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Confidence And Connectedness: A Mixed Methods Study On Patients Managing Co-Occuring Physical And Behavioral Health Conditions

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CONFIDENCE AND CONNECTEDNESS: A MIXED METHODS STUDY ON PATIENTS MANAGING CO-OCCURRING PHYSICAL AND BEHAVIORAL HEALTH CONDITIONS

By

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A MIXED METHODS STUDY ON PATIENTS MANAGING CO-OCCURRING
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Abstract

Treating chronic illness is becoming increasingly team-based, yet most team building concepts relate to the team as a dichotomous unit: the medical team and the patient. Patients are expected to be “engaged” and “activated” members of the team, yet there is a gap in knowledge regarding how patients most effectively integrate into the team. Exacerbating the complexity of patient as team member is the multifaceted, ever-changing mood state of patients with co-occurring medical and mental health conditions. The medical field is well aware of the correlations between mental health and chronic illnesses. The purpose of this study is to investigate, from the patient’s perspective, what factors influence the patient’s sense of connectedness to the patient’s care team and how these factors mediate the patient’s positive health behaviors relative to self-care. Findings from a mixed-methods approach showed that the level of perceived confidence relative to self-care of chronic illness was mediated by the presence of a mental health diagnosis. Mixed-methods data also showed that high levels of patient confidence relative to self-care of their chronic illness had no statistical connection to patient’s increased sense of connectedness to their care team.
Keywords: Team-based care, Relational Coordination, confidence, chronic disease management, mental health
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Doctor of Education
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“The single biggest problem in communication is the illusion that it has taken place.”

~George Bernard Shaw
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CHAPTER 1

INTRODUCTION

Treating chronic disease makes up three-quarters of healthcare expenditures (Hoffman, Rice, & Sung, 1996). Patients living with chronic illness often have multiple medical providers, numerous medications, and complex care plans. According to one study, a typical Medicare beneficiary sees seven different physicians in four separate practices in a year (Pham, O'Malley, Bach, Martinez-Saiontz, & Schrag, 2009). Another report, by Berenson and Horvath (2002), showed that for the most complex populations (patients living with five or more chronic illnesses, including mental health) yearly statistics reach 37 office visits, 14 different medical providers, and up to 50 prescriptions per patient. It is easy to see how complex the management of the treatment and coordination of providers can become. As a result, over the past few decades a paradigm shift has occurred, and, subsequently, new models of chronic disease management have arisen. One result of this shift relates to seeing the management of chronic illness as a diachronic, ever-changing process with many interconnected components.

A paternalistic medical model puts the physician in a dominant role and has the patient as the passive recipient of care (Charles & Gafni, 1999; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). Although current leadership is focusing more on team-based care, teams have members that are chronically dissatisfied (Marlow, Manusov, & Teasley, 2012) and are often referred to as “led by a physician” (Military Health System Patient Centered Medical Home Guide, 2011, p. 1). This could prove troubling to collaborative care, for the physician is often the least likely to adopt patient-centered behaviors (Audet, Davis & Schoenbaum, 2006; Karnieli-Miller &
Eisikovits, 2009). As well, team support staff often are not working to the top of their license and there is an overall lack of team and job satisfaction (Marlow et al., 2012).

Significant changes in both philosophy and practice have changed the way medical providers now interact with patients. Patients are required to be engaged and active in the decision-making process (Wasson & Coleman, 2014); however, they are still often seen as passive recipients of care. Patient Centered Medical Home (PCMH) principles are based on a patient-centered model of care and have begun focusing on integrated primary care teams (National Committee on Quality Assurance, 2011; Scholle, Torda, Peikes, Han, & Genevro, 2010; Taylor, Machta, Meyers, Genevro, & Peikes, 2013).

With the momentum of team-based, patient-centered care comes the potential of “symbiogenisis . . . the formation and emergence of new organisms through symbiotic mergers” (Miller & Cohen-Katz, 2010, p. 335). These mergers require individuals to collaborate as heterarchal units (Rouse, 2008) and often include not only medical providers, such as physicians, nurses, and behavioral health providers (Military Health Systems, 2011), but also the patients and their family members (Boise & White, 2004) or other informal caregivers (Weinberg, Lusenhop, Gittell, & Kautz, 2007). Seeing the patient as an active member, and perhaps even the leader of the care team, could prove to be the next step in refining the care team matrix and subsequently achieving better healthcare outcomes. Relative to chronic disease management, it makes sense to actively include the patient in his or her own care management. Seen mathematically, the patient is predictably the only constant variable in the entirety of the let us get the patient better equation.

The inclusion of patients in the decision-making process is called upon by many patients (Frosch et al., 2012) and supported by numerous organizations (Noel, Lanham, Palmer, Leykum,
& Parchman, 2013; Peek, 2010). The Center for Medicare and Medicaid Innovation’s Health Care Innovation Challenge promotes opportunities “for compelling new models of health care delivery that can improve health, improve quality, and reduce costs” (Veroff, Marr, & Wennberg, 2013, p. 286).

Although it is both sensible and effective to include the patient as part of the care team, it is not the standard of care (Charles & Gafni, 1999). Furthermore, researchers have yet to fully notice the importance of evaluating team performance from the view of the patients as participants in their production (Gittell, 2011, p. 406).

Improving team dynamics can improve care outcomes (Weinberg et al., 2007). One way researchers are investigating how to improve teamwork is through Relational Coordination (Gittell, 2009). Relational Coordination is based on effective (timely, frequent, accurate and problem solving oriented) communication as well as shared goals, knowledge, and respect amongst all members of the team.

According to Noel et al. (2013), a basic premise of chronic disease management is that the integrated primary care teams work proactively with “informed, activated patients who accept responsibility for being part of the team in the management of their own chronic illness” (p. 21). Activation and engagement are often seen as analogous in the primary care setting. Research has shown that an “effective proxy for engagement” (Wasson & Coleman, 2014, p. 9) is confidence of healthcare management. This concept is measured via a 10-point scale and can be a useful in predicting patient outcomes. Although we know many factors contribute to low health confidence, it is often connected to patients with low socioeconomic status (Watson, 2013) as well as with multimorbidities, such as chronic pain and mental illness (Tai-Seale, Foo, & Stults, 2013; Wasson, Johnson, & Mackenzie, 2008).
A regional study performed by Fauth and Tremblay (2011) investigated five Integrated Primary Care (IPC) centers across the state of New Hampshire. The study focused on assessing the level of integration and emotional distress of patients within these identified IPC centers. Emotional distress was measured by assessing depression, anxiety, and perceived function over three domains (school, family, work). One organization measured the level of emotional distress among patients living with co-occurring chronic illness (such as diabetes, hypertension, cardiovascular disease, etc.) and a mental health condition (depression, anxiety, bipolar disorder, etc.) (Fauth & Tremblay, 2011). This study showed that almost 50 percent of the patients living with co-occurring chronic illness were severely or extremely distressed according to the emotional distress measure.

Much has been done to improve patient care, including Care Coordination Agreements, improving planning and workflows, and advancing Relational Coordination among teams (Carrier, Dowling, & Phram, 2012; Craig, Eby, & Whittington, 2011; Cramm & Nieboer, 2012b); however, more has to be done. As primary care offices continue to adopt EHRs and IPC teams into their typical workflows, coordinating teams that provide complex care for patients living with chronic illness and behavioral health disorders will inevitably becoming increasingly relevant.

**Statement of the Problem**

Care of complex co-occurring disorders is becoming increasingly team-based, yet most team-building concepts relate to the team working around the patient, not with the patient. There is a lack of insight into the function of a medical care team when the patient is considered part of the team. Furthermore, while there is increasing awareness of the correlations between mental
health and chronic illnesses, the medical field lacks insight into how to best proactively integrate this population into the team for both prevention and treatment efforts.

**Purpose of the Study**

The purpose of this study is to investigate, from the patient’s perspective, what factors influence the patient’s sense of connectedness to the patient’s care team and how these factors mediate the patient’s positive health behaviors relative to self care.

**Hypotheses:**

1. The patient’s level of perceived confidence relative to self-care of their chronic illness is mediated by the presence of a mental health diagnosis.

2. High levels of patient confidence relative to self-care of their chronic illness increase their sense of connectedness to their care team.

**Research Questions**

1. How does the presence of a mental health condition influence the patient’s level of confidence and connectedness to the other members of the patient’s care team?

2. What correlation exists between patient confidence and connectedness relative to the patient’s overall perception of team-based care?

3. What factors influence the patient’s role as a member of the care team?

4. What factors increase the concept of team from the patient’s perspective?

**Definitions of Terms**

For the purpose of this study, the following terms are defined.

*Behavioral Health:* A universal definition of care that may focus on one or more of the following elements: mental health and substance abuse conditions and health behaviors as well
as life stressors and crises, stress-related physical symptoms, and ineffective patterns of health care utilization (Peek, 2013).

_Care Team:_ For the sake of the research focus of this article, care team will be referred to as the collective team that includes the Primary Care Provider, Registered Nurse, Medical Assistance, Behavioral Health Provider (BHP), and Patient.

_Co-occurring Chronic Illness:_ A condition when a patient is living with a chronic illness in addition to a diagnosed mental illness (including a substance use disorder). An example would be cardiovascular disease and bipolar affective disorder.

_Dual Diagnoses:_ Dual diagnoses is a term reserved for persons living with a mental illness and a substance use disorder. An example would be Major Depression and Alcohol Use Disorder Severe.

_Electronic Health Record:_ An electronic version of a patient’s medical record designed to be patient-centered and modifiable in real time. Such records are often shared between locations of care and instantly and are securely accessible by authorized users. The Electronic Health Record contains the patient’s treatment history, labs, current and past medications and problems lists, immunization dates, allergies, and care plans.

_Important Condition:_ For the purpose of this study, an important condition is considered either type II Diabetes Mellitus or hypertension. These were medical conditions identified by the organization regarding their efforts to meet PCMH Level III status.

_Integrated Multidisciplinary Care Plan:_ A cohesive care plan designed to represent the multiple providers working with patients living with co-occurring chronic illnesses across the continuum of care. The diachronic plan is aggregated so as each entity updates that entity’s portion of the plan, that modification is represented in one overarching organizational place in
the EHR. This is designed to facilitate and organize the complex nature of managing chronic disease.

*Perceived Importance, Confidence, and Connectedness Scale (PICCS):* A combined scale utilizing a scale related to the patient’s perceived importance of self-care, Confidence (Miller & Rollnick, 2013) and the Relational Coordination Survey (Gittell, 2009).

*Relevant Visit:* Identified medical visits scheduled for all patients in the target FQHC that have an active diagnosis of Diabetes Mellitus and/or hypertension. The goal of these visits is to focus on medication reconciliation, assessing needs, gaps in services and coordinating care as well as tending to any acute medical concerns.

**Conceptual Framework**

The conceptual framework for the study is rooted in transformative-emancipatory (Hanson, Plano Clark, Petska, Creswell, & Creswell, 2005) pragmatism. Identifying the conceptual framework is paramount in guiding the understanding of the researcher’s philosophical underpinnings and the scientific intent. This study sought to explore the views of patients living with co-occurring medical and mental health conditions. The purpose was to identify the role a patient wants to play regarding the patient’s care team as well as investigate what is required to improve the patient’s sense of connectedness to the care team. Creswell (2013) pointed out that, regarding this interpretive framework, “reality is known through using many tools of research that reflect both deductive and inductive evidence” (p. 37). See Figure 1 for the conceptual framework for this study.

This study relied on a two-dimensional mixed-methods approach (Collins, Onwuegbuzie, & Jiao, 2007). Quantitative survey data was collected and used to inform the selection of patients to participate in follow-up qualitative interviews. These interviews were designed to inform a
grassroots change process regarding the care of patients living with co-occurring disorders. The patient-based information gleaned from the mixed methods approach was utilized to inform future change processes within the organization.

![Conceptual framework](image)

**Figure 1.** Conceptual framework.

**Assumptions and Limitations of the Study**

One major assumption of this study is that all participants would answer the survey questions and interview questions honestly and that the data saturation that was reached would provide a relative constant to an ever-changing emotional state: the patient’s lived experiences.

The most significant limitation to this study regards the fact that it was conducted in a Federally Qualified Health Center (FQHC) in a small coastal community in New Hampshire. The sample diversity is subsequently limited due to the criterion-based sampling method chosen. Lack of diversity within the patient population of the FQHC where the data was collected influenced the generalizability of the outcomes. The potential for self-selection could also have
been a limiting factor regarding generalizability. Although the Principal Investigator (PI) took all precautions to account for a diverse group, participants were able to opt in and out of the interview process.

Another factor affecting the generalizability of the data outcomes regards the fact that although patients living with chronic illnesses often have similar experiences, this study focused on patients living with two specific chronic illnesses: Type II Diabetes Mellitus and hypertension. Furthermore, the select population also had co-occurring chronic illnesses; meaning they also had a mental health diagnosis of either depression and/or anxiety. Due to this, the data may not be generalizable to other patient populations that may not have a co-occurring disorder.

