge in the community regarding collaborative counseling and health care. Due to the lack of knowledge on CCHC it may have been difficult for participants to assess their interest in the services and envision how they would like these services structured. While a short description of collaborative services was provided to participants before taking the survey, participants may not have fully understood the concept due to the newness of the field. Secondly, the diversity of methods used in advertising the research study at health centers may also serve as a limitation in this study. There was a lack of consistency in areas such as, communicating who was eligible or purpose of the research that may have hindered potential participants by limiting their access to research flyers. Either a live presentation or written directions accompanied recruitment flyers to educate health center staff on the study and on participant recruitment. However, due to the large amount of

staff and the busyness of the health centers, not all staff may have received the information.

#### Definition of terms

Three important terms need to be defined in the current study to provide clarification and consistency to the research. For the purpose of this study a medical concern is defined as an acute or chronic physical illness or disease experienced by an individual. Collaborative/integrative counseling services are defined as the integrative treatment of a person (and the individual's family) struggling with a medical concern by professionals such as doctors, spiritual leaders and therapists. Finally, for the purpose of this study Medical family therapy and CCHC are referring to the same type of treatment and care.

## CHAPTER II

### LITERATURE REVIEW

#### The Connection between Physical and Mental Health

The connection between the mind and body has been contemplated for thousands of years. However, with growing empirical research we now have a better understanding of how it is that they connect. Littrell (2008) reported that, while the mind and the body might once have been seen as separate domains, the proliferating results demand an appreciation of the interconnection between mental states and physical processes. Currently, considerable research exists in the fields of both physical and mental health that support the interconnections between these processes.

In Littrell's research she explored environmental factors such as stress and the impact the environmental factors have on the body, and found that stress diminishes white blood cell response to viral infected cells and to cancer cells. This could be visualized as a cycle; stress causes a decrease in the function of the immune system, which then causes a person to worry about her or his immune deficiency.

Zittel, et al. (2002) found the newest research on the mind and body connection gained strength by the discovery of the role of neurotransmitters and neuropeptide networks and their effect on emotions and behavior. Littrell (2008) also expressed the importance of the role that stressful events have on medical outcomes and how clinical psychological interventions can produce a positive impact on disease

outcome. This research further supports the notion that the mind and body are not mutually exclusive.

While Littrell (2008) discussed environmental factors such as stress and the effect they can have on the body, conversely physical health can also cause emotional stress. Yoon and Bernell (2013) found that when individuals are confronted with experiences such as a new diagnosis, unexpected hospitalization, or major surgery, feelings such as anxiety or depression may arise or increase for some individuals. In these situations several things may cause the emotional distress or psychiatric disorder, such as the uncertainty of health outcomes associated with the medical concern, financial strain, or the inability to do everyday tasks (Yoon & Bernell, 2013).

Weaver and Hadley (2011) discussed the relationship between chronic illness and poor mental health. They stated that the relationship between chronic illness and poor mental health is likely at least partially due to societal influences, however it undoubtedly has important social consequences, such as poor social relationships. Yoon and Bernell (2013) found it imperative to study the extent to which an individual's adverse physical health event actually influences the utilization of mental health services. They found that physical health events substantially increased the utilization of mental health care, and mental health service use increases with the severity of a physical health condition. This research supported the important role a medical concern can play in the need for mental health services. Much research has been conducted to expose the symbiotic relationship between the mind and body. However, the importance and approach of how to treat the mind and body together is still under review.

## Family Impact

Papadopoulos (1995) stated that people are all influenced by and influence their environmental and relational surroundings. She continued on to say that events such as illness change not only intrapersonal climates but also interpersonal relationships, affecting individuals' perceptions of their position and role both within the family and within larger society. Papadopoulos also noted that the family system is not necessarily defined by a biological relationship but can also be defined by a close social union between two or more people.

The impact of a medical concern on mental and physical wellbeing is not exclusive to the individual; the entire family can be affected as well. Illness is both an individual and a relational issue (McDaniel et al.,1999). According to McDaniel et al., medical concerns can bring a family closer together through caregiving or it can cause misunderstanding, doubt and despair in a family. Furthermore, when a family member struggles with a medical concern, caregiving may be a necessary part of the family member's treatment or recovery. This caregiving duty often falls to a family member. Papadopoulos et al. (2011) found that caregivers of cancer patients had significantly worse mental health than the person to whom they provided care. Schulz and Sherwood (2008) stated that clinical observations and early empirical research found that assuming a caregiving role can be stressful and burdensome. This indicated the strong impact the medical concern has on the family and how it can lead to family members' own development of physical and mental concerns.

In many cases the family system is a person's most important social system, and has the capacity to either aid or hinder the growth and development of any particular member depending on the family's beliefs and interactions (Papadopoulos, 1995). Not only does a medical concern affect the family, in turn the family can influence the medical concern as well. This influence can be positive or negative and be emotional and physical in nature. The family's impact on health, and vice versa, is also relevant in regards to how a family adjusts to and copes with illness (Papadopoulos & Bor, 1995). Papadopoulos and Bor discussed the importance of family members involvement in counseling because it is almost inevitable that they will be involved in the patient's illness experience. Be it genetic or behavioral, the family not only affects health and illness behaviors but also the modification of these behaviors (Papadopoulos, 1995). Papadopoulos also reported that support from family members has been found to be predictive of successful health modification endeavors. Walker and Chen (2010) reported that mobilizing the entire family may be effective for administering medications appropriately and regularly, which can aid in recovery of the ill person. This suggests that family involvement can have a beneficial effect on the physical health as well as the mental health of the person struggling with a medical concern.

Conversely, in some cases inappropriate family support or lack thereof can have adverse effects on the individual struggling with a medical concern. Maintenance of poor health practices can come about if the family does not support the person struggling with a medical concern to have a positive and healthier lifestyle (Papadopoulos, 1995). In some cases families can provide too much support and may smother a patient

emotionally in a futile attempt to prevent dissolution of the family as they know it, running the risk of incapacitating the patient and burning out the caregiver (McDaniel et al., 1999). According to McDaniel et al., some family members who are frightened by the medical threat and faced with the reality of death may respond by distancing themselves from the ill patient. These concepts stress the importance of appropriate support from a family system due to the profound effect they may have on the person struggling with a medical condition.

From analyses of clinical experience with families struggling with a medical concern, McDaniel et al. (1999) established ten emotional themes related to illness: denial vs. acceptance, despair vs. hope, secrecy vs. sharing, guilt vs. forgiveness, burden vs. relief, isolation vs. connection, passivity vs. taking charge, fear vs. courage, loss vs. renewal, and senselessness vs. meaning. Not all families will experience all of the themes or will experience them to the same degree. The history and experiences of the families will help determine their susceptibility to each particular theme (McDaniel et al., 1999).

Exploring the emotional theme of secrecy vs. sharing, McDaniel et al. (1999) recognized that for many Americans, illness, like sex and money, should be kept private. The western value of privacy can cause the person struggling with a medical illness to hold back emotions and thoughts, which then have the potential to cause greater harm. McDaniel et al. go on to say that such secrecy may extend from a learned privacy about our bodies, or may be a means to be brave and not burden loved ones. In other words, not only is a person struggling with a medical concern, the person is also struggling with

deciding what level of disclosure will be least harmful to the entire family. The person struggling with the illness and that individual's family are in a constant state of unknowing about the outcome. The family fluctuates between hope and despair regarding the medical concern and can either be at the mercy of these oscillations of emotion, or learn to anticipate and cope with them, discovering ways to modulate the stormy highs and lows (McDaniel et al., 1999). The influence of the themes can be very strong and felt by the whole family. Due to the shared and overlapping experience of the themes by the family, it can be advantageous to treat and heal the family system together.