The study was conducted within an FQHC that employed an integrated Behavioral Health Provider (BHC). Although this is becoming more popular, not all primary care organizations employ an integrated BHC. This is relevant because the PICCS survey asks how the patient relates to their on-site behavioral health provider. As other research has shown, communication between patients, medical providers, and on-site and off-site behavioral health providers varies drastically (Collins, Hewson, Munger, & Wade, 2010; Koenig, Maguen, Daley, Cohen, & Seal, 2012).

Lastly, there could be a self-sampling bias with the patient population that was chosen for the initial quality-improvement survey questions. The self-sampling bias is plausible because of the fact that survey completion was voluntary and not mandatory in nature.

**Significance of the Study**

Medical decision-making processes are becoming increasingly team-based wherein the management of chronic co-occurring conditions is shared between the medical team and the
patient. An extreme example of this is shown by the efforts from the Collaborative Family Healthcare Association members who are spearheading a movement for the inclusion of the entire family in treating complex conditions. As the number of care team members increase there is an increased need for coordinating the relationships and communications between these members; thus fostering the concept of *team*.

This research focused on what constructs are important to team members relative to enhancing trust, conflict resolution, commitment, accountability, and positive goal orientation. The results of this study have implications for all members of the care teams working with patients living with co-occurring medical and mental health conditions, specifically towards increasing the relational coordination between members as well as simultaneously focusing on the positive strengths and attributes of the patients.

Currently, little is known regarding what factors enhance collaboration for primary care teams operating within an integrated primary care (IPC) setting. Furthermore, there is a dearth of knowledge regarding team dynamics when the patient is actively considered a team member. This organic approach was designed to enlist input from the people at the center of the team-based disease management process; the patient. Patient team members were requested to provide very specific and personalized input regarding this process; specifically, what factors may enhance their sense of connectedness to the team, such as trust, conflict resolution, commitment, accountability, and positive goal oriented behaviors within the IPC teams. Unlike past research on Relational Coordination (RC) in IPC settings, this study focused on the patient members of the care team. By elucidating the wants and needs of all members of the care team, a grassroots change process was conducted. The data will be used to improve both existing workflows and protocols and the knowledge management tools within the EHR.
Conclusion

The purpose of this study was to investigate two factors: (a) How the presence of a mental health condition influences the patient’s confidence level and subsequently their ability to maintain healthy behaviors relative to their chronic illness, and (b) How the patient’s level of confidence (relative to maintaining their chronic illness) influences their sense of connectedness to their care team. In Chapter 2, relevant literature about coordinating complex relationships within integrated primary care settings will be presented. Chapter 3 will discuss the methodology of the study. Chapter 4 will present the results and the conclusions, and Chapter 5 will offer the researcher’s interpretation of the findings.
CHAPTER 2

REVIEW OF THE LITERATURE

This chapter will present a selective review of literature relative to the topic of study. In this chapter, various concepts relative to the care of patients living with complex co-occurring chronic diseases are presented. The first section explores team care in the primary care setting; specifically focusing on Integrated Primary Care, Relational Coordination, and Patient Centered Medical Homes. This chapter ends with an exploration into the constructs related to patient engagement including shared decision-making, connectedness, and confidence.

Team Concepts

Although healthcare in the United States is the world’s most expensive among developed countries, the outcomes are some of the worst (Bates, 2009). As many reports have shown, other well-performing countries have primary care at the center of their medical care delivery system (Davis, Schoen, & Stremikis, 2010). Historically, however, the United States has not, and the wide variance in outcomes within the Unites States has been associated with the lack of primary care throughout the care delivery system (Carver & Jessie, 2011). To address this significant service gap, the National Committee for Quality Assurance (NCQA) has created a structure for putting the primary care provider at the center of the delivery system.

The Patient Centered Medical Home model provides common clinical and service guidelines for primary care offices seeking PCMH certification. Patient Centered Medical Home concepts were developed by a collaboration of the American College of Physicians (ACP), the American Academy of Family Physicians (AAFP), the American Academy of Pediatrics (AAP), and the American Osteopathic Association (AOA). PCMH guidelines have been created to serve
as an objective baseline measurement tool to assess health care delivery and quality (National Committee on Quality Assurance, 2011).

One basic tenet of the PCMH is that physician-led medical teams, at the practice level, provide ongoing, coordinated care for patients. The PCMH model requires both a philosophical and behavioral shift from provider-centered to patient-centered care delivery that focuses on all aspects of the person’s health, including their mental health (Croghan & Brown, 2010), substance use, and health behavior change (DeGruy & Etz, 2010). This concept will require a shift in thought and behavior from both the provider (teams) and the patient to achieve maximum outcomes. The Patient Centered Medical Home (PCMH) model is not clinician-, institution-, or disease-centered. It is patient-centered. For this to happen, the patient must be put at the center (Peek, 2010). Patients must not be just recipients of care but active and engaged members of the team. Gruman, Jeffress, Edgman-Levitan, Simmons, and Kormos (2009) stated,

What is lacking from the model of the medical home is recognition that patients are not the object of care, but that they are full-fledged participants in it—and unless that participation is active and informed, the impact of healthcare, whether services, drugs, surgery or devices, is severely, muted. (p. 3)

Mental Health

The National Institute of Mental Health (2013) reported in 2008 that one of every four Americans over the age of 18 would meet the criteria for a diagnosable mental health disorder. This translates to approximately 57.7 million people. Many research studies over the past quarter of a century have discovered significant links between chronic illnesses and mental health conditions (Hudson, Bundy, Coventry, & Dickens, 2014; Paschalides et al., 2004; Smith et al., 2013). These co-occurring disorders, which are defined as a physical disorder accompanied by a
mental health condition, are highly linked to each other, and nearly 50 percent of those individuals meeting the criteria of one mental health condition also meet the criteria for two or more disorders (Collins et al., 2010). Nearly 70 percent of all primary care visits are for psychosocial reasons (Robertson & Reiter, 2009), and the data gleaned from the PRIME-MD 1000 validation study (Kroenke et al., 1994) showed a significant positive correlation between the number of physical symptoms and the number of psychological symptoms a patient has reported. As physical symptoms increase, so do psychological ones and vice-versa. These two lines run parallel and appear to be indivisible.

**Integrated Primary Care**

To fully understand the complexity of treating chronic illness, it is crucial to transcend the canonical perspective of compartmentalizing patients into either biomedical or psychosocial silos. Desegregating these concepts and subscribing to the biopsychosocial model allows providers to focus on the whole body experience relative to treating a patient. A proven step in this direction is the concept of Integrated Primary Care (IPC) (Butler et al., 2008) in which organizations employ a trained Behavioral Health Provider (Psychologist, Clinical Social Worker, Medical Family Therapist, etc.) as an integral member of the traditional health care team.

In the past few decades, significant research has been conducted regarding IPC operations, billing, reimbursement (Monson, Sheldon, Ivey, Kinman, & Beacham, 2012), privacy-law (Hodgson, Mendenhal, & Lamson, 2013), and overall efficacy of integrated care (Collins et al., 2010). Randomized clinical trials have shown that IPC is effective in many clinical settings (Butler et al., 2008) where the most efficacious IPC settings employ integrated BHP, mental health screening, stepped-care (Unutzer et al., 2002), multiple contacts with a care
manager (Oxman, Dietrich, & Schulberg, 2005), and enhanced provider communication via EHR (Reitz, Common, Fifield, & Stiatsny, 2011).

There are many different forms of integrated care within a primary care setting. Most follow three basic concepts: medical and behavioral healthcare that is coordinated, co-located, and integrated. Doherty, McDaniel, and Baird (1996) described five distinct levels: minimal collaboration, basic collaboration at a distance, basic collaboration on-site, close collaboration in a partly integrated system, and close collaboration in a fully integrated system. The most defining quality of the close collaboration in a fully integrated system is that the patient has one shared care plan with both medical and behavioral health providers. The Association for Healthcare Research and Quality (AHRQ) recently published the Lexicon for Behavioral Health and Primary Care Integration: Concepts and Definitions Developed by Expert Consensus (Peek, 2013). This document outlines 6 clauses and 12 parameters comparing similar components within an IPC. For the purposes of this study, the level of IPC was defined using the criteria set forth by the most recent AHRQ publication.

Teams need to function together as one unit to provide optimal outcomes (Eubank, Orzano, Geffken, & Ricci, 2011; Gittell, 2009; Moore, 2006) and recent healthcare reform efforts call for improved teamwork within primary care settings (Institute of Medicine, 2001; Martin et al., 2004). Effective use of multiple member care teams in medicine has been shown to improve safety (Baker, Gustafson, Beaubieu, Salas, & Barach, 2003), and cost effectiveness (Amundson, 2001), lead to self-reported patient well-being and care satisfaction, and reduce the number of overall visits (Adam, Brandenburg, Bremer, & Nordstrom, 2010) for patients living with chronic illnesses. Research suggests that these outcomes are due to better functioning teams that ultimately make better decisions, produce more integrated care plans, have improved
coordination in efforts and deal with complex tasks more efficiently and effectively (Dean, LaVallee, & McLaughlin, 1999; Grumbach & Bodenheimer, 2004; Wagner, 2000). These findings suggest that effective teamwork and integration of care are key components of the Patient Centered Medical Home (Patient Centered Primary Care Collaborative, 2007).

Relational Coordination (RC) is a concept developed in the airline industry (Gittell, 2001) where the coordination of teams was deemed critical for overall efficiency. Transferring the concept over to the healthcare industry developed later (Gittell, 2002). Since then, RC has been shown in multiple studies to improve overall healthcare outcomes including chronic disease management (Cramm & Nieboer, 2012a; Hagigi, 2011; Noel et al., 2012), and organizational team work (Gitell & Hagigi, 2014; Havens, Vasey, Gittell, & Lin, 2010; Valentine, Nembhard, & Edmondson, 2013). Additionally, case studies on implementing decision support for patients showed value relative to RC factors and team based decision-making by physicians and multi-member care teams (Elwyn, Grande, Gittell, Godfrey, & Vidal, 2013). The RC measure focuses on evaluating the fundamental relationship process between all members of the care team. According to Relational Coordination theory, organizations that have frequent, high quality communications, reinforced by mutual respect and shared goals and knowledge, perform better as a team and are more likely to achieve improved outcomes (Gittell, 2009).

Cramm and Nieboer (2014) focused on the use of RC measures in the medical field from the patient’s perspective. Aside from this work, there is a dearth of literature focusing on Relational Coordination and the consumer. Although not necessarily in the medical setting, Warfield, Chiri, Leutz, and Timberlake (2014) and Plé (2013) focused their research on the consumer. Warfield et al. (2014) focused on family well-being in an autism waiver program and Plé (2013) focused on “customer participation” (p. 5) in the banking world; both used the RC
measure. Weinberg et al. (2007) and Gittell and Hagigi (2014) have focused on the important role of Informal Caregivers (ICG) and Relational Coordination regarding patient’s chronic illness. This research clearly shows that Relational Coordination between non-medical caregivers matters regarding healthcare outcomes. Marrying the concepts of patient, informal caregiver, and formal caregiver together, however, has yet to be investigated relative to its impact on Relational Coordination.

**Individual Patient Concepts**

Self-determination theory (Deci & Ryan, 2000) has been studied quite extensively regarding personal empowerment and its effects on health behavior change, such as smoking cessation (Williams, Ryan, & Deci, n.d.), weight control (Silva et al., 2008), medication adherence (Williams, Rodin, Ryan, Grolnick, & Deci, 1998), and improved psychological states such as decreased depression and anxiety (Ryan, Patrick, & Williams, 2008). This theory is grounded in the belief that people who feel capable of performing the task, feel connected to the team involved in the task, and feel autonomous in their actions are more likely to succeed at that given task. This may appear obvious, but relative to patient care, this patient-centered concept is new compared to the historically authoritarian physician-centered care of the past (Frosch et al., 2012).

Determination to engage is only part of the communication dyad. Shared Decision-Making (SDM) is the shared process between clinicians and patients where the best available evidence is used in the task of making decisions and where patients are supported in the consideration of options to achieve optimal outcomes (Elwyn et al., 2013). The principles of SDM are well-documented as is guidance about how to accomplish the approach. Additional models have also been created that account for decision-making within a care team. As noted by
Legare et al. (2011), most research on SDM has focused on the dyad of patient and physician, but has ignored the rest of the care team members potentially involved in the SDM process. A common SDM process within primary care not only involves an entire care team, but also occurs over an extended period of time. Although the process of SDM is built on the foundation of the original interaction, this diachronic process will most likely include multiple decisions made by multiple members over an undefined period of time.

Studies show that patients want to be partners in the decision-making process (Berckalaer et al., 2012; Guadagnoli & Ward, 1998). Although physicians endorse shared decision-making as a philosophy, a process that improves patient connectedness and confidence, they rarely follow these principles behaviorally (Bernabeo & Holmboe, 2013). There still exists a gap between theory and practice relative to how patient-centered care is delivered.

Patient activation, engagement, self-efficacy and self-management have all been used to describe a patient’s behaviors towards health promotion. Wagner et al. (2001) found that confidence is one of the most significant factors in managing a chronic illness. Measuring a patient’s level of confidence relative to their self-care (self-efficacy) is seen as a proxy for engagement (Wasson & Coleman, 2014) and could be measured with a simple 1-10 scale. The patient’s experience with their illness is in constant flux (Carver & Jessie, 2011) due to many internal and external triggers such as mental health conditions, substance use disorders, and situational stressors. Subsequently, the patient expresses this fluctuating experience in many ways; one of them via their perceived level of confidence.

Although there is no specific structure outlining how providers should or should not act with patients, there is common agreement to the fact that the patient-provider relationship is important for effective clinical encounters (Makoul, 2001; Mead & Bower, 2000). Due to this
ever-changing state of the patient’s subjective experience, the relationship with the patient and provider must also remain flexible, with the provider being vigilant to the patient’s current level of confidence. The individual’s phenomenological experience matters. As this awareness increases, the provider is able to accommodate to the level of treatment and support reflected by the intensity of the individual patient’s needs at that moment. As noted by Lorig et al. (2012), a key predictor of any positive health outcome is confidence and control, not a specific behavior change.

Confidence and importance related to personal change is a core factor of the widely-known evidence-based practice of Motivational Interviewing (MI) (Miller & Rollnick, 2013). Although this study will not be based on the entirety of MI techniques, it is partly grounded in the theory and overarching MI spirit relative to self-perceived confidence and importance (Bates, 2009). Since the first edition of the MI text, the confidence/importance ruler has been utilized to gauge a person’s readiness for change (Miller & Rollnick, 2013).

A team-based approach to care is essential to the PCMH (National Committee on Quality Assurance, 2011). According to social determination theory, how a patient relates to and interacts with their provider team is essential to the overall outcome of that patient. This positive interpersonal interaction amongst significant others is often described in terms of connectedness. Researchers have explored the relationship-centered concept of connectedness in many arenas, including anthropology (Leidy & Haase, 1999), psychotherapy (Ong & Allaire, 2005), and primary care medicine (Scott, Cohen, Dicicco-Bloom, Strange, & Crabtree, 2008). Although medical research exists that explores the concept of connectedness and the patient-provider relationship, there is a dearth of information relative to how patients relate to a care team as a
member of the team, including the primary care provider, nurses, behavioral health providers, and medical assistants.

A definition of connectedness by Phillips-Salimi, Haase, and Kookan (2012) is useful in comprehending the complex nature of the term. According to them, connectedness is a social relationship in which a person perceives that he/she has a close, intimate, meaningful, and significant relationship with another person or group of people. This perception is characterized by positive expressions (i.e., empathy, belonging, caring, respect, and trust) that are both received and reciprocated either by the person or between people through affective and consistent social interactions (Phillips-Salimi et al., 2012, p. 7).

**Conclusion**

Care management of co-occurring chronic illness necessitates more than the coordination of services around the patient. More so, as care management becomes increasingly team-based, the coordination of care necessitates enhancement of team interactions. Significant research has been conducted around team-based care and thus provided robust support for the concept. What is lacking, however, is support for the concept of team-based care that includes the patient; who is the only true constant in the equation of healing.

Through the lens of Relational Coordination, researchers can investigate key elements of team collaboration and inter-connection. Frequent, timely, and accurate communication supported by shared knowledge and goals, and respectful problem solving behaviors have been shown to improve team relatedness (Gittell, 2009). What is still not known is how the patient fits into this concept; specifically how patients perceive confidence and how their perceptions of the importance of healthcare management relate to their perception of connectedness to the healthcare team. This study investigated how the concept of importance and confidence of self-
care is related to the interconnectedness of care team members working together towards co-occurring chronic disease management.
CHAPTER 3

METHODOLOGY

In this section, the methodology is outlined via explanation of the research design, research partners, population and sampling, data collection and analysis, and the limitations. The purpose of this study is to investigate two constructs. The first was, from the patient’s perspective, what does the concept of team mean; specifically what factors influence their sense of connectedness to their medical care team? Secondly, how does the presence of a mental health condition, such as depression and/or anxiety, influence the patient’s level of perceived confidence relative to self-management of their chronic illness?

The principal investigator (PI) in this study is an employee of the organization being studied. According to Coughlin and Brannick (2010), study of one’s organization must be done intentionally as a strategic move to bring an in-depth understanding of the problem due to the PI’s intimate knowledge of both the organization and the patient population. This knowledge informs the researcher, and allows him or her to bring assumptions and some bias about what the profession can do to improve patient care. The researcher strived to control any biases by using research-based survey questions, reviewing all assumptions with other professionals, and evaluating the data systematically.

A two dimensional mixed-methods sampling model (Collins et al., 2007) is used to further the understanding of this often-marginalized (Cain, 2012; Crooks, Agarwal, & Harrison, 2012) patient population. Human science researchers often rely on a quantitative approach to data gathering. However, qualitative methods are growing in popularity in the psychological (Hanson et al., 2005; Haverkamp, Morrow, & Ponterotto, 2005; Palinkas, Horwitz, Chamberlain,
Hurlburt, & Landsverk, 2011; Riessman, 2008), health (Collins et al., 2010), and social (Collins et al., 2007; Katerndahl, Burge, Ferrer, Becho, & Wood, 2012; Mertens, 2013) sciences. Furthermore, when a mixed-methods approach is utilized, research results are enriched by the multimodal approach; more so than when a single form of data gathering is used. Mixed-methods allow for researchers to “simultaneously generalize results from a sample to a population and to gain a deeper understanding of the phenomenon of interest” (Hanson et al., 2005, p. 224).

This research study relied on the evaluative powers of both quantitative survey and qualitative narrative analysis. A two-phase sequential exploratory design using a criterion-based sample (Collins et al., 2007) was employed to achieve both a breadth and depth of analysis (see Figure 2). The qualitative data set gleaned from individual and focus group interviews was used to support and enhance the quantitative data obtained through a Likert-designed survey. Both approaches provide robust data with the potential to inform a transformative process within the organization and are often used when one data set is insufficient in answering the research question (Creswell & Plano Clark, 2007).
Figure 2. Mixed methods sampling design.

Site and Scope of the Setting for the Research

The study setting is a Federally Qualified Healthcare Center (FQHC) located in a coastal urban area of New England. The FQHC operates under an integrated primary care model with multiple care offerings including adult and pediatric medical, dental, and behavioral health (both mental health and substance use disorders) services as well as family support services, home visiting, and parent education. Additionally, this organization offers off-site medical, dental, and behavioral health services for homeless persons using two mobile health vans and numerous stationary sites within the community.

In their annual report (FY 2013), the observed organization provided the following profile. There were 12,560 medical visits (including behavioral health) and 5,440 dental visits. The population was made up of 97 percent Caucasians and 3 percent other. Twenty-five percent were men, 42 percent were women, and 33 percent were children under the age of 21. Average annual patient income rates showed that 60 percent of the population was at or below the poverty
level and another 32 percent lived within 101-200 percent of the poverty range. As of 2013, over 55 percent were uninsured, while 29 percent were insured with Medicaid, 8 percent with Medicare, and another 8 percent had other private insurance coverage.

**Participants and Sample Size**

To create a sample that can best contribute to the development of the research theory (Creswell, 2013) the participants were selected by a non-probability, criteria-based sampling process. A low inference and diverse sample population was sought for maximum variation in sample (Sandelowski, 2000). All participants in the case were selected via a set of specific criteria identified by the principal investigator. To assure interpretive consistency—the consistency between research design and the researchers implication—specific samples sizes were pursued. For the quantitative portion of this mixed methods study, a minimal sample size of 82 participants was necessary for a one-tailed analysis (Collins et al., 2007). For the quantitative portion, Creswell (2013) suggested a sample size of 6-12 participants to provide adequate data saturation and maximum interpretive consistency.

Patients were selected from a list of specific criteria. All patients had to be 18 years or older and be an established patient at the identified organization. All patients in this sample must also have had a chronic illness and been identified as having an “important condition” according to the organization’s PCMH guidelines. Inclusion conditions for chronic illnesses for this study were type II Diabetes Mellitus and hypertension. Lastly, all patients must also have at least one behavioral health condition. For a list of the specific participant criteria, refer to Appendix A.

**Stakeholders**

Stakeholders in this study are manifold and range from the micro to the macro. On the micro and meso-levels, examples of stakeholders in this study include the caregivers and patients
living with co-occurring chronic illness, community social service providers, the FQHC staff, and the FQHC board members. Additionally, on the macro level, stakeholder groups range from the local to national organizations. Locally, the Seacoast Community Collaborative, and one of the lead coordinators of our Regional Health Information Exchange, the Community Health Access Network, are very interested in these outcomes. Nationally, examples of interested stakeholders are the Collaborative Family Healthcare Association, and the Agency for Healthcare Research and Quality.

**Data Collection Instrumentation**

Data collection was conducted in a sequential approach with a criterion-based sample of FQHC patients (see Figure 3). First, general demographics and selection criteria were obtained by accessing existing patient data within the medical center’s EHR. Second, this selected sample of patients was assessed for their scores on a recent quality improvement survey (see Appendix B) that was given to the patients over a 90-day period from November 2014 through February 2015. The survey utilized a pre-established confidence and importance ruler to assess the patient’s status of both states relative to a scale from 1-10. The second portion of the survey was used to assess how patients perceived their connectedness to the care team. Two subscales were used to measure the two domains.

![Figure 3. Research collection flow chart.](image-url)
**Confidence ruler.** The Confidence Ruler (Miller & Rollnick, 2013; Wasson & Coleman, 2014) is a 1-10 interval scale used to measure the patient’s level of perceived confidence relative to managing their co-occurring illnesses (see Appendix B). This scale has been used for rating patient level of confidence relative to the management of chronic illness (Wasson & Coleman, 2014). Rating a patient’s confidence is also commonly used as a tool in interviewing individuals regarding their readiness to change (Miller & Rollnick, 2013). In this study, perceived confidence was assessed along with the connectedness scale in order to gauge if confidence and importance of self-care correlated with the perception of connectedness with the healthcare team.

**Relational coordination.** Connectedness and productive interaction were measured via a 5-point Likert scale, using the validated Relational Coordination survey (see Appendix B) (Gittell, 2011). Although this instrument was originally developed for the airline industry (Gittell, 2001), it has been used in multiple studies including hospitals (Hartgerink et al., 2013; Hartgerink et al., 2013), primary care (Cramm & Nieboer, 2012a, 2012b), and community settings (Cramm, Hoeijmakers, & Nieboer, 2013).

For this study, the RC instrument was used to measure the patient’s perception of the quality of interactions with their healthcare professionals including medical providers, behavioral health consultants (BHC), care coordinators, and their own family caregivers. Two domains were measured within the RC survey: quality of communication and relationships. The first domain was measured via four questions on the frequency, accuracy, timeliness, and problem-solving nature of communication. The second domain measured the shared knowledge and goals and mutual respect perceived between patient and provider(s).
Questions were structured with a 5-point Likert scale. Cronbach’s alpha for the RC instrument was 0.96.9, showing excellent reliability. The two scales will collectively be referred to as the Perceived Importance, Confidence, and Connectedness Scale (PICCS). Individual semi-structured, open-ended (Merriam, 2009) interviews were conducted subsequent to the gathering of the survey data. The interview data were used to explore, in detail, the data gleaned from the PICCS surveys. All participants provided informed consent for the study (Appendix C), which was approved by the University of New England’s Institutional Review Board.

**Data Collection Procedures and Timeframe to Conduct**

Data collection procedures for this research study occurred sequentially. Quantitative data was obtained via a paper-based surveys distributed to all patients identified within the PCMH *important conditions* list, which included patients with type II Diabetes Mellitus and hypertension. The survey was given to all patients during visits identified as relevant visits. In order to accumulate a large enough sample size the survey was given for a 3-month period, from November 1, 2014 through February 31, 2015. The PICCS survey tool was used to measure the patient’s confidence and perception of the importance of managing their co-occurring medical and mental health complications as well as their perceived level of connectedness to the care team. The data gleaned from the patient portion of the survey was used to inform the selection process of the initial patient sample.