### Family and Culture

The western societal value of independence is widely practiced by many Americans. However, many subset cultures in American place a higher value on the family as a unit instead of the individual, and consequently affects the way decisions are made by an individual. In collectivist societies the entire family may need to be involved in making decisions around stressful events, which can include health care and other life choices. This is exhibited in Chinese society, where the family rather than the individual is the structural and functional unit (Simpson, 2005). Therefore, the diagnosis and treatment of a medical concern becomes a family affair (Simpson, 2005).

Kennedy et al. (2010) reported that in Pakistani culture, individuals place much importance on subordination of the desires of the individual to that of the nuclear family. Venezuelans also have a strong family system that extends beyond the typical nuclear family to include grandparents, aunts, uncles and cousins all of which are considered to be important when making family choices (Guanipa, Nolte & Guanipa,

2002). The belief that family needs are more important than individual needs is also something essential to consider when treating Indian Hindu families (Pillari, 2005). Moreover, African American families tend to be involved in individual decision making due to the collectivist nature of the culture (Hines & Boyd-Franklin, 2005). This involvement extends beyond biological bonds to include the entire community into their extended family system, which may need to be considered in therapy (Hines & Boyd-Franklin, 2005). In other words, it might be very challenging for individuals to make a difficult life choice without their family. The strength of the family system as seen in these and other cultures further stresses the importance of providing inclusive family services in physical and mental health care.

Not only are views on decision making different in other cultures, but beliefs regarding symptomology and the etiology of mental and physical illness varies across families as well. Bischoff et al. (2011) stated that patients' experience of disease (or whatever it is that prompts them to seek care) exists within biological, social, psychological, and spiritual systems. Therefore, it is important for medical and mental health care providers to understand that not all physical and emotional symptoms are distinct. This is due to the fact that in some cultures individuals may manifest symptoms in nontraditional Western ways such as psychosomatically. Psychosomatic symptoms that can include physical and mental symptoms such as fatigue, headaches, dizziness, nausea, weakness, insomnia, and memory impairment, are the most common complaints in primary care (Weng et al., 2010). An example of this is when Korean American clients may express psychological discomfort as physiological discomfort. Psychosomatic

complaints, such as heartburn, are sometimes caused by mental distress but manifest as physical distress because in Korean American culture, it is more acceptable to have physical symptoms rather than emotional ones (Kim, 2005). Therefore, it is imperative to understand that physical symptoms do not always have a physical cause but instead may be caused by emotional distress.

Simpson (2005) reported evidence that cultural beliefs play an important role for Chinese women with cancer. She goes on to say that some Chinese women think worry, stress, and depression cause illness including breast cancer, while others who reported a sense of being invulnerable to cancer often linked causation to bad luck or fate. In Pakistani culture, some people believe mental illness is a result of any one or a combination of three factors: spirit possession, black magic, or a test from God (Nath, 2005). Lastly, Hines and Boyd-Franklin (2005) reported that African American families may view psychiatric symptoms as possible spiritual possession. These psychosomatic and spiritual expressions of mental illness confirm the importance of treatment collaboration between spiritual/religious, mental health, and physical health professionals.

Spirituality may be beneficial to address when treating a family with a medical concern, especially in cultures that have a strong spirit essence. Spiritual beliefs can hinder or help treatment within a family. Kim (2005) stated that attending to Korean American clients' spirituality not only helps them find meaning in life but also helps them resolve issues of "unforgiveness" which can be an underlying cause of various mental health problems. Kim continued to say the inability to forgive creates relational stress

and is a factor in the increasing number of divorces among Korean Americans. Another example that supports the importance of considering spirituality in treatment is Islamic understanding of mental illness as a test of one's faith (*iman*) in which one must struggle within one's self (*nafs*) not to succumb to the habitual tendency of the egocentric or lower self (Kennedy et al., 2010).

For Indian Hindu families there may be no separation between spirituality and everyday life (Pillari, 2005). Finally, in the African American culture spirituality may be in conflict with the problem or used to help resolve it (Black & Jackson, 2005). For instance, evangelicals may take a more passive role in treatment because they believe it will be resolved through "God's will" (Larsen, 1978). As Western society moves toward a more collaborative approach to healthcare it is wise to consider consumers' cultural values and beliefs, as well as the importance of offering treatment to the family system along with the individual.

Stigma can impact many areas of a person's life, including physical and mental health as well as treatment options. According to Link and Phelan (2001) stigma can be expressed as labeling, stereotyping, separation, status loss, and discrimination. Due to stigmas, many people who might benefit from mental health services choose not to obtain them or do not fully adhere to treatment regimens once they begin (Corrigan, 2004). Two types of stigma have been found in mental health, public stigma and self-stigma, both of which can serve as important barriers to seeking mental health services (Corrigan, 2004). Public stigma is the perception held by a group or society that an individual is socially unacceptable and often leads to negative reactions toward them

(Vogel, Wade & Haake, 2006). Self-stigma is the reduction of an individual's self-esteem or self-worth caused by the individual self-labeling herself or himself as someone who is socially unacceptable (Vogel et al., 2006). Fear of stigma or labeling by the public may also hinder a person from seeking physical health services. The negative impact of public stigma is also observed in the community health care system; people labeled mentally ill are less likely to benefit from the depth and breadth of available physical health care services compared to people without these illnesses (Corrigan, 2004).

Not only can people diagnosed with a mental illness feel stigmatized, their family members may be victims of stigma as well. Among families of Japanese patients diagnosed with schizophrenia, internalized stigma may not only hinder help-seeking behaviors but also result in family members attempting to provide care themselves in order to decrease the stigma felt by all members of the family (Hanzawa et al., 2012). Chinese Americans are more likely than European American to think it is important to know a marriage partner's family history of mental illness, due to mental illness stigma not only affecting the individual who has the illness, but also the individual's associates and the family members in Chinese societies (WonPat-Borja, Yang, Link & Phelan, 2012).

Van der Sanden, Bos, Stutterheim, Pryor and Kok (2013) reported that perceived public stigma and stigma by association contribute to psychological distress among family members of people diagnosed with a mental illness. Stigma can be associated with physical health as well. Logie and Gadalla (2009) reported that high

stigma levels in HIV participants were consistently and significantly associated with lack of social support, poor physical health, poor mental health, and lower income. Stigma can create significant challenges for families struggling with medical and mental health concerns.

### Integrative and Collaborative Services

With a more encompassing form of health care on the rise, many professionals, such as doctors, therapists, policy makers, and social workers will need to become fluent in the new system in order to provide superior care to consumers. In 2009 the Institute of Medicine (IOM) published a report on the increased interest by consumers in integrative health care and the use of complementary and alternative therapies, such as acupuncture (Kreitzer, Kligler & Meeker, 2009). With the increased interest in integrative health care, health professionals need to be sufficiently informed about integrative health so they can effectively care for their patients (Kreitzer et al., 2009). Boon, Verhoef, O'Hara, and Findlay (2004) stated policy makers will need to consider a health care system that incorporates a number of different practice models for different types of care, rather than focusing on a single model (i.e., "one size fits all" approach). If professionals are unaware of integrative services the person with the medical condition may miss out on a host of treatments or opportunities that may be beneficial to recovery.