The PICCS data were collected and analyzed, and then the qualitative data was procured in a sequential manner (see Figure 2). Patients were invited to participate in either individual interviews, focus group interviews, or both. See Appendix D for interview questions. Patients were contacted via outreach phone calls or face-to-face during routine follow-up medical appointments. Details such as informed consent, incentives, time, and location of interviews and
the participant’s role in the study were discussed at this point. This information was reviewed again during the interview process, prior to starting the actual interview. Thematic organization and coding of the data occurred during and subsequent to each interview session using both iterative and simultaneous coding protocols (Creswell, 2013). Specific coding protocols are described below in the data analysis section.

Other data elements were gathered to support the investigation of the study’s phenomenon. Demographic data such as age, gender, and amount of time participant had been a patient were gathered in addition to biological data such as blood pressure, A1C readings, and body mass index. In addition numerous psychometric data was gathered such scores on recent PHQ-9 and GAD-7 scores, number of mental and behavioral health diagnoses, and type and number of psychotropic medications.

**Ethical Considerations**

One consideration that cannot be ignored is the fact that the project PI was one of the members of the integrated care teams. Mehra (2002) pointed out that, according to the qualitative research paradigm [the] researcher is an important part of the process. The researcher cannot separate him or herself from the topic/people he or she is studying, it is in the interaction between the researcher and researched that the knowledge is created. So the researcher’s bias enters into the picture even if the researcher tries to stay out of it. (para. 27)

The concept of bias was embraced and brought to awareness of all research participants before the onset of the investigation through the disclosure statement, informed consent, and verbal conversation prior to the onset of the interviews (Mehra, 2002). A second consideration regarded the level of confidentiality needed by the patients and safeguarding during focus group
meetings. Focus group members were encouraged to respect the confidentiality of the other group members yet confidentiality cannot be guaranteed.

**Pilot Study**

A pilot study was conducted between November and December 2014. The PI followed the proposed research flow stated above. The pilot study served the purpose of both elucidating errors in all steps of the research processing and refining the survey and interview questions. Due to the selected criterion for this study, there were a limited number of total participants available at the research site. Due to this limitation, the PI recruited only one member from each role; totaling two participants in the qualitative portion of the pilot study. Two participants were identified for the survey portion of the pilot study.

**Data Analysis**

Data was gathered and analyzed for the first phase of the study via the PICCS assessment tool. The closed-ended data (Creswell & Plano Clark, 2007) was analyzed and assessed for correlational relationships; specifically between confidence and both attainment of self-care and level of connectedness. Results from the survey were used to identify patients for individual and group interviews. All data gleaned from the interviews was recorded and then transcribed. A qualitative thematic analysis of text data (Creswell & Plano Clark, 2007) was used to analyze the transcribed data. Interview questions were designed to promote the creation of themes used to support the quantitative data gleaned from the surveys.

The RC measure that was used in this study, as part of the PICCS assessment, was a fully validated measure of teamwork and an often used assessment tool for evaluating the interplay between unbound team members that span multiple boundaries within the healthcare delivery system (Valentine et al., 2013). Relational Coordination was measured using seven survey
questions: four that focused on communication (frequency, timeliness, accuracy, and problem-solving) and three that focused on relationships (shared goals, shared knowledge, and mutual respect). The RC measure has proven internal consistency, structural validity, content validity (Gittell, 2002), interrater agreement, and reliability (Gittell, Seidner, & Wimbush, 2010).

Most often, the RC measure has been used to evaluate multiple members and the interplay between them. The RC measure for this study was used in a slightly different manner than the norm. As with Warfield et al. (2014) and Cramm and Nieboer (2012a), this study focused on using the RC measure from a single person’s perspective. For this study, the PI’s unipolar focus was the patients’ view of their experience with their medical team. The slight difference in this case, relative to other RC research, was the fact that the PI asked patients to respond to the survey (and qualitative interview questions) as if they too were part of the team.

Missing data can often pose a problem in quantitative research designs (Cox, McIntosh, Reason, & Terenzini, 2014). As noted by one author, “the only really good solution to the missing data problem is not to have any” (Alison, 2002, p. 2). In this study there were cases of missing data with the RC survey; specifically regarding the care coordinator and family caregiver subsets. All missing data was dealt with in a pair-wise fashion. Although there is some bias expected with this empirical data set, both in direction and magnitude of analysis, it was expected to be small (Graham, 2009).

**Data Treatment**

All paper data, including surveys and archival data, were kept in a locked drawer within the researcher’s office. All interview data was sent away in digital form with all identifiers removed from the recordings. Recordings were sent to an on-line transcription service for verbatim analysis and transcription. Once the PI received the transcription documents, they were
verified for accuracy and completion. Average return time on all recordings was 2.5 days from sending in to receiving the completed transcript. All digital data (including audio recordings, transcriptions, and some quantitative data) was stored on an IronKey pen drive for secure storage. A password-protected back-up copy of all data was kept on the PI’s work computer desktop.

**Significance of the Study**

Medical decision-making processes are becoming increasingly team-based wherein the management of chronic co-occurring conditions is shared between the medical team and the patient. An extreme example of this is shown by the efforts from the Collaborative Family Healthcare Association members who are spearheading a movement for the inclusion of the entire family in treating complex conditions. As the number of care team members increases so does the need for coordinating the relationships and communications between these members.

This research focused on what constructs are important to team members relative to enhancing the trust, conflict resolution, commitment, accountability and positive goal orientation. The results of this study have implications for all members of the care teams working with patients living with co-occurring medical and mental health conditions, specifically towards increasing the relational coordination between members as well as simultaneously focusing on the positive strengths and attributes of the patients.

Currently, little is known regarding what factors enhance collaboration for primary care teams operating within an integrated primary care (IPC) setting. Furthermore, there is a dearth of knowledge regarding team dynamics when the patient is actively considered a team member. This organic approach was designed to enlist the input from the people at the center of the team-based disease management process: the patients. Patient team members were requested to
provide very specific and personalized input regarding this process. Concepts that were explored included but were not limited to what factors may enhance their sense of connectedness to the team, such as trust, conflict resolution, commitment, accountability, and positive goal-oriented behaviors within the IPC teams.

Few studies have focused on the patient as an active member of the team. A few recent RC studies (Cramm & Nieboer, 2014; Ple, 2013; Warfield et al., 2014) focused on the patient and/or customer as the central construct of assessment. Most research on Relational Coordination in primary care settings however, has focused on the interplay of medical team members. This study, however, focused on the patient members of the care team. By elucidating the wants and needs of the patients, a grassroots change process was conducted. The data will be used to improve both existing workflows and protocols and the knowledge management tools within the EHR.
CHAPTER 4

FINDINGS

In this chapter, the results of this study are presented corresponding with the research hypotheses; reflecting the examination of how confidence of self-care and perception of connectedness influences interpersonal team dynamics for patients managing co-occurring chronic medical and mental health conditions. Quantitative data gathered via the PICCS survey and supportive interview-based qualitative data regarding the patient’s lived experiences were used in combination to examine the research questions proposed.

This chapter is organized under the corresponding research hypotheses and subsequent applicable research questions.

Hypothesis 1. The patient’s level of perceived confidence relative to self-care of their chronic illness is mediated by the presence of a mental health diagnosis.

Hypothesis 2. High levels of patient confidence relative to self-care of their chronic illness increase their sense of connectedness to their care team.

Data Collection and Analysis

Data collection was conducted sequentially with the quantitative data collected first. All members that were identified by the organization as having an important condition according to the organization’s PCMH level III guidelines were asked to fill out the PICCS survey. A sample size of 82 participants was pursued. Table 1 shows the demographic characteristics of the participants in this study. Gender breakdown was 54% female with an age range of 31 to 80 years (median of 53.5 years; mode of 60 years). All participants in this study had been established as medical center patients in this FQHC for at least one year. The average time a
participant had been established was 5.96 years (range 1-14 years; mode 1 years, median 5.00 years). The diverse sample of men and women had a confirmed diagnosis of either type II Diabetes Mellitus and/or hypertension.

Table 1

**Demographic Characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Mean (years)</th>
<th>Standard Deviation</th>
<th>Median (years)</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>54.29</td>
<td>10.85</td>
<td>53.5</td>
<td>31</td>
<td>80</td>
</tr>
<tr>
<td>Time at FQHC (years)</td>
<td>5.96</td>
<td>4.48</td>
<td>5.00</td>
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<td>14</td>
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</tbody>
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<table>
<thead>
<tr>
<th></th>
<th>(n)</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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<td></td>
</tr>
<tr>
<td>Male</td>
<td>38</td>
<td>46.35</td>
</tr>
<tr>
<td>Female</td>
<td>44</td>
<td>53.65</td>
</tr>
</tbody>
</table>

Within the 3-month period from November 2014 through February 2015 all patients that were identified with an important condition were asked to fill out the PICCS survey (see Appendix B). Due to workflow and other prioritizing medical related concerns there was attrition; of 118 visits, 104 patients were requested to fill out the survey. Of those 104 patients, 10 PICCS surveys were incomplete to the point where the data was not usable and 26 patients refused to fill out the survey. Eighty-two patient participants completed the survey, which made for a response rate of 69.5%. Of those 82 participants that filled out complete surveys, 22 were followed up for interviews. Of those 22 patients invited to interview, 10 responded positively to the request (response rate of 45.5%) and partook in the interview process. Archival data was collected in concurrence with PICCS survey data to assure maximum data points for analysis.
All quantitative data were collected via the PICCS survey and the organization’s EHR. Data was processed using SPSS v.23 software. Results were considered statistically significant if one-tailed $\rho$-values were $\leq 0.05$. All qualitative data were collected via individual interviews and coded on QSR NVivo software version 10.2.0. Thematic analysis data coding occurred (see Figure 4) both during and subsequent to the interviews. The four central themes were discussed following the appropriate hypothesis and used to support the collected quantitative data.

![Quantitative coding analysis](image)

**Figure 4:** Quantitative coding analysis.

**Hypothesis 1:** *The patient’s level of perceived confidence relative to self-care of their chronic illness is mediated by the presence of a mental health diagnosis.*

An *a priori* power analysis (Faul, Erdfelder, Buchner, & Lang, 2009) was run for a linear multivariate regression model to estimate the sample size for this study. For a one-tail, medium
effect size \( (f^2 = .5) \) with a power of .99 \((1-\beta \text{ err prob})\) an appropriate sample size was estimated to be 82 participants. This matched the sample size suggested by Collins et al. (2007). The design examined the relationship between mental health, confidence, and control of specific biological indicators associated with each disease state (i.e., diabetes and hypertension).

Quantitative data was gathered on the following components: presence and type of one or more mental health diagnoses, patient’s level of confidence regarding their self-care (1-10 scale with 10 being extremely confident and 1 being not at all confident), and blood pressure and hemoglobin A1C readings. Diastolic and systolic measurements as well as hemoglobin A1C readings were gathered respectively according to patient’s medical diagnoses of hypertension and/or type II Diabetes Mellitus (see Table 2). In this study, confidence was found to be significantly correlated to three different concepts: control of hypertension, the number of mental health diagnoses and participant scores on PHQ-9 and GAD-7 scales.

Table 2

Blood Pressure and A1C Reading

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Median</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>BP Systolic</td>
<td>133</td>
<td>15.83</td>
<td>134</td>
<td>90</td>
<td>168</td>
</tr>
<tr>
<td>BP Diastolic</td>
<td>80</td>
<td>9.21</td>
<td>82</td>
<td>54</td>
<td>100</td>
</tr>
<tr>
<td>A1C</td>
<td>7.4</td>
<td>1.10</td>
<td>7.30</td>
<td>5.1</td>
<td>9.7</td>
</tr>
<tr>
<td>BMI</td>
<td>34.06</td>
<td>7.96</td>
<td>31.90</td>
<td>18.82</td>
<td>63.50</td>
</tr>
</tbody>
</table>

Theme 1: Confidence and Self-Care

Confidence plays a significant role in self-care and is often considered a primary indicator whether or not a patient will be successful with their chronic disease management
(Wasson & Coleman, 2014). According to Lorig et al. (2012), confidence to make a change is seen as more important than any specific behavior change itself. For this study, a 1-10 scale was used to measure participant’s individual confidence level regarding their ability to manage their chronic illness. A score of 10 meant the participant was extremely confident and a score of 1 showed no confidence at all. For the entire sample population, the average confidence score was 8.29 (median 9.0, mode 10, range 1-10). For the subset of 10 patients that were interviewed, the average confidence score was 6.50. A confidence score of 7 or more demonstrates an activated patient, willing to engage in their self-care (Wasson & Coleman, 2014).

Multivariate regression analysis was run for hypothesis 1 as follows. First, a regression analysis was performed to see if a relationship exited between confidence and controlled hypertension and/or diabetes. The model summary for this analysis showed that the relationship between confidence and controlled hypertension was significant at .042 (t = -2.069; β = -.234; SE = .533). The relationship between confidence and controlled type 2 Diabetes Mellitus however was not significant at .871 (t = -.164; β = .018; SE = .418). Diabetes remained insignificantly connected to confidence for the following two regression analyses explained below.

A second regression analysis was run to identify an association between the patient’s level of confidence and their status of whether they had one or more mental health diagnosis (depression and/or anxiety). The association between these two was shown to be significant at the .024 level (F = 3.315, MS = 10.251, SS = .114, r = .338). The last regression was run to identify if the presence of a mental health diagnosis could be mediating the effect confidence played on the patient’s ability to manage their hypertension. This last regression was insignificant for hypertension (p = .085; t = -1.749; Beta = -.191; SE = .527).
The analysis showed a lack of significance level on the last regression, implying that control of the patient’s hypertension was no longer significant due to the mediating (controlling) factor of the presence of a mental health diagnosis. Thus hypothesis 1 was found to be true for patients living with hypertensive disorder: The level of patient confidence relative to self-management of hypertension was mediated by the presence of a mental health diagnosis such as depression or anxiety. The dependent variable in this case was control of confidence and the two explanatory (independent) variables were control of chronic illness and the presence of a mental health diagnosis. A Pearson product-moment correlational coefficient was also computed to assess the relationship between confidence and control of hypertension and diabetes (see Table 3). Note that confidence was related to the management of hypertension but not diabetes. The other correlation this chart shows was the strong connection between managing hypertension and managing diabetes. This data suggests that if you are not managing your diabetes, you are unlikely to be managing your hypertension. The reverse would be implied as well.

All participants were given an illness-severity score and were stratified according to four clinical areas: number of mental health diagnoses, number of combined medical diagnoses (diabetes, hypertension and other), control of diabetes and/or hypertension, and BMI. The creation of the severity index was based on a similar 2002 study on disease-severity index and evaluation of healthcare costs (Rozenzweig, Weinger, Poirier-Solomon, & Rushton, 2002). A post-hoc analysis showed a significant correlation ($r = -.227$) between patient severity score and their level of confidence of self-care ($p = .020$).
### Table 3

**Confidence and Control**

<table>
<thead>
<tr>
<th></th>
<th>Confidence</th>
<th>Control Hypertension</th>
<th>Control DM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confidence</td>
<td>Pearson Correlation</td>
<td>1</td>
<td>-.232*</td>
</tr>
<tr>
<td>Sig. (1-tailed)</td>
<td></td>
<td>.019</td>
<td>.267</td>
</tr>
<tr>
<td>n</td>
<td></td>
<td>82</td>
<td>82</td>
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<tr>
<td>Hypertension</td>
<td>Pearson Correlation</td>
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<td>1</td>
</tr>
<tr>
<td>Sig. (1-tailed)</td>
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<td>.002</td>
</tr>
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<td>n</td>
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<tr>
<td>DM</td>
<td>Pearson Correlation</td>
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<td>-.329**</td>
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<tr>
<td>Sig. (1-tailed)</td>
<td></td>
<td>.267</td>
<td>.002</td>
</tr>
<tr>
<td>n</td>
<td></td>
<td>82</td>
<td>82</td>
</tr>
</tbody>
</table>

* Correlation is significant at the 0.05 level (1-tailed).

** Correlation is significant at the 0.01 level (1-tailed).

The data suggested that the presence of a mental health diagnosis impacted a patient’s confidence. Answers to why may be found in the fact that the patient’s lived experience relative to their mental health was in constant flux, and subsequently so was their level of confidence. An interviewed participant demonstrated this connection by stating, “Yah, my confidence directly relates to my depression, if I’m feeling bad about myself, I feel less confident that I can do it [manage self-care].” This patient continued by stating, “It also has to do with awareness. If I’m less depressed, I’m more aware and when I’m [more] aware of my actions I make better choices . . . then I get healthier.” This reflection demonstrated the difficult nature of teasing out what is
most impactful on self-care: the person’s mood state or their confidence. Perceptions of physical and emotional status is intimately entwined.

Motivation varied between patients. Most did agree however that “seeing results . . . just watching things get better,” “mastering something,” “setting attainable goals,” or “just having simple tools” for self-management improved their level of confidence. Other concepts reported by patients that increased their confidence in self-care related to trusting the medical team.

“Trust equals confidence to me,” stated one patient, “if I trust you, I’ll feel more confident in my choices . . . trusting that you are all telling me the right course of action.” Shared decision-making seemed to be directly associated with trust for those interviewed. Multiple interviewees reported, “What works with me is talking about it with [my doctor]. I mean the decision is made with both of our input, not just hers and not just mine.” Another patient supported this by reporting, “You are all on top of things here but you still take what I think into consideration.” Put quite simply by another patient, “Shared goals and shared-decision-making increases my confidence I want a partnership.”

Patient participants also reported numerous actions that decreased their confidence. Interestingly enough, one patient reported that “taking the easy route . . . just throwing more pills at me instead of making a real change, like in what I eat and what I do . . . that is what discourages me.” Not being treated with respect was also reported as a factor that decreased confidence. “I don’t care if [you] worked on the Pope, if you can’t be nice than what good are you to me?” reported one participant. He continued by saying,

How you treat me goes a long way. You all here are wonderful but there are other doctors that I do go to, they know how to do their job but I don’t have confidence in them because I don’t like how their staff treats me.
This last statement exemplified the connection between confidence and interpersonal relationship with the entirety of staff; it was more than a simple bidirectional relationship between the patient and the provider. The entire staff played a role in creating the overarching experience that the patient experienced.

Intrapersonal conversations also played a role in participant’s level of confidence. Self talk such as, “Well I’m afraid it’s not really easy to describe. I’ve been this way so long; the depression and all . . . it is almost like an injury that I’ve grown accustomed to having. Like my attitude is that I just can’t change.” Other patients reported negative self-talk as well. In this instance a participant provided an example of negative self-talk that exacerbated their anxiety. They stated, “I keep thinking I'm going to die, sometimes, I wake up in the middle of the night having panic attacks, thinking I’m going to die from this [cardiac-related issue]. It’s freaking me out.” That same patient reported later that “I keep thinking I’m gonna’ start losing organs.”

Chronic illness is long-term. Hypertension, diabetes, and even depression are not conditions that are typically “cured” but more so managed. Given this, many patients voiced being discouraged by the long-term nature of chronic illness. One patient stated, “Everything in my life has had a beginning, middle and end . . . but not diabetes . . . it just keeps going.” Another described their situation with clear melancholy

I don’t know. It’s some kind of surrender and I'm almost incapable . . . I'd say I've been wounded in battle, but I'm still walking and trying to fight it. I haven't really surrendered and who do you surrender to, because when I leave your office and I go down that road there and then I'm back alone and that is the best I can do I guess, just keep on going.

Level of Confidence and PHQ-9.GAD-7 Scores. The second significant correlation related to how participants scored their level of confidence relative to their scores on a Patient
Health Questionnaire-9 (PHQ-9) and the Generalized Anxiety Disorder-7 (GAD-7) assessment. The PHQ-9 and GAD-7 assessments are commonly used to assess patient’s level of symptoms relative to depression and anxiety (SAMHSA-HRSA Center for Integrated Health Solutions, n.d.). Scores on the PHQ-9 range from 0-27: 1-4 = minimal depression; 5-9 = mild depression; 10-14 = moderate depression; 15-19 = moderately severe depression; 20-27 = severe depression (SAMHSA-HRSA Center for Integrated Health Solutions). Scores on the GAD-7 range from 0-21: 1-4 = minimal anxiety; 5-9 = mild anxiety; 1-14 = moderate anxiety; and 15-21 = severe anxiety (Spitzer, Kroenke, Williams, & Lowe, 2006).

The identified organization used the PHQ-9 and GAD-7 scales as re-occurring assessment tools for patients identified with a mental health condition. In a past study conducted at the identified organization, 45% of the identified patient population with both a chronic disease and identified mental health condition were found to be moderately to severely distressed (Fauth & Tremblay, 2011). The scale used to measure level of distress was a combination of the PHQ-9 and GAD-7 scales.

As shown in Table 4, there is a statistically significant correlation between confidence scores and both PHQ-9 and GAD-7 scores. This data suggested that as PHQ-9 and GAD-7 scores increased, the level of patient’s confidence to manage their chronic illness decreased. Furthermore, the data showed a significant relationship between PHQ-9 and GAD-7 scores, suggesting that as the patients’ level of depression increased so did their level of anxiety.

Although not heavily supported by the interview data, a few participant responses spoke directly towards the relationship of anxiety and depression. One patient noted, “Whenever I have depression I get anxiety . . . it is all mixed into one.” Another female patient noted the complexity of it all, stating, “Sometimes when my diabetes is better, my thyroid might be off and
that effects my mood, my anxiety, just my general thinking.” Another patient supported the
connection in another way by showing the impact of mood and anxiety-related issues on sleep.
The participant noted that he was sinking into a deeper depression and it was getting “so bad that
the anxiety just kicked in. I was feeling hopeless and helpless and now I can’t even sleep it’s so
bad . . . I’m only getting four hours [of sleep] a night.”
Table 4

Correlation Matrix Confidence, PHQ-9 and GAD-7

<table>
<thead>
<tr>
<th></th>
<th>Confidence</th>
<th>PHQ-9</th>
<th>GAD-7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confidence</td>
<td>Pearson correlation (r)</td>
<td>1</td>
<td>-.353*</td>
</tr>
<tr>
<td></td>
<td>p one-tailed</td>
<td>.035</td>
<td>.042</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>PHQ-9</td>
<td>Pearson correlation (r)</td>
<td>-.353*</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>p one-tailed</td>
<td>.035</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>GAD-7</td>
<td>Pearson correlation (r)</td>
<td>-.339*</td>
<td>.795**</td>
</tr>
<tr>
<td></td>
<td>p one-tailed</td>
<td>.042</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>27</td>
<td>27</td>
</tr>
</tbody>
</table>

*. Correlation is significant at the 0.05 level (1-tailed).

**. Correlation is significant at the 0.01 level (1-tailed).

Confidence and Number of Mental Health Diagnoses. For this study, confidence to
manage one’s own care was measured on a 1-10 scale, and was found to be significantly
correlated with the number of mental health diagnoses a patient had (nonspecific to which mental
health diagnosis). At a .05 level, one mental health diagnosis correlated with a confidence at
$r = -.200$ and two mental health diagnoses at $r = -.315$. A second correlational analysis was run on the total number of mental health diagnoses compared to confidence scores. This analysis showed a confidence level of .003 with a Pearson correlation of -.307. This data suggested that as the number of mental health diagnoses increased the patient’s confidence level decreased.

There is a common sense rationale here. Logic offers that the more a person has to manage, the less confidence that person has to manage the bigger picture. In this study, the majority of diagnoses identified were depression- and anxiety-related and, as shown above, depression and anxiety were directly related to hypertension and diabetes. Once again we witness the inescapable cyclical nature of these co-occurring illness. When a patient gets one, they have a good chance of getting another and possibly another. With this potential imminent, their confidence to manage increasing complexity decreases.

**Theme 2: Complications of Co-Occurring Mental Health and Medical Diagnoses**

The presence of a mental health diagnosis, as shown by the results in this study, was a mediating factor regarding the patient’s level of confidence relative to self-care of hypertension but not for diabetes. Although the quantitative data only showed a significant connection between confidence, mental health and hypertension, for the purpose of this study, both hypertension and type II Diabetes Mellitus will be discussed. This decision was made because there was rich and bountiful qualitative data for both disease states; therefore the PI chose to show both qualitative data sets even though the quantitative data only showed a significant connection for patients with hypertension.