Collaborative services require adaptability of all professionals involved in the care team to accommodate these changes. Boon et al. (2004) stated a health care system that incorporates different models for different types of care creates flexibility, especially if patients are allowed to choose the type of care they believe best suits their needs. One

example of integrative services that incorporate flexibility and choice can be seen in mental health care. In wraparound services, a dedicated care coordinator works together with a family and youth (if developmentally appropriate) to identify strengths, needs, and potentially effective strategies, culminating in a single, coordinated, individualized plan of care. Wraparound services connects the family with a community team and would involve collaboration with many professionals such as therapist, mentors, in-home behavioral support services, child welfare case workers, and juvenile probation officers (Bruns et al., 2010). Wraparound services are team based and strive to include the family and youth's voice on choices and goals (Bruns et al., 2010). These principles are consistent with those of collaborative medical services.

Bischoff et al. (2011) discussed patients' multisystemic (e.g. psychological, social, biological and spiritual) experiences of disease and that, for successful treatment to occur, a provider must be willing to work within and between these systems. Due to the highly collectivistic nature of the African and African American community, Kanya (2005) suggested that in working with African American families treatment should be highly collaborative, where the family along with the provider ask questions and learn together. This therapeutic collaboration is parallel with integrative medical services, where all members of the team work and grow together. Providers are no longer treating a disease, but a person with a disease (Bischoff et al., 2011). With patient-centered care that focuses on healing the whole person—mind, body, and spirit- in the context of community (Kreitzer et al., 2009). It appears that, as a result of caring about a patient and seeing the complexity of their experience, a provider may have a natural desire to

prioritize the patient's voice and to empower the patient in her or his role as a collaborator in the care team (Bischoff et al., 2011).

Although medical school provides some basic counseling training, it is not the primary focus of the curriculum. Papadopoulos and Bor (1995) believe collaborative services should also help colleagues of the therapist, such as doctors, to improve their therapeutic skills for dealing with patients who present with emotional or psychological issues or problems. It could also be inferred that the therapist would benefit from the collaborative relationship by gaining a better understand of the physiological components of medical concerns. When providers collaborate this communicates to the patient that the care team is working to facilitate relief of distress in multiple systems of a patient's experience (Bischoff et al., 2011). Bischoff et al. stressed that collaborative communication about patients' stories helps them to feel heard and cared for, which empowers them and increases patient agency. The presence of a counselor on a primary health care team can not only benefit the individual patients seen by the counselor, but can also benefit the health care team as a whole (Papadopoulos & Bor, 1995). In other words, health care providers would receive increased support and collaboration to provide more insight and expand the possibilities for the person seeking treatment and his or her family.

As interest in integrative services increases, so does patients' involvement in, and responsibility for their health care. As patients with medical concerns becomes more involved in their health care, their role in the care team becomes stronger (Boon et al., 2004). Instead of taking a passive role in their health care, people with the medical

concerns are now involved in treatment decisions and are considered a critical part of the care team. Bischoff et al. (2011) reported a key ingredient to the practice of integrated care is expanding the care team to include the patient, relevant people in the patient's natural social systems (e.g., family members), and other professionals who can help address the various dimensions of the patient's biological, psychological, social, and spiritual experience of disease. The authors state that, by allowing a patient to take a more active role in their health care, this elevates a patient's role to that of a collaborator on a care team. Patients' active roles in health care decisions can take many forms, such as who they want involved in their care team and where they want to receive their services.

The interest and need for integrative services has required professionals in many fields to develop approaches to accommodate the patient's needs. One of the most notable approaches to integrative services is Medical Family Therapy or MedFT (Pratt, 2003). In Pratt's interview with Susan McDaniel, one of the pioneers of MedFT, McDaniel's stated that it was in the early 1980's when Family Medicine and family therapy began to be integrated. Since the creation of MedFT, numerous definitions now incorporate many different aspects of collaborative services. Linville, Hertlein, and Lyness (2007) combined many definitions of MedFT and defined it as a biopsychosocial-spiritual approach to health care, which is informed by systems theory and spans across a variety of clinical settings. Linville et al.'s definition also indicated the patient's interpersonal relationships are believed to play a key role in collaborative approach, and the importance of collaboration between the family therapist and other health care

practitioners. According to Bischoff et al. (2011) MedFT may expand the definition of what many practicing the biomedical approach consider to be a successful treatment outcome to include improved functioning in psychological, social, and spiritual systems. This definition continues to adapt and grow alongside the field and the families it serves.

The merging of what were two exclusive fields, mental and physical health, was revolutionary at its time and allowed for a new method of approaching the treatment of a medical concern by considering not only the patient but also that individual's family system. The field of MedFT bridges psychosocial and physical health, examining the correlations between family, context, and an individual's physical functioning, offering family therapy interventions for medical illnesses (Linville, et al., 2007). In MedFT, the patient as a person, in all his or her complexity and wholeness, is at the center of health care (Bischoff et al., 2011). Bischoff et al. found those practicing MedFT appear to do this by (a) recognizing and respecting the patient's multisystemic experience of disease, (b) developing a caring relationship with the patient, and (c) elevating patients in their role in the health care team. MedFT and other integrative services offer open communication between professionals and the family regarding types of services, treatment, and the family's shares experiences with the medical concern.

According to McDaniel et al. (1999) medical family therapy offers an opportunity for communication to occur between the patient and her or his family. They continue on to say that this new connection provides clarity of the patient's experience, and offers new intimacies and new understandings between the family members. Bischoff et al. (2011) stated that eliciting a patient's stories about her or his experience,

allows providers to understand the complexity of a patient's experience of both the disease and treatment. They go on to say that this new understanding of the patient's experiences allows providers to work within the multiple systems of the patient's experience. A cornerstone of medical family therapy is the belief that illness journeys are eased when they are shared with others (McDaniel et al., 1999). This concept can be extended out beyond the family to include community members, spiritual leaders, and friends that are significant in a patient's life. In conclusion, many powerful aspects make up MedFT, such as communication, patient empowerment, and family support that constitute Medical family therapy. However, at the core of MedFT are the unique individuals and family members that are struggling with the medical concern. In MedFT it is essential to operate under the belief that these families are so much more than the medical concern they are struggling with. This uniqueness is why continued research and understanding of collaborative counseling and health care is so essential.

#### Research Questions

The intention of the present research study was to develop a greater understanding of consumers' perceptions on collaborative health care and counseling. Although research in the field began in the early 1980's, collaborative counseling and health care is still being defined today, and thus many questions are still left unanswered, such as what consumers want collaborative services to look like and a better understanding of their perceptions of the services. The current study focused on structure of collaborative counseling, family relationships, and the perceived benefits from the

perspective of both persons struggling with a medical concern as well as family members of a person struggling with a medical concern.

The current study posed four primary research questions. Research Question 1 (RQ1): What do consumers and their family members want the format and structure of collaborative services to look like? RQ2: What are the perceived benefits and perceptions of collaborative counseling and health care as seen by the consumer and family? RQ3: Is there a relationship between family functioning and satisfaction with health care services, use of mental health services in the past, and the perceived emotional benefit of CCHC services? RQ4: How do demographic differences relate to perceptions of collaborative counseling?