The sample size was made up of both patients living with hypertension and those living with type II Diabetes Mellitus. Table 5 shows 84.10% of the sample population had hypertension and 41.46% had diabetes. Importantly, out of the 82 participants in this sample, 85.4% had a
secondary or tertiary diagnosis complicating the management of the identified primary diagnosis of hypertension or diabetes. All identified diagnoses were taken from the patient’s EHR.
Table 5

*General Participant Illness Profile*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total patients in this study</td>
<td>82</td>
<td></td>
</tr>
<tr>
<td>Patients with Hypertension</td>
<td>69</td>
<td>84.10%</td>
</tr>
<tr>
<td>Patients with Type II Diabetes Mellitus</td>
<td>34</td>
<td>41.46%</td>
</tr>
<tr>
<td>Other Dx:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypothyroidism</td>
<td>6</td>
<td>07.31%</td>
</tr>
<tr>
<td>Hyperlipidemia</td>
<td>25</td>
<td>30.48%</td>
</tr>
<tr>
<td>COPD</td>
<td>9</td>
<td>10.91%</td>
</tr>
<tr>
<td>Obesity</td>
<td>11</td>
<td>13.41%</td>
</tr>
<tr>
<td>Myocardial Infarction</td>
<td>6</td>
<td>07.31%</td>
</tr>
<tr>
<td>Sleep Disorder</td>
<td>5</td>
<td>06.09%</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>12.19%</td>
</tr>
<tr>
<td>None</td>
<td>12</td>
<td>14.63%</td>
</tr>
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</table>

**Depression and self-care.** The correlation between chronic illness and mental health has been well documented. Studies have shown that type II Diabetes Mellitus is highly correlated with depression (Hudson et al., 2014; Paschalides et al., 2004; Wing, Phelan, & Tate, 2002), cardiovascular disease (Seldernrijk et al., 2015), and other medical conditions (Wing et al., 2002). As seen in Tables 6 and 7, in this study, 44.93% of patients with hypertension and 44.12% of patients with diabetes had a mood-related disorder (major depression, bipolar, depression NOS, or dysthymia).
Table 6

*Diabetic Participant Characteristics*

<table>
<thead>
<tr>
<th>Variable</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Total patients in this study (n = )</td>
<td>82</td>
<td>100%</td>
</tr>
<tr>
<td>Patients with type II Diabetes Mellitus</td>
<td>34</td>
<td>41.46%</td>
</tr>
<tr>
<td>Patients with controlled DM (A1C &lt;7)</td>
<td>24</td>
<td>70.59%</td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
<td>44.12%</td>
</tr>
<tr>
<td>Age</td>
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<td>Years</td>
</tr>
<tr>
<td>Average Confidence Score</td>
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<td></td>
</tr>
<tr>
<td>PHQ 9 score &gt;9</td>
<td>9</td>
<td>26.47%</td>
</tr>
<tr>
<td>GAD-7 score &gt;7</td>
<td>5</td>
<td>14.71%</td>
</tr>
<tr>
<td>PHQ 9 score &gt;9 &amp; GAD&amp; score &gt;7</td>
<td>5</td>
<td>14.71%</td>
</tr>
<tr>
<td>Patients with mood related disorder</td>
<td>15</td>
<td>44.12%</td>
</tr>
<tr>
<td>Patients with unipolar depression</td>
<td>6</td>
<td>17.65%</td>
</tr>
<tr>
<td>Patients with bipolar disorder</td>
<td>3</td>
<td>8.82%</td>
</tr>
<tr>
<td>Patients with dysthymic disorder</td>
<td>3</td>
<td>8.82%</td>
</tr>
<tr>
<td>Patients with depression NOS</td>
<td>3</td>
<td>8.82%</td>
</tr>
<tr>
<td>Patients with anxiety related disorder</td>
<td>7</td>
<td>20.59%</td>
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<tr>
<td>Patients with panic disorder</td>
<td>0</td>
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<tr>
<td>Patients with generalized anxiety disorder</td>
<td>3</td>
<td>8.82%</td>
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<tr>
<td>Patients with PTSD</td>
<td>1</td>
<td>1.79%</td>
</tr>
<tr>
<td>Patients with OCD</td>
<td>1</td>
<td>1.79%</td>
</tr>
<tr>
<td>Patients with anxiety disorder NOS</td>
<td>2</td>
<td>3.57%</td>
</tr>
<tr>
<td>Patients with both a mood and anxiety disorder</td>
<td>4</td>
<td>7.14%</td>
</tr>
</tbody>
</table>
Depression has shown to mediate health outcomes by impacting patient adherence to self-care (Deschenes, Burns, & Schmitz, 2015). Wing et al. (2002) discussed how adherence directly relates to the concept of “partnership between the patient and the medical provider in all aspects of medical care” (p. 877). Every patient that was interviewed for this current study endorsed the fact that, “in some way or another, my mental health condition changes how I take care of myself.” For some patients that interplay was more significant than others. What seemed to be an important factor related to self-care was the level of confidence and activation the patient had to manage his or her own health. When asked what percentage depression plays in managing their health, one patient responded, “Oh about 90%.” Another stated,

Oh boy, my mood, it plays a huge role in how I take care of myself. If I have a bad day, like yesterday, I just don’t take my meds, I eat what I want and I just sit around. Now I know this is not good for me but I do it anyway. I went to bed early and then woke up feeling like crap again. My mood hits every part of my life and my health.

This speaks directly towards the concept of adherence that Wing et al. (2002) referred to in their study on the mediating effects of depression on self-care. Depression, in a way, cripples the patient, deactivating them. A third interview reflected this exact concept. The patient stated, “It must be my depression that does it, like when I have depression, I just don't care about taking care of myself, I don’t do the things I need to do.” Another respondent commenting on their mood and hypertension stated “when my mood goes up and down, so does my blood pressure . . . and thus, I can be pretty inconsistent and well, pretty bad at self regulating my medications.”

One very specific way depression impacts individuals living with co-occurring conditions relates to diet and exercise. Although only eleven individuals had an active diagnosis of obesity (13.4%), 71.9% of the sample population had a BMI over 30 (see Table 3); a condition directly
related to both hypertension (Bays, Chapman, & Grandy, 2007; Gelber, Gaziano, Manson, Buring, & Sesso, 2007) and diabetes (Bays, Chapman, Grandy, 2007; Ganz et al., 2014). One patient commented on her weight gain by saying,

All of my friends who don't have depression [they] don’t understand. Like my girlfriend said “My God you weigh that much, how can you handle it?” Then I said, “I don’t even see it.” Then all of a sudden when the depression is less, it is like you look in the mirror and say “What happened to me? Who did that?” You don't even know that you're the one that ate the food.

Other patients in this study commented on the placating effects of food. Similar to drugs and alcohol, sugars act as pacifying agents in the brain by releasing chemicals in the reward center called dopamine (Dovey, 2015). They feel depressed and seek a way to improve their mood. In what felt like a confession, one patient stated

Ahhh, sugar I know it is making me sicker. I know I shouldn’t eat it. I fight it all the time, but it puts me in a good mood . . . it brings me down like two levels. It’s a coping mechanism. I don’t smoke anymore, I don’t drink anymore, I don’t do drugs, but sugar! I love sugar. I can’t win, physically I feel like crap but mentally I feel good when I do [eat sugar].

A national Canadian survey of patients living with diabetes and mental illness (Deschenes, Burns, Schmitz, 2015) showed a relationship between patients with diabetes depression and generalized anxiety; but not for just diabetes and anxiety. Results from the current study showed the strong link between depression and chronic illness as well. Impact however varied considerably, depending on the individual. As seen in this study, the impact of
depression on self-care ranges from lack of medication adherence and/or physical exercise to the patient’s destructive relationship with food.

**Anxiety and self-care.** As noted above, the correlation between chronic illness and mental health has been well documented. Studies have shown a strong link between anxiety and diabetes (Smith et al., 2013), hypertension (Wu, Chien, & Lin, 2014), and cardiovascular disease (Seldernrijk et al., 2015). As seen in Tables 6 and 7, in this study 28.99% of patients with hypertension and 20.59% of patients with diabetes had an anxiety-related disorder (GAD, Anxiety NOS, panic disorder, OCD, or PTSD).

As with depression and chronic illness, there is also a direct link between anxiety and chronic illness. Lin, Korff, Alonso, Argermeyer, Anthony, Bromet, (2008) examined data from 42,797 participants who took part in a World Mental Health Survey and found that patients with diabetes were all significantly more likely to have an anxiety disorder such as Generalized Anxiety Disorder (GAD), agoraphobia/panic disorder, social phobia, or Post Traumatic Stress Disorder (PTSD). As seen in Tables 6 and 7, 28.99% of the patients with hypertension and 20.59% of patients with diabetes lived with a co-occurring anxiety-related disorder (GAD, PTSD, panic disorder, OCD etc.). This study also showed that 17.39% of the sample population had both an anxiety and mood-related disorder.
### Table 7

**Hypertensive Participant Characteristics**

<table>
<thead>
<tr>
<th>Variable</th>
<th>(n)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total patients in this study (N = )</td>
<td>82</td>
<td>100%</td>
</tr>
<tr>
<td>Patients with hypertension</td>
<td>69</td>
<td>84.10%</td>
</tr>
<tr>
<td>Controlled hypertension (SBP&lt;140 &amp; DBP&lt;90)</td>
<td>27</td>
<td>39.13%</td>
</tr>
<tr>
<td>Male</td>
<td>32</td>
<td>46.38%</td>
</tr>
<tr>
<td>Age</td>
<td>56.07</td>
<td>years</td>
</tr>
<tr>
<td>Average Confidence Score (10 being the highest)</td>
<td>8.52</td>
<td></td>
</tr>
<tr>
<td>PHQ 9 score &gt;9</td>
<td>19</td>
<td>27.54%</td>
</tr>
<tr>
<td>GAD-7 score &gt;7</td>
<td>14</td>
<td>20.29%</td>
</tr>
<tr>
<td>PHQ 9 score &gt;9 &amp; GAD&amp; score &gt;7</td>
<td>19</td>
<td>27.54%</td>
</tr>
<tr>
<td>Patients with mood related disorder</td>
<td>31</td>
<td>44.93%</td>
</tr>
<tr>
<td>Patients with unipolar depression</td>
<td>14</td>
<td>20.29%</td>
</tr>
<tr>
<td>Patients with bipolar disorder</td>
<td>6</td>
<td>8.70%</td>
</tr>
<tr>
<td>Patients with dysthymic disorder</td>
<td>6</td>
<td>8.70%</td>
</tr>
<tr>
<td>Patients with depression NOS</td>
<td>5</td>
<td>7.25%</td>
</tr>
<tr>
<td>Patients with anxiety related disorder</td>
<td>20</td>
<td>28.99%</td>
</tr>
<tr>
<td>Patients with panic disorder</td>
<td>5</td>
<td>7.25%</td>
</tr>
<tr>
<td>Patients with generalized anxiety disorder</td>
<td>5</td>
<td>7.25%</td>
</tr>
<tr>
<td>Patients with PTSD</td>
<td>1</td>
<td>1.45%</td>
</tr>
<tr>
<td>Patients with OCD</td>
<td>1</td>
<td>1.45%</td>
</tr>
<tr>
<td>Patients with anxiety disorder NOS</td>
<td>8</td>
<td>11.59%</td>
</tr>
<tr>
<td>Patients with both a mood and anxiety disorder</td>
<td>12</td>
<td>17.39%</td>
</tr>
</tbody>
</table>
Along with patient demographics, the doctor-patient relationship and its social context along with the levels of stress are key predictors of self-care behaviors for patients living with chronic illness such as diabetes (Albright, Parchman, & Burge, 2001). Patients living with an anxiety disorder reported high levels of stress regarding their day-to-day activities and this directly impacted their self-care regimen. The struggles of self-management were often amplified by busy lives. A common theme with the interview group regarded being “spun out” and “having so much on my mind, I just can not seem to remember to do all the things I need to do.” One patient voiced,

The daily struggle of always leaving my house without doing the things I need to do . . . like [to] take my meds or remember to bring my [diabetes] log. I just left the house because my brain is just like ‘I can’t remember every damn little thing anymore’ . . . it is actually pretty simple, I just don't’ have enough time to do it all. I also have no time to get exercise and I'm just too tired as well. It feels like I have just lost the control of time to do anything to take care of myself.

Another patient reported that if he had more time he would eat better. “I mean I know I have diabetes and all and eating better helps with that but I’m so busy in the morning, I leave the house and stop and get doughnuts for breakfast.”

Mental health conditions also played a role regarding interpersonal communications between patient and provider as well. When in the doctor’s office, one patient reported fewer depressive symptoms but more anxiety-based symptomology, stating, “Yah, a lot of the time, I’m just sitting there, in my head going ‘yeah, yeah, yeah’ and not listening yah know cuz’ I’m in hyper-brain mode, I really don’t hear a thing.”
The patients were often worried about how they appeared to the primary care provider. Multiple patients reported that at the time of their medical visit they were “worrying so much” about their condition that this often interfered with the visit. Their reports ranged from “I didn’t want to have bad numbers” regarding their A1C or blood pressure to “Every time I go in there, my blood pressure rises and that’s not good cuz that is what I’m being seen for . . . high blood pressure.” Another patient stated, “I get so overwhelmed by all of the other stuff going wrong with me that I forget the things I want to ask. I don’t ask the questions I need to ask because I’m so worried about how I look [health-wise].”

That same patient continued by saying that she often gets discouraged while waiting for the provider to come in. Her interpersonal conversations were somewhat of a demoralizing agent: “I keep saying to myself, your gonna’ look like crap again [A1C numbers] and nothing good is gonna’ happen blah blah blah.” This is the conversation she was having even before the provider enters the room. Other patients reported that they often were not in the state of mind to receive feedback regarding their current medical situation.

As with the patient mentioned above with the demoralizing self-talk prior to the doctor’s visit, many patients reported having negative self-talk during the visit. One patient reported, “I’m always talking to myself, punishing myself. Like telling myself see I told you you were going to have bad readings. Then I just stop listening to the rest of the visit.”