The current study also posed two hypotheses. Hypothesis 1 (H1): Healthy family functioning will be positively correlated to current health care satisfaction. H2: Individuals that are less satisfied with their current health care will be more likely to be interested in CCHC services.

## CHAPTER III

### METHODOLOGY

#### Participants

A total of 80 participants (74 females, 6 males) with a mean age 30.61 participated in this research. From the 80 participants, 15.8% identified themselves a person struggling with a medical concern, 57.9% as a family member of a person struggling with a medical concern and 26.3 % as both a family member and a person struggling with a medical concern. Regarding ethnic identity, participants identified themselves as: 53.8% White/Caucasian, 16.3% Asian, 15% Hispanic or Latino, and 12.5% multiracial. Regarding relational status, 51.3% of the participants identified themselves as never been married, 18.8% identified themselves as married, 18.8% as member of an unmarried couple, and 7.5% as divorced. The religious preference of most participants was Christianity (32.5%), while 22.5% of participants reported no religious preference. Almost half of the participants reported having attended some college but not having finished (46.3%). When participants were asked about previous mental health services, 66.2% of participants reported they had received some type of counseling services in the past. Of these participants, 60.4% reported having received multiple mental health services in the past (i.e. counselor, psychiatric, family), while only 10% reported a counselor/MFT as their only previous mental health experience.

## Measures

Two measures were used in the current study. The first was the Family APGAR questionnaire, used in medical settings to assess family connectedness and functioning. The second survey was constructed solely for the purpose of this study to address patients' and their family members' perceptions on integrating family counseling with medical treatment. This survey is referred to as Perceptions on Collaborative Counseling and Health Care (PCCHC, see Appendix A). In addition, 12 demographic questions were included in the online survey to address: ethnicity, spirituality, marital status, education level and previous exposure to mental health services. In this section participants were also asked to identify who in their family system has a medical concern: themselves, or a family member, or both.

Family functioning was measured using the Family APGAR questionnaire (Smilkstein, 1978). The questionnaire is comprised of one 5 item rating scale and a series of open-ended questions both of which assess family functioning in the areas of adaptation, partnership, growth, affection and resolve. The open-ended questions are divided into 7 sections to assess the 5 areas of functioning. The Likert rating scale consists of 5 questions with responses ranging from 0 points (*hardly ever*) to 2 points (*almost always*). Smilkstein (1978) reports a score of 7 to 10 on the Family APGAR suggests a highly functional family, while a score of 4-6 indicates a moderately dysfunctional family and a score of 0-3 suggests a severely dysfunctional family. In a validity study by Smilkstein, Ashworth, and Montano (1982) they found the Family

APGAR to be positively correlated with the Pless-Satterwhite Family Function Index ( $r=0.80$ ) and therapist estimate ( $r=0.64$ ), both supporting the validity of the measure.

A measure of perceptions on collaborative counseling and health care was constructed for this study (PCCHC). Questions were designed by taking into consideration the current literature in the field in addition to collaboration between researchers and community health providers regarding the mental and physical health needs of the community. A total of 15 items were written to assess perceptions of collaborative health care and counseling. The first 6 items were written to gain information on the desired format and structure of collaborative counseling services. These questions addressed areas such as desired location of the sessions and desired professional and nonprofessional involvement in the counseling services. The remaining questions (9 items) aimed to gain an understanding of the impact the medical concern has on the family and possible benefits of collaborative counseling for the family. A range of question styles were used including 5-point Likert rating scales, multiple choice, and open ended; this allowed the participants to elaborate where needed on particular topics and gain further insight on the perceptions of these services.

### Procedures

Participants were recruited through fliers posted in various community health centers. Additionally fliers were also posted on a college campus and campus health center. All participants read the online informed consent, which included information on the voluntary nature of the study and the right to withdraw at any time. Participants acknowledged their agreement to participate by checking a box at the bottom of the

informed consent prior to beginning the online survey. The online survey was facilitated by Questionpro, and all information was password protected on the secure site. In order to protect participants' anonymity the survey did not include questions regarding identifying information. All participants received the survey questions in the same order. Demographic questions were asked first, preceded by a brief written explanation of integrative services. Next participants were prompted to answer questions on their perceptions of collaborative health care and counseling and lastly the Family APGAR assessment was presented. Each participant received as much time as needed to complete the surveys, as there was no time limit to the survey. The average time to complete the online survey was 17 minutes. The setting of the testing area was at the participant's discretion.

## CHAPTER IV

### RESULTS

#### Descriptive Data

When participants were asked about what nonprofessional people they would want involved in CCHC, 50% of participants reported they wanted family members involved in CCHC services, while 22.5% reported wanting both family and friends involved in counseling. In addition, 54.2% of participants wanted multiple professionals involved in CCHC services, such as a nutritionist, an occupational or a physical therapist. Where as, 18.8% of participants reported they only wanted a doctor included in collaborative services with the counselor. When asked, 49 (61.3%) of participants stated they had received previous mental health care. Participants were also asked how much time they would like to spend in each session and 55.7% reported 60 minutes as their desired time, while 40% reported only desiring 30 minutes. Finally, 61.4% of participants preferred to attend collaborative counseling at a counselor's office, while 25.7% preferred a health care setting and 12.9% had no preference. When participants were asked why they would prefer the location, 43.8% stated for convenience versus 26.3% reported for comfort.

Likert scale questions were used to acquire data on participants' perceptions of possible benefits to mental health, physical health and family involvement in CCHC. Other Likert scale questions assessed current satisfaction with health care and

general interest in CCHC. The descriptive data for these 5 questions are shown in Table 1.

Table 1

*Likert Scale descriptive statistics (from 1 strongly disagree to 5 strongly agree)*

	N	Minimum	Maximum	Mean	Standard Deviation
Perceived Emotional Benefits	80	1.0	5.0	3.812	.8433
Interested in CCHC	80	1.0	5.0	3.263	1.0523
Perceived Physical Benefits	79	1.0	5.0	3.646	.8921
Family Involvement	80	1.0	5.0	3.450	1.0542
Current health care satisfaction	77	1.0	5.0	3.078	1.0609

#### Quantitative Data

A series of bivariate correlations were used to analyze the possible relationships between various variables in this study, such as current health care satisfaction, interest in CCHC and family APGAR scores. Two-tailed correlation analyses at the .05 alpha level were used for all correlations. Four significant correlations were found. Current health care satisfaction was positively correlated with family APGAR scores ( $r=0.39$ ,  $p<0.01$ ). While current health care satisfaction was inversely

correlated with interest in CCHC services ( $r=-0.24$ ,  $p=0.04$ ) and perceived physical benefits of CCHC services ( $r=-0.28$ ,  $p=0.01$ ). Additionally, perceived physical benefits of CCHC services were positively correlated to perceived emotional benefits of CCHC services ( $r=0.77$ ,  $p<0.01$ ). Finally, two insignificant relationships should be reported, receiving past mental health services and the family APGAR score ( $r=.16$ ) and perceived emotional benefits of CCHC with the family APGAR score ( $r=-.21$ ). No significant relationship existed between previous mental health services, demographic information, family APGAR score and interest in CCHC or perceived benefits of CCHC. The family APGAR scores ( $M=6.45$ ,  $SD=3.07$ ) are shown in Table 2.

Table 2

*Family Apgar Scores*

	Family APGAR Score	N	Percent
	.0	4	5.0
Severely Dysfunctional Family (.0-3.0)	1.0	2	2.5
	2.0	4	5.0
	3.0	7	8.8
Moderately Dysfunctional Family (4.0-6.0)	4.0	7	8.8
	5.0	6	7.5
	6.0	3	3.8
Highly Functional Family (7.0-10.0)	7.0	10	12.5
	8.0	11	13.8
	9.0	9	11.3
	10.0	17	21.3

### Qualitative Data

Due to the exploratory nature of the current research study, several open-ended research questions were used to gain a richer understand of perceptions on CCHC. A total of 15 open-ended questions were used to allow participants to elaborate on perceptions of CCHC in areas such as changes in relationships caused by the medical concern and goals for CCHC. Open coding was used to categorize the data. The categories that were found are shown in Table 3-17 (See Appendix B) along with providing the number of participants represented by each category and examples of direct quotes.

## CHAPTER V

### DISCUSSION AND CONCLUSION

#### Introduction

The main objective of this research study was to investigate perceptions on collaborative counseling and health care. Although MedFT and collaborative services are relative newcomers as treatment approaches, there is great interest in the scholarship of these approaches with research and literature devoted to advancing the practice. However, it is still unclear what this approach to treatment looks like. For example, who will be involved professionally (i.e., doctors and nurses) and nonprofessionally (i.e., family and friends) and time spent in each session (Bischoff et al., 2011). This illustrates the importance of the current research.

Several areas of research support the importance of integrative services. The first area of support to consider is the mind-body connection. The effect that the mind and body can have on one another is now better understood. For example, Clark, Long and Schiffman (1999) found that women who participated in frequent vigorous exercise and long walks had significantly higher life satisfaction scores than the less active short walkers and inactive women.

In addition to the mind-body research support, research has also been conducted on the connections between family functioning and medical concerns. Illness and contact with medical services may create or exacerbate difficulties in family

functioning (Johnson, Kent & Leather, 2005). Medical concerns can be life changing for the entire family. Both the people struggling with the medical concern and their family members may need time and space to process the medical concern and life changes. Although therapeutic models that focus on family relationships have been used primarily within mental health contexts, for example by psychologists or therapists working in family therapy settings, they are also applicable to medical settings where physical health is the main concern (Johnson et al., 2005). This research supports the appropriateness of collaborative services for families struggling with a medical concern.

Research has shown the impact that the family can have on a medical concern, likewise, cultural values can play a role as well. Families are shaped by both biological and social components, such as genes, and culture. That being said, not only does culture impact one's identity, but it is also involved in decision-making regarding mental and physical health care choices. Consequently, cultural values and beliefs play a role in all forms of health care. In collectivistic cultures input from the family system is highly welcomed and may take precedence over the opinions of the individual (Hines & Boyd-Franklin, 2005). As a result, it is important to explore the family's perceptions on collaborative services.

Finally, collaborative services consider a patient's psychological, social, biological, and spiritual experience of an illness (Bischoff et al., 2011). The holistic nature and flexibility of this treatment approach can incorporate family and cultural values as well as take into consideration the mind-body connection all in one setting. In addition, family interventions can be instrumental in increasing physical care, use of

appropriate coping strategies, lowering stress levels, or any combination of these factors (Johnson et al., 2005).

## Research Questions

### Research Question 1

The first research question focused on what consumers and their family members want the format and structure of collaborative services to look like. When participants were asked about the preferred meeting place for collaborative services, 61.4% of participants reported that a counselor's office would be preferred over a health care center (25.7%). When asked why they would prefer this location, participants reported that this was due to feeling more comfortable in that particular setting (26.3%) while 43.8% of participants reported convenience. Participants must have been considering another type of convenience other than medical availability when they indicated preferring a counseling center. The original expectation was that consumers and family members would prefer meeting in a health care center for more convenient collaboration with medical staff and the possibility of experiencing less mental health stigma. Additionally, this result was expected because health care centers have been found to be beneficial locations for providing collaborative services, and currently most collaborative services take place in the health care centers (Papadopoulos & Bor, 1995). According to the results, participant's valued comfort level and the convenience of the therapy office, over the desire for more direct access to medical professionals and services.

Research Question 1 also addressed who participants would like involved in CCHC services. When participants were asked what professionals they would like involved in CCHC, 83.4% reported that they would want at least one medical professional to collaborate with the counselor. Furthermore, over half of these participants reported wanting multiple professionals involved such as nurses, nutritionists, and doctors. These findings indicate participants are interested in receiving collaborative care by professionals. Additionally, 82.6% of participants desired family involvement in CCHC services. The interest in desired family involvement suggests that illness is a family experience (Johnson et al., 2005; McDaniel et al., 1999; Papadopoulos, 1995).

#### Research Question 2

The second research question addressed perceived benefits and perceptions of collaborative counseling and health care as seen by the consumer and family. Several categories emerged from the open coding when participants were asked about perceived benefits to physical health (See Appendix B, Table 5) including the mind-body connection ( $n=13$ ) and knowledge of treatment options ( $n=6$ ). For example, participants reported that CCHC could help reduce stress which would, in turn, benefit their physical health. This notion is consistent with past research that indicates a reciprocal relationship between the body and mind (Littrell, 2008; Yoon & Bernell, 2013). Also, knowledge of treatment options would empower people struggling with the medical concerns to take a more active role in their health care. This is something MedFT supports and encourages (Bischoff et al., 2011). A significant positive correlation was found between perceived

physical benefits of CCHC (i.e., an increase in knowledge of treatments, and increase in self-care) and perceived emotional benefits (i.e., an increase in understanding and acceptance) of CCHC ( $r=0.77$ ,  $p<0.01$ ). These results make sense in light of the established mind-body connection. It is reasonable to expect that perceived benefits from CCHC on mental and physical health would increase together.

As expected, an inverse correlation between current health care satisfaction and interest in CCHC occurred ( $r=-0.24$ ,  $p=0.04$ ). In other words, participants who were happy with their current health care services were less interested in CCHC, while those that were unhappy with their current health care services were more interested in CCHC services, which supports Hypothesis 2. An inverse correlation was also found between current health care satisfaction and perceived physical benefits of CCHC ( $r=-0.28$ ,  $p=0.01$ ). That is, as current health care satisfaction increases, perceived physical benefits of CCHC decrease. This is in contrast to Marshall, Hays and Mazel's (1996) research, which indicated a significant positive correlation between health care satisfaction and mental health but not with physical health.

Previous literature may provide possible explanations regarding why an inverse relationship was found between current health care satisfaction and perceived physical health benefits of CCHC. For example, Xiao and Barber (2008) found that health care satisfaction was influenced by a person's self-perceived health status. They reported that individuals who perceived themselves as being in good health were more likely to be satisfied with their health care. Further research is needed to explore why

people who are unhappy with their current health care are more likely to be interested in new services and see the possible benefits from them.

### Research Question 3

The third research question explored the possible relationship between family functioning and satisfaction with health care services, use of mental health services in the past, and the perceived benefit of CCHC to mental health in the future. According to the data from the family APGAR questionnaire, on average the participants reported a family APGAR score of  $M=6.45$ ,  $SD=3.07$  (See Table 2) which indicates a moderately dysfunctional family (Smilkstein, 1978). A significant positive correlation also was found between family APGAR scores and current health care satisfaction ( $r=0.39$ ,  $p<0.01$ ). These results support Hypothesis 1. Participants that reported high family functioning in the five family APGAR subscales also reported higher satisfaction with their current health care. Current research on people living with HIV and their support person found that healthy family functioning was indirectly positively correlated with life satisfaction, when family coping skills were used (Darling, Olmstead & Tiggleman, 2010). From this it could be inferred that healthy family functioning can also lead to satisfaction in other areas of life such as health care.