It is difficult to tell the true etiology of these symptoms but what was clear was the impact they had on the patient’s ability to be an active participant in their own self-care. Additionally, understanding which diagnosis precipitated the other was often quite elusive. Was the patient chronically depressed first, which led to poor management of their health condition, thus leading to diabetes, or did the patient become depressed after living with a chronic illness
for years; trying and failing over and over again to manage a very complex disorder? One patient noted that he “got depressed about 10 years ago which came after fighting diabetes, high cholesterol and being overweight for 10 years before that.” Another patient voiced her thoughts on the origins of her medical condition related to her depression.

My marriage was filled with depression and anxiety and I kind of would get a lot of illnesses along with it, I just kept getting sick, I would get respiratory [illness] after respiratory, then I would get strep throat, then respiratory again, then it turned into pneumonia, then chicken pox pneumonia, then I’d gain more weight and get more depressed.

For the majority of those interviewed the following was true: it was difficult to pinpoint what came first, the medical or the mental health conditions. It was also very difficult to separate the medical and mental health as far as what was the most difficult to manage. Summarizing this clearly one patient noted, “It’s really hard to separate your mood from your thyroid, from your diabetes. It all kind of just goes together.” The overall connection of multiple chronic conditions is poorly understood; however research has shown that “some diseases may be associated with disability only in the presence of other specific diseases” (Vogeli, Shields, Lee, Gibson, Marder, Weiss, & Blumenthal, 2007, p. 392). From this observation, new strategies are being developed to target specific disease-to-disease interactions (Fried, Bandeen-Roche, Kasper, & Guralnik, 1999).

**Hypothesis 2:** High levels of patient confidence relative to self-care of their chronic illness increase their sense of connectedness to their care team.

A second design was established to run a correlational analysis of the relationships between confidence and the Relational Coordination (RC) measure. For a medium-effect size
\( F^2 = .4 \) an a priori power analysis suggested a sample size of 59 with a total power of .95 (1-\( \beta \) err prob). The independent variable for this was level of confidence in self-care and the dependent variable was perceived connectedness. Gittell (personal communication, June 15, 2015) suggested using a very careful risk adjustment when assessing the impact on RC and performance. All participants were categorized with a level of risk adjustment by identifying the number of medical and mental health diagnoses that existed. A patient with diabetes and depression, for example, would be risk level 2 whereas a patient with diabetes, hypertension, depression, and anxiety would be risk level 4.

Correlational analysis was run for the entire population between Confidence in Self Management and three versions of the Relational Coordination Index: Overall RC score (RCS), RC Communication score (RCC), and RC Relationship score (RCR). Though RC is a well-validated measure for care providers, it is at an earlier stage of development as a measure for patients. The two sub-scores of RC (RC Communication and RC Relationship) are relatively undeveloped for any population. Therefore all three RC scores used in this analysis are treated as exploratory and developmental.

The analysis showed no significant relationship between Confidence in Self Management and overall RC or RC Communication. However, there was a marginally significant relationship (\( p\)-value=.058) between Confidence in Self Management and RC Relationship (see Table 8). Reliability analysis showed that the Cronbach’s alpha on RC Relationship (three items including Shared Goals, Shared Knowledge and Mutual Respect) was .709, which is an acceptable level of reliability for a measure that is under development.
Table 8

*Correlational Matrix for Confidence and RC*

<table>
<thead>
<tr>
<th></th>
<th>Confidence</th>
<th>RC AVE</th>
<th>RCC</th>
<th>RCR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Correlations</td>
<td>Confidence</td>
<td>1.000</td>
<td>.128</td>
<td>.075</td>
</tr>
<tr>
<td></td>
<td>RCAVE</td>
<td>.128</td>
<td>1.000</td>
<td>.956</td>
</tr>
<tr>
<td></td>
<td>RCC</td>
<td>.075</td>
<td>.956</td>
<td>1.000</td>
</tr>
<tr>
<td></td>
<td>RCR</td>
<td>.175</td>
<td>.936</td>
<td>.792</td>
</tr>
</tbody>
</table>

| Sig. (1-tailed)      | CONF       | .126   | .252  | .058  |
|                      | RC AVE     | .126   | .000  | .000  |
|                      | RCC        | .252   | .000  | .000  |
|                      | RCR        | .058   | .000  | .000  |

| N                    | CONF       | 82     | 82    | 82    | 82    |
|                      | RC AVE     | 82     | 82    | 82    | 82    |
|                      | RCC        | 82     | 82    | 82    | 82    |
|                      | RCR        | 82     | 82    | 82    | 82    |

Posthoc analysis of the regression data showed a relationship between Confidence in Self-Management and one subset of the RC Index: a combination of average scores for both Shared Goals and Mutual Respect. This subgroup had a \( p \)-value of .033 and a Pearson correlation of .205 (SD = .813, M = 4.192, N = 82). The R Square for this model was \( RS = .203 \) suggesting that over 20% of Confidence in Self-Management was due to the number of mental health diagnoses a patient had, and the level of Shared Goals and Mutual Respect shared between patients and their care team members. The Durbin-Watson score was 1.476, suggesting that there was a temporal relationship between these variables. Although risk adjustment was performed
for Confidence in Self-Management, the research did not focus on the relationship of RC to a performance factor such as the outcomes of diabetes or hypertension management.

These results suggest that the confidence patients have in managing chronic conditions such as diabetes and hypertension depends on the quality of relationships with their care providers, particularly the extent to which care providers are perceived to share the patient's goals for care, and respect the patient's role in their own care.

**Theme 3: Confidence and Connectedness**

The quantitative data analysis suggested no correlation between patient confidence and their perceived connectedness to their medical team-based members; as assessed via the Relational Coordination survey. As seen in Table 7, there was no significance between patient confidence of self-care and the RC measure as an entirety. One subgroup, however, Mutual Respect and Shared Knowledge, was significant ($p = .033$, $r = .205$, $n = 82$). This concept was reinforced repeatedly by the qualitative data, with patients reflecting on the importance of mutual respect with both the medical and behavioral health providers. Multiple patients reported that “feeling listened to” was a concept that made them feel respected. One patient reported,

> With my [specialist], I don’t feel in a partnership, because I’m not comfortable, I don’t feel like he really gets it . . . its kind of like he just cares about my numbers [diabetes-related information] and is like, ‘oh I’ve got to listen to this depression stuff again’. He just doesn't’ get that it is all part of me.”

Another patient continued this concept by saying, “You all listen to it all, I feel like I get whole care here, all of me is taken care of. I feel respected, nurtured even.”

As noted earlier, confidence of self-care and subsequent self-care behaviors are influenced by mental health conditions. According to the research findings in this study however,
confidence did not seem to be related to the patient’s perception of connectedness to their team. One patient stated,

How I feel doesn’t really effect how I relate to you all . . . I mean, even if I’m feeling bad, I’m coming in to see because I want to not because I have to. I might be a bit more quite but I know I’m coming in to better myself.

Furthermore, regardless of the patient’s confidence level, patients were often engaged and interactive with their provider team. One patient noted,

I have a lot of confidence in you all even when I’m not feeling well [depression], we [patient and provider] talk about the changes in my care . . . it's a partnership. If I say ‘no, I don't want to try that’ then we’ll take another approach.

Conversely, however, another patient reported, “Depression really doesn’t change how I interact with the team really except for the fact that if I'm depressed, I simply don’t interact, I don't come in.”

Although the quantitative data gathered from this study did not support the hypothesis, deductive reasoning implies at least a moderate relationship between confidence and connectedness. The data gleaned from this study showed that mental health severity (as measured by number of mental health diagnoses and PHQ-9 and GAD-7 scores) had a negative correlation to level of confidence; as severity of mental health increased, confidence decreased. Furthermore, even though patients were not consciously (and quantitatively) connecting their mental health with their connectedness to the medical provider team, qualitative data did infer a connection.

More than 40 percent of interview respondents reported simply “not coming in” to the medical office when depressed. Therefore, it seems plausible that if mental health impacts
confidence and mental health also impacts self-care and connectedness that there could be some connection between confidence and connectedness; however, it would need to be measured in a different manner than what was set up in this study.

One patient’s report clearly supported this assumption. “If I’m confident, I feel sure of what I’m talking to the doctor about, like if I know something is not working, I can talk about it and get it changed.” She continued by saying, “If my confidence is low though, I just don’t want to engage at all, I don’t want to talk about it at all, with anyone, and I know that is not good.”

**Patients needs: Frequent, timely, accurate, problem-solving communication.**

Relational coordination theory posits that for communication to occur in a functional manner, four key components must exist. Communication must be frequent, timely, accurate, and problem-solving oriented (Gittell, 2009). The qualitative and quantitative data for this section were conflicting. Although the quantitative data showed no significant connection between these communication components and confidence of self-care, the qualitative data showed how these four key elements could be connected to confidence within medical settings.

Consider a simple phone call between a patient and the triage nurse regarding the modification of a medication for asthma treatment. One patient reported a significantly memorable interaction with a nurse that “went bad real quick” as she said, “If I’m messed up, I can take people on the ride really quick with me.” She qualified her statement and added, “I mean sometimes, misconstrued communication can be my interpretation, and not necessarily what somebody is telling me.” Conversely, another patient reported that one thing that directly increases their confidence in self-care is to be able to “be in touch with you all [providers] to ask questions when I need to.” This speaks towards the timely nature of communication.
Patient comments regarding what decreased their confidence ranged from interpersonal to intrapersonal reasons. Multiple patients reported that poor communication with any member of the medical team played a significant role in the patient’s confidence. Confusion regarding instructions on how to take or obtain medications was often cited. One patient reported an incident where she was trying to figure out the correct dose of a medication that took “10 days to get an answer” from her pulmonologist. This patient reported,

It was too difficult to handle over the phone but then I had to pay $100 just to see the doctor to try to correct an obvious mistake. . . . I’ve been taking the same dose for years but she couldn’t give me the permission, [so] I had to talk to the doctor in order for me to still take the one puff I’ve been taking all along.

For this patient, the communication was not timely, accurate, frequent, or problem-solving oriented. As she stated, “It was ludicrous.”

The aforementioned example is one that involved a very complex case. However, the majority of communications were rather straightforward. As seen in Table 9, the RC scores regarding communication were very high. Out of five points, patients reported the following: frequency–4.48, timeliness–3.81, accuracy–4.07, and problem-solving–4.07, with a total communication subscale of the RC of 4.11. This score was out of five points, thus implying very strong communication between patients and all members of their care team including medical providers, behavioral health, care coordinators, and their own family caregiver. The majority of patients responding to the interview reinforced the frequent, timely, accurate, and problem-solving communication by the staff at this organization. Multiple patients responded, “I always get my questions answered” and “I even had one lady say, hey you don’t worry about that, I’ll take care of it for you.”
Another theme identified regarding communication was inter-office communications between primary care providers and external specialty providers. A patient noted quite clearly, “You guys at [research organization] talk to me often enough but what you may need to work on is communicating with external offices.” She continued by saying, “More often than not, what seems to happen is that we thought they were doing it, they thought we were . . . no one had their facts straight.” This comment supports the need for improvement in communication between primary care offices and specialty providers in the community.

Another potential implication of this data is the need for improving communications between patients and both care coordinators and their own family caregivers. The average RC subscale score on communication between patients and Care Coordinators was 3.77 out of 5.00. Out of the sample population, 40.24% reported “yes” to the following question: Do you have a non-medical caregiver [such as a family member, loved one, friend, or neighbor] who helps you with your healthcare needs such as picking up medications, talking to doctors, taking you to appointments or assisting in other ways? The average RC subscale score for communication
between patients and family caregivers was 3.91 out of 5.00. These were the lowest two subscales identified in this research.

Posthoc analysis of the data showed that accurate and frequent communication were important for two domains. Accurate communication with the medical provider was statistically significant for patients who were in control of their hypertension ($r = .290$, $p = .000$), $M = 4.52$, SD = .892). For those with managed diabetes, frequent communication with the medical provider was significant ($r = .375$, $p = .022$, $M = 4.85$, SD = .547). No other significant correlations existed in this data set between team members and patients with diabetes or hypertension.