Additionally, an insignificant positive relationship between receiving past mental health services and the family APGAR score ( $r=.16$ ) was found, indicating that past mental health services does not have a significant relationship with current family functioning. Although this relationship is not significant, the positive correlation does correspond with previous research. In a study on individuals struggling with anorexia

nervosa and that individual's family, Wallin and Kronvall (2002) found that family function increased in many areas such as cohesion after receiving family therapy. Also, when participants were asked about perceived emotional benefits of CCHC there was an insignificant negative correlation with the family APGAR score ( $r=-.21$ ), indicating that perceived emotional benefits of CCHC do not have a significant relationship with current family functioning. The inverse nature of this relationship is as expected. Families that have health functioning are able to provide emotional support which can positively influence medical outcomes (Palmer & Glass, 2003). Therefore, higher functioning families would be less likely to see the benefit in collaborative services. These results are consistent with previous literature indicating MedFT consumers report an increase in feeling cared for when they are provided the support they need, which includes helping patients and families connect and communicate with each other (Johnson et al., 2005).

Numerous categories were coded from the relational questions. The relational questions addressed topics such as the impact of the medical concern on family relationships, and changes in these relationships as a result of the medical concern and ways that CCHC services can help. When participants were asked how family relationships had been impacted by the medical concern, six categories emerged including: Increase Strength in Relationship, Strain on Relationships, Denial, Financial Hardship, Misunderstanding, and Shared Feelings (See Appendix B, Table 6). In other words, some families become closer when struggling with a medical concern while others become more distant due to a lack of communication and shared resources. Many of these categories are comparable to the 10 themes McDaniel et al. (1999) discovered when

assessing the emotional experience shared by a family struggling with a medical concern, such as denial verse acceptance, isolation verse connection, fear verse courage, and senselessness verse meaning.

Likewise, four categories (Increase Togetherness, Increase Communication, Greater Understanding, and Increase Support [See Appendix B, Table 7]) emerged when participants were asked how CCHC could help with changes in relationships as a result of the medical concern. The categories that emerged suggest that CCHC can foster a collaborative environment where the family can come together to feel safe and supported when struggling with a medical concern. These four categories also correspond well with the goals of MedFT (Linville et al., 2007). For example, Linville et al. stated that a key component to MedFT is collaboration between family members and the person struggling with the medical concern and, according to participants in the current study, this is what they believe CCHC can do.

#### Research Question 4

The fourth research question focused on possible differences in perceptions of benefits and interest in CCHC due to demographic differences. No significant relationships were found regarding demographic information (i.e., religion, ethnicity) and perceptions regarding interest and perceived benefits of CCHC. The lack of significant correlations may be due to the small sample size ( $N=80$ ) and lack of ethnic diversity in the research study.

### Limitations and Recommendations

While several strengths of this study were evident such as finding significant relationships between current health care satisfaction and interest in CCHC, some limitations also existed. Lack of ethnic diversity was a major limiting factor in this study. No African American/ Black participants and very few Latinos participated in this study. Today, therapists must not only learn to understand the variety of personalities and psychopathologies entering therapy, they must also learn to work effectively with a variety of ethnic groups (Richeport-Haley, 1998). That being said, it is important to understand possible differences and similarities between cultures when offering collaborative services. In the future, a larger sample size including a more diverse population is needed. Along these same lines, the study was only offered online and only in English. This limited participation to those that had a computer, felt comfortable using it, had internet access (i.e., high socioeconomic status and higher education) and to those that read and understood English. This limitation may have skewed the data this representing only those that could participate and limiting generalizability.

While the exploratory nature of this study was a strength, it also created limitations. This study explored different perceptions regarding collaborative services; however, no causation can be inferred from the information collected. Experimental models of research should be considered in the future to examine cause and effect information.

Future research should also be conducted to gain a better understanding of what consumers and professionals already know about collaborative services and what is

working well in collaborative health care. This would help assess the future direction of CCHC. For example, in a study where cancer patients and their family members were receiving MedFT treatment, some participants reported not knowing how a MedFT could help them (Hodgson, McCammon, Marlowe, & Anderson, 2012). While we do not yet know much about the format of effective CCHC services, the current research supports the need for, and consumer interest in, these services in the community. Further steps should be taken to explore how these needs can be met.

Despite these limitations, the current research provided insight on consumers' perceptions and the desired structure of collaborative counseling and health care services. This research may help professionals better understand what consumers are looking for in collaborative services, including what they would like the services to look like and how they would be beneficial. For example, it could be beneficial to combine the comfort of a therapy office with the convenience of both mental and medical health services offered by hospitals; this could be accomplished by providing comfortable meeting rooms for this purpose. This research may also help professionals to better understand the common experiences of families struggling with a medical concern, and may be used to normalize these experiences and help family members recognize that they are not alone.

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## APPENDIX A

## Informed Consent

Title of Research: Perceptions on Collaborative Counseling and Health Care, IRB# 113-01

You are invited to take part in this research study. Before agreeing to participate in this research study, it is important that you read the following explanations of this study.

### **What will be done during this research study?**

Participation in this study involves completing an anonymous online survey, which includes information on your background, as well as your perceptions on the incorporation of family counseling with medical concerns and suggestions on the format of these integrative services. It should take you 15 to 20 minutes total to complete the survey questions. After you have completed the survey, you have completed the study.

### **What are the possible risks of being in this research study?**

You might have some uncomfortable feelings such as sadness or frustration when you reflect on your experiences. You do not have to answer any questions that make you feel uncomfortable. You can stop at any time without penalty.

### **What are the possible benefits to you?**

You might learn about how family counseling can play a role in medical concerns and treatment. Also you will be given a chance to reflect on your perceptions and experiences with medical and mental health care. You might feel a sense of personal satisfaction from knowing that you are helping others by sharing your information. However, you may not get any benefit from being in this research study.

### **What are the possible benefits to other people?**

The information you share may be used to help shed light on the usefulness of medical family counseling and what the therapeutic process should look like.

### **Are there incentives?**

After the completion of the study you will have the option of entering your information in a drawing for a 1 in 50 chance to win a \$25 Visa gift card. There is no penalty for non-participation.

### **What are the alternatives to being in this research study?**

Instead of being in this research study, you can choose not to participate. There is no penalty for non-participation.

### **How will information about you be protected?**

The online survey is conducted anonymously. Confidentiality will be maintained to the degree permitted by the technology used. Your participation in this online survey involves risks similar to a person's everyday use of the Internet.

The information from this study may be published in scientific journals or presented at scientific meetings, but your identity will be kept strictly confidential.

For further information about the nature of this research or about your rights as a research participant please contact Brandy Thomas or Dr. Elise Cole:

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**By completing the online survey you are agreeing to participate in this research.**

## Perceptions on Collaborative Counseling and Health Care, IRB#113-01

## Demographic questions

Do you identify yourself as:

- A person struggling with a medical concern
- A family member of a person struggling with a medical concern
- Both

Do you identify yourself as:

- Male
- Female

What is your age?

What is the highest level of education you have completed?

- Elementary school only
- Some high school, but did not finish
- Completed high school
- Some college, but did not finish
- Two-year college degree / A.A / A.S.
- Four-year college degree / B.A. / B.S.
- Some graduate work
- Completed Masters or professional degree
- Advanced Graduate work or Ph.D.

What, if any, is your religious preference?

- Christianity
- Catholicism
- Islam
- Hinduism
- Buddhism
- LDS / Mormonism
- Judaism
- No Preference / No religious affiliation
- Prefer not to say
- Other

How would you describe your current employment status?

- Employed full time
- Employed part time
- Unemployed / Looking for work
- Student
- Homemaker
- Retired
- Other

Would you describe yourself as:

- American Indian / Native American
- Asian
- Black / African American
- Hispanic
- Latino
- White / Caucasian
- Pacific Islander
- Prefer not to say
- Other

Are you:

- Married
- Divorced
- Widowed
- Separated
- Never been married
- A member of an unmarried couple

Have you received mental health services in the past?

- Yes
- No
- Considering in the future

If you have received mental health services, how many sessions did you attend and over what period of time?

Who provided the mental health services?

- Psychiatrist
- Psychologist
- Counselor
- Social worker
- Primary Medical Doctor
- Other:

What type of mental health services have you received?

- Individual
- Family
- Group
- Other:

If you would like, please tell us what medical concern you/your family member is struggling with:

### Perception questions

The stress of medical concerns can impact not only the person who is struggling with the medical concern, but their family as well. Collaborative counseling services would incorporate family counseling with medical concerns and treatment. This study aims to identify the essential elements of collaborative counseling and the possible effects it may have on the individual and their family.

How interested would you be in collaborative counseling services?

- Not interested at all
- Not interested
- Unsure
- Interested
- Very interested

If you are interested in collaborative counseling, how many sessions would you like to attend?

Number:

How much time would you like to spend in a collaborative counseling session?

- 30 minutes
- 60 minutes
- 90 minutes
- Other:

What professionals would you want involved in collaborative counseling?

- Doctor
- Nutritionist
- Nurse
- Occupational Therapist
- Physical Therapist
- Other:

What additional people would you want involved in collaborative counseling?

- Family
- Friends
- Community members (Role: \_\_\_\_\_)
- Spiritual leaders
- Other:

Would you prefer to attend collaborative counseling if it were located in the health/medical center or outside of the center in a counselor's office?

- Health center
- Counselor's office
- Other:

Do you feel collaborative counseling would be beneficial to your/your family member's emotional/mental health? How so?

Not beneficial at all  
Not beneficial  
Unsure  
Beneficial  
Very beneficial

Do you feel collaborative counseling would be beneficial to your/your family member's physical health? How so?

Not beneficial at all  
Not beneficial  
Unsure  
Beneficial  
Very beneficial

How important to you is it that you/your family be involved in the collaborative counseling process?

Level of Quality – 5 point  
Not important at all  
Slightly important  
Unsure  
Important  
Very important

Explain:

How have your relationships been impacted by your/your family member's medical concerns?

Explain:

How could collaborative counseling help with changes in your relationship?

Explain:

What goals would you live to achieve through collaborative counseling?

Explain:

What would you want to gain from collaborative counseling?

Explain:

What has been your satisfaction with your/your family member's health care experience thus far?

Not satisfied at all  
 Not satisfied  
 Unsure  
 Satisfied  
 Very satisfied

Explain:

What changes would you suggest to your/your family member's health care services?

Increase in time spent with professionals  
 More information  
 Feeling of being understood  
 Other:

#### Family APGAR (Smilkstein, 1978)

Response to all questions: Almost always, Some of the time and Hardly ever.

I am satisfied with the help that I receive from my family when something is troubling me.

I am satisfied with the way my family discusses items of common interest and shares problem solving with me.

I find that my family accepts my wishes to take on new activities or make changes in my life-style.

I am satisfied with the way my family expresses affection and responds to my feelings such as anger, sorrow and love.

I am satisfied with the amount of time my family and I spend together.

#### Open ended questions

How have family members aided each other in time of need?

In what way have family members received help or assistance from friends and community agencies?

How do family members communicate with each other about such matters as vacations, finances, medical care, large purchases and personal problems?

How have family members changed during the past year? How has this change been accepted by family members?

In what way have family members aided each other in growing and developing independent life-styles?  
How have family members reacted to your desires for change?

How have members of your family responded to emotional expressions such as affection, love, sorrow or anger?

How do members of your family share time, space and money?

## APPENDIX B

Table 3

*Categorized Data and Direct Quotes on Medical Concern*

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Q: If you would like, please tell us what medical concern you/your family member is struggling with.

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Diabetes (n=9)	“My grandmother has dealt with Diabetes and trying to incorporate healthy habits has been difficult. Language barriers and traditional food have made it difficult for her to focus on good eating habits.”
Mental Health (n=27)	“Living with a veteran who has PTSD.”
Cancer (n=10)	“My father recently passed away from cancer.”
Physical Ailment (n=10)	“I have back pains and it pains me that I cannot do anything since I have no health insurance to help me but buy on the counter medication to lessen the pains.”

Table 4

*Categorized Data and Direct Quotes on Emotional Benefits*

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Q: Do you feel collaborative counseling would be beneficial to your/your family member's emotional/mental health? How so?

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Increase Understanding (n=21)	“I think understanding and awareness are essential to healing on a "global" level for any of us who have or know someone who is chronically ill. It is easy to tell people to push through...but what happens when you cannot push any longer? If I am walking around, it is assumed that I feel like doing so, when in fact every step is difficult...I just don't complain about it.”
Increase Positive Relationships (n=11)	“Teach us healthy communication, allow us to voice our concerns and feelings, be able to move in a positive direction with our lives and relationships.”
Acceptance (n=4)	“Peace of mind about their medical condition. Accepting the possibility of death at any moment.”
Decrease Negative Emotions (n=12)	“Taking time to focus as a group, rather than her feeling like she is going through this alone.” “I think that it would be a great way to release some of the stress and emotions built up from the situation.”

Table 5

*Categorized Data and Direct Quotes on Physical Benefits*


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Q: Do you feel collaborative counseling would be beneficial to your/your family member's physical health? How so?

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Mindy Body Connection (n=13)	<p>“Physical ailments can be directly tied to mental/emotional issues.”</p> <p>“Our mental health influences our physical health and the other way around.”</p>
Increase Self-care (n=11)	<p>“If he starts feeling better, than he might start taking better care of himself.”</p>
Knowledge of Treatment Options (n=6)	<p>“Maybe helpful for lupus if a physical therapist was to be there to help suggest things that can be done to help. Also sometimes getting therapy can help reduce stress (Stress has been known to cause illness and pain).”</p>

Table 6

*Categorized Data and Direct Quotes on Relational Impact*


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Q: How have your relationships been impacted by your/your family member's medical concerns?

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Increase Strength in Relationship (n=8)	"We have explored medical issues openly and have strengthened our relationships as a result."
Strain on Relationships(n=23)	"Marital separation, distancing, emotional shut-down." "Relationships with my family members have dwindled. Some of us do not speak to each other and if we do, we never talk about our concerns."
Denial(n=2)	"Some family members have been able to accept depression in one of my family member, but others deny it."
Financial Hardship (n=2)	"We are currently financially strapped as a result of my medical concern. It has been difficult to continue working as much as I had been (at least for right now). My family has had to let me borrow quite a bit of money to help pay expenses."
Misunderstanding (n=5)	"Kids may not understand my occasional lack of energy. They may assume it is their fault. We could be impatient with each other."
Shared Feelings (n=4)	"When he feels like giving up and gets depressed it negatively affects the whole family."

Table 7

*Categorized Data and Direct Quotes on Change to Relationships*


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Q: How could collaborative counseling help with changes in your relationship?

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Increase Togetherness (n=9)	“It will bring family together, and become more supportive of the situation.”
Increase Communication (n=15)	“It could improve communication and rekindle ties that have been broken. It would also help my family work passed past issues.”
Greater Understanding (n=13)	“My mom and I could understand it better and hopefully relate to each other better.” “It could help in the families understanding of what my dad goes through since he barely talks about it, and it would also allow him to feel validated.”
Increase Support (n=10)	“It can help us understand what's going on in each other’s bodies and provide each other with ways to support ourselves and family.” “I would feel more supported knowing that my mother has the ongoing support network she needs to heal.”

Table 8

*Categorized Data and Direct Quotes on Gains*


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Q: What would you want to gain from collaborative counseling?

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Peace (n=7)	“Peace of mind knowing my loved one is in a balanced place emotionally.”
Understanding (n=15)	“I would be able to understand my dad’s experience and probably be able to express that I feel bad for holding it against him when I was younger.”
Complete Care (n=4)	“More complete care. Feeling of being cared for and validated by medical expert, counselor and family.”
Strength (n=10)	“Unity and strength to help her.” “Being positive and greater self-esteem.”

Table 9

*Categorized Data and Direct Quotes on Goals*

Q: What goals would you like to achieve through collaborative counseling?	
Open Communication (n=8)	<p>“I would like to get better at knowing how to communicate with doctors.”</p> <p>“My goals is for him to hear what I have to say.”</p>
Increase Knowledge of Medical Concern and Treatment (n=12)	<p>“Assistance with medical information.”</p> <p>“Create plans on how to cook/choose meals that are good for my health.”</p>
Foster Closer Relationships (n=12)	<p>“Demonstrating to my mother that she is NOT ALONE in her struggles and there is a network of support available to her if she accepts it.”</p>
Overall Awareness (n=8)	<p>“Understanding would be such a relief. If people were aware, including professors when applicable, it would relieve enormous amounts of stress for me. I am so disappointed in myself; the pressure of being judged or misunderstood because of my health only adds to the stress. To sum it up, I think everyone could benefit, because empathy is too often left out of the health equation.”</p>

Table 10

*Categorized Data and Direct Quotes on Current Health Care Satisfaction*

Q: What has been your satisfaction with your/your family member's health care experience thus far?	
Discouragement (n=8)	<p>“We all get discouraged when dealing with health care because most of us are uninsured &amp; it makes it harder to get good health care.”</p>
Lack of Communication (n=7)	<p>“Usually health care providers are rushed and want to get there patient in and out. This causes us to forget questions we want to ask and I feel that things are not explained properly.”</p>
Not Feeling Supported (n=12)	<p>“Nothing has gotten better.”</p> <p>“Also, there has been disagreements with what is best for the patient rather than what is easier for the physician.”</p>
Satisfied (n=13)	<p>“I think that my family is mostly satisfied but we all could have benefited by some outlet to cope with the situation.”</p>

Table 11

*Categorized Data and Direct Quotes on Family APGAR Question 1*


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Q: How have family members aided each other in time of need?

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Emotional Support (n=23)	<p>“Always help each other during hardship and love each other.”</p> <p>“My family is a very emotional family so when one is upset about something we made sure we are there to comfort them and hold them as well as talk about things that are bothering them.”</p>
Family Dialog (n=16)	<p>“Communication multiple times a day, whether to discuss normal day events or to listen to problems/issues.”</p> <p>“We talk on the phone very regularly and always keep a consistent dialogue despite not all living in the same city.”</p>
Financial Support (n=10)	<p>“Loaned money, cars, and personal time.”</p> <p>“We have supported each other financially and emotionally when needed.”</p>

Table 12

*Categorized Data and Direct Quotes on Family APGAR Question 2*


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Q: In what way have family members received help or assistance from friends and community agencies?

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Counseling (n=12)	“Counseling in order to create better bridges of communication.”
Overall Support (n=9)	“Friends have watched children while family members are in the hospital, cooked dinner for family, etc.”
Church (n=2)	“Small groups at church have given them lots of support”

Table 13

*Categorized Data and Direct Quotes on Family APGAR Question 3*


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Q: How do family members communicate with each other about such matters as vacations, finances, medical care, large purchases and personal problems?

---

No Communication (n=16)	“We don't discuss these things.”
Open Communication (n=35)	“We always discuss things together and keep an open dialogue.”
Head of the House (n=3)	“Most of these issues are discussed within my immediate family, but my mom makes the final decisions. She also does the bills and makes most of the large purchases.”

Table 14

*Categorized Data and Direct Quotes on Family APGAR Question 4*


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Q: How have family members changed during the past year? How has this change been accepted by family members?

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Alienation (n=9)	“They have just been alienated from the family and lack their support.”
Decrease Acceptance (n=6)	“My family is very accepting of those changes.”
Accommodating (n=15)	“My sister got a divorce and moved back from Texas. We welcomed her back with open arms.”
Growth (n=10)	“Family members have grown from life experiences, especially from challenges. Other members are supportive of such growth and value opportunities to learn and to improve over time.”

Table 15

*Categorized Data and Direct Quotes on Family APGAR Question 5*


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**Q: In what way have family members aided each other in growing and developing independent life-styles? How have family members reacted to your desires for change?**

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Lack of Support (n=4)	“Reluctantly with a lot of doubts and criticism. Not well. They don't like change and do not see that it is necessary unless it is something that they agree with or understand.”
Change is Negative (n=8)	“Change is never good in my family.”
Positive Support (n=38)	“They are open-minded. When they have questions, they ask. But generally, they are there to support and help in any way necessary.”
Trust (n=5)	“They let you make decisions and try things even if they do not necessarily agree, because they want you to figure it out yourself, but they can also be very supportive at times.”

Table 16

*Categorized Data and Direct Quotes on Family APGAR Question 6*


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**Q: How have members of your family responded to emotional expressions such as affection, love, sorrow or anger?**

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Openly (n=31)	“My siblings and my dad are very openly affectionate with each other. We call each other frequently since we live far away from each other. We are also there for each other in times of need.”
Lack of Response (n=10)	“Culture doesn't allow us to be demonstrative.” “My grandparents grew up in a generation where no affection was shown, so they don't really have remorse or any sense of expression of emotion.”
Negative Response (n=9)	“Keep it bottled up. Substance abuse. Running away (figuratively). Denial.” “Sometimes there's judgment and no understanding”

Table 17

*Categorized Data and Direct Quotes on Family APGAR Question 7*


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Q: How do members of your family share time, space and money?

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Financial Care (n=9)	“My brother and I moved out, but we still help our parents financially because my father cannot work.”
Family Time (n=16)	“We have family dinners and movie nights together.”
Unable/Unwilling to Share Financial Resources (n=11)	“Very poorly. My parents have been struggling financially for some time now due to poor money handling and poor priority organization for bills etc.”
None Shared (n=11)	“Very different lifestyles so everyone is kind of on their own”