**Sense of belonging: shared goals, mutual respect, shared knowledge.**

Interestingly enough, for many patients, it was “the little things” that allowed them to feel welcomed, respected, and part of their care-team. One patient stated, “Yah know when I walk in, they say ‘Hi [patients name]. How are you today?’ That feels awesome.” Another patient stated, “From the moment I walk in to the moment I leave, I know you guys want to help me. I see a nice lady when I’m coming in, and then I see someone like [BHS] or my doctor and then the finale would be [check out].” Another patient reflected, “It starts with a ‘hello’ and ends with a ‘goodbye’. It is like a sandwich.” Another patient reported that “When I came in I had an insurance paperwork problem and the girl at the desk said, ‘Hey don’t you worry about that, we’ll deal with that’, yah know, she could have been a doctor that day.” These past examples speak towards the mutual nature of respect and what actions assist in reinforcing this concept.
Table 10

*Relational Coordination Relationship Components*

<table>
<thead>
<tr>
<th></th>
<th>Medical Provider</th>
<th>Behavioral Health</th>
<th>Care Coordinator</th>
<th>Family Caregiver</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared Goals</td>
<td>4.26</td>
<td>4.14</td>
<td>3.77</td>
<td>3.97</td>
<td>4.04</td>
</tr>
<tr>
<td>Shared Knowledge</td>
<td>4.24</td>
<td>4.07</td>
<td>3.44</td>
<td>3.90</td>
<td>3.91</td>
</tr>
<tr>
<td>Mutual Respect</td>
<td>4.36</td>
<td>4.20</td>
<td>3.88</td>
<td>4.00</td>
<td>4.11</td>
</tr>
<tr>
<td>Average</td>
<td>4.29</td>
<td>4.14</td>
<td>3.70</td>
<td>3.96</td>
<td>4.02</td>
</tr>
</tbody>
</table>

Although the average scores showed modest connections between the relationship variables and the identified staff members (see Table 10), there was no direct significance between the relational factors and confidence. As shown above, posthoc analysis shows a significant correlation between confidence and the subgroup of shared goals and knowledge. Although it is difficult to locate literature that references the specific concepts of shared knowledge and goals regarding patient outcomes there is an abundance of research regarding shared-decision-making within the medical setting (Legare & Witteman, 2013). The qualitative data reinforced the connection between shared decision-making and improved confidence.

Numerous participants did reference the importance of shared-decision making during the interview process. One participant noted that sharing the decision-making process with her provider increased her confidence in managing her diabetes. This patient stated, “Confidence equals trust and when we work together, in a partnership, that goes a long way.” During the interviews, another patient displayed something that resembled fear when the mere idea of managing her diabetes alone was mentioned. The participant was asked how confident she was regarding her self-care and she stated only “with the assistance of [identified organization] or if I
was just cut loose,” as her face dropped. She continued by saying, “It is hard to separate what is worse, my mood or my disease,” and then continued, “just like it is hard to separate who helps me more [with managing her chronic illness], you all here or me.”

As many participants have validated in this research, it is difficult to separate the mental health from the medical health. There also seems to be a difficulty in identifying who the most important members of the team are regarding self-care of co-occurring disorders–be it the front desk personnel, the participant, the medical provider, or the behavioral health provider. All have been identified as key members of the medical care team.

**Theme 4: Identified Team Members**

Patients were interviewed regarding who they perceived as active members of their care delivery team. Universally, patients responded that the medical providers [physicians and advanced practice registered nurses] and [registered] nurses were part of the team (100%). Medical Assistants were mentioned as part of the team 80% of the time as were Behavioral Health Providers (BHP). Although BHPs were only mentioned 80% of the time as “team members,” two interviewees stated, “My [off-site] counselor and I mostly just talk about my emotional stuff, not my physical stuff.” Conversely, 37% of patients with on-site BHS reported that they felt it was important to discuss “my entire health, my mind and my body.” One patient reported, “When I come and see you, you all care about all of me . . . it is like you get it, there is more to me than just a [blood pressure] number or a pill.” The dental provider located on-site was mentioned by 10 percent of the interviewees. The administrative staff, including front desk check-in and back desk check-out staff were mentioned as part of the team by 40% of patients interviewed. One patient noted, “Everybody here is on my team . . . everybody.”
However, one striking theme identified in the data was that numerous patients (40%) responded when asked, “When was the last time you felt part of the team regarding your care?” reported that they did not feel as part of the team. One patient responded “I don't really see myself as part of the team. Actually, now that you mention it, I just feel like you all do the work and I come in. I’m a passive recipient,” Another patient reported, “I feel a little arrogant saying I’m part of the team, I mean I feel like the team is [working] for me but I’m not part of it . . . the team works around me.” With some humor, one patient noted, “Oh, I’m not part of the team, I’m just a client or a victim, you know what I mean? Humm, I guess I should be part of the team.”

Interestingly enough, these responses did not appear to reflect negative feelings. One patient clarified, “Don't get me wrong, I know I’m taken care of, I get everything I need…it is just that I’m not part of the team that’s all.” This is concerning for many reasons. If patients do see themselves as part of the team then they will not act like it. And it raises the question whether, in order to be active and engaged, does the patient need to be part of the team? The medical field lacks assessment tools that measure team operability from the patients.

**Summary**

The purpose of this study was to investigate patients’ perceptions of confidence of self-care regarding their co-occurring chronic illness. Quantitative data combined with supportive personal interviews and demographic information was used to express the perspectives of the population sample. Four key themes identified were: Confidence in Self-Care, Complications of Co-Occurring Mental Health and Medical Diagnoses, Identified Team Members, and Confidence and Connectedness.
CHAPTER 5

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

This study set out to investigate how a patient’s perceived level of confidence relative to self-care of their own chronic illness influenced how they related to their caregiving team, as well as to determine: (a) whether mental health conditions impacted how patients relate to their team and (b) how mental health conditions influenced the patients’ perceived level of confidence for self-care. The research community lacks extensive insight into how patients view their role as a member of a care-giving team. Chapter 5 outlines the author’s summary of findings, implications of the study, recommendations of action, and recommendations for further study.

Review of Methodology

A two dimensional mixed-methods sampling model was used to allow the researcher to gain a deeper understanding of the phenomenon of interest. The research study relied on the evaluative powers of both quantitative survey and qualitative narrative analysis. A two-phase sequential exploratory design using a criterion-based sample was employed to achieve both a breadth and depth of analysis. The qualitative data set gleaned from individual and focus group interviews was used to support and enhance the quantitative data obtained through a Likert-designed survey.

To create a sample that could best contribute to the development of the research theory the participants were selected by a non-probability, criteria-based sampling process. All participants in the case were selected via a set of specific criteria identified by the principal investigator. To assure interpretive consistency, specific samples sizes were pursued. Collins et al. (2007) suggested a minimal sample size of 82 for the quantitative portion of this mixed
methods study. For the qualitative portion, Creswell (2013) suggested that a sample size of 6-12 participants provided adequate data saturation and maximum interpretive consistency. Both suggested sample sizes were met for this study.

**Summary Findings**

**Hypothesis 1:** *The patient’s level of perceived confidence relative to self-care of their chronic illness is mediated by the presence of a mental health diagnosis.*

Multivariate regression analysis was run for hypothesis 1. The first regression analysis showed that the relationship between confidence and controlled hypertension was significant at .042 (t = -2.069, β = -.234, SE = .533). The relationship between confidence and controlled type 2 diabetes mellitus however was not significant at .871 (t = -.164, β=.0181, SE = .418). Diabetes remained insignificantly connected to confidence for all three regression analyses. The second regression analysis showed an association between these two as significant at the .024 level (F = 3.315; MS = 10.251; SS = .114; r = .338). The last regression was run to identify if the presence of a mental health diagnosis could be mediating the effect confidence played on the patient’s ability to manage their hypertension. This last regression was insignificant for hypertension (p = .085, t = -1.749,β = -.191, SE = .527).

The analysis showed a lack of significance level on the last regression, implying that control of the patient’s hypertension was no longer significant due to the mediating (controlling) factor of the presence of a mental health diagnosis. Thus hypothesis 1 was true for patients living with hypertensive disorder: The level of patient confidence relative to self-management of hypertension was mediated by the presence of a mental health diagnosis such as depression or anxiety.
Qualitative data based on the 10 interviews conducted with the identified population sample revealed four central themes. Two of these central themes were used to support the first hypothesis. These two themes were: Confidence in Self-Care and Complications of Co-Occurring Mental Health and Medical Diagnoses. This qualitative data provided robust and intimate insight into the lived experiences of the participants. These examples were used to exemplify the quantitative findings gathered via the PICCS survey and other relevant medical data.

The first theme, Confidence and Self-Care, had two subthemes that were identified. These subthemes were: Level of Confidence and PHQ-9.GAD-7 Score and Confidence and Number of Mental Health Diagnoses. The results from this study supported past findings by Tai-Seale et al. (2013) about patients with mental illness having a higher propensity for low motivation of self-care.

The second theme, Complications of Co-Occurring Mental Health and Medical Diagnoses, also had multiple subthemes. The two subthemes under this second major theme were: Depression and Self-Care and Anxiety and Self-Care. Both the qualitative and quantitative data results from this section reinforced the deep connection between chronic disease and mental health conditions.

**Hypothesis 2:** *High levels of patient confidence relative to self-care of their chronic illness increase their sense of connectedness to their care team.*

Correlational analysis was run for the entire population between Confidence in Self Management and three versions of the Relational Coordination Index: Overall RC score (RCS), RC Communication score (RCC), and RC Relationship score (RCR). Though RC is a well-validated measure for care providers, it is at an earlier stage of development as a measure for
patients. The two sub-scores of RC (RC Communication and RC Relationship) are relatively undeveloped for any population. Therefore all three RC scores used in this analysis are treated as exploratory and developmental.

The analysis showed no significant relationship between Confidence in Self Management and overall RC or RC Communication. However, there was a marginally significant relationship ($p$-value=.058) between Confidence in Self Management and RC Relationship (see Table 8). Reliability analysis showed that the Cronbach’s alpha on RC Relationship (three items including Shared Goals, Shared Knowledge and Mutual Respect) was .709, which is an acceptable level of reliability for a measure that is under development.

Posthoc analysis of the regression data showed a relationship between Confidence in Self-Management and one subset of the RC Index: a combination of average scores for both Shared Goals and Mutual Respect. This subgroup had a $p$-value of .033 and a Pearson correlation of .205 ($SD = .813, M = 4.192, N = 82$). The R Square for this model was $RS = .203$ suggesting that over 20% of Confidence in Self-Management was due to the number of mental health diagnoses a patient had, and the level of Shared Goals and Mutual Respect shared between patients and their care team members. The Durbin-Watson score was 1.476, suggesting that there was a temporal relationship between these variables. Although risk adjustment was performed for Confidence in Self-Management, the research did not focus on the relationship of RC to a performance factor such as the outcomes of diabetes or hypertension management.

These results suggest that the confidence patients have in managing chronic conditions such as diabetes and hypertension depends on the quality of relationships with their care providers, particularly the extent to which care providers are perceived to share the patient's goals for care, and respect the patient's role in their own care.
Qualitative data based on the 10 interviews conducted with the identified population sample revealed four central themes. Confidence and Connectedness was the first theme under the second hypothesis. This theme had two subthemes identified with it: Patients Needs—Frequent, Timely, Accurate, Problem Solving Communication and Sense of Belonging—Shared Goals, Mutual Respect, Shared Knowledge qualitative data for this portion partially conflicted the quantitative data.

The second theme, Identified Team Members, provided important findings for this study. The interview questions were designed for this study to intentionally determine whether the patient identified as part of their caregiving team. As expected, the majority of participants noted that the medical provider was on their team. Furthermore, those patients who had had contact with the on-site BHC also identified them as part of their team. The small number of participants that had an off-site mental health provider, however, did not mention them as part of the team. These individuals actually made a point of separating them from the team. The most striking result from the interviews regarding this theme was the fact that multiple participants (30%) reported that they themselves did not feel as if they were part of the team. They reported that they felt completely taken care and satisfied with their care, but that they were not part of the care team.

At the end of the interview, participants were asked, “Is there anything else you would like to add that you have not already said during the interview period?” The responses varied, ranging from relief that the interview was over to pride–knowing that what they shared may help improve patient care at the identified organization. The one participant that voiced his satisfaction with the interview coming to an end stated, “That was really hard, yah know, I never thought it would have been at first but living with this [depression and diabetes] is really tough,
just talking about it is tough, never mind living with it.” Another patient stated, “Well I’m not sure I could offer anything else, I’m glad I could help with this and I hope it can make a difference for someone else down the line.”

**Limitations**

Although the *a priori* power analysis (Faul et al., 2009) suggested a sample size of \( n = 82 \), when the subgroups were broken up (patients with hypertension or diabetes), the subgroups did not meet the recommended sample size. This factor may reflect the fact that, for the first hypothesis, for patients with hypertension, confidence of self-care was mediated by the existence of a mental health diagnosis, but for the patient population with diabetes, confidence of self-care was not mediated by a mental health diagnosis. Thus the first hypothesis was only partially supported by the quantitative data collected in this study. The second hypothesis was not supported by the data, and due to the lack of significant results for the second hypothesis it is difficult to know if in fact connectedness, as measured with the RC measure, was impacted by the patient’s level of confidence for self-care.

One factor that directly impacted the sample size was the voluntary status of patient participation. Significant insight was derived from personal conversations with other members of the care team. On multiple occasions, both nurses and medical assistants reported that the patient in the office at that time did not want to participate in filling out the PICCS survey. Reasons ranged from “I’m spun out” and “I have no time to fill that out” to “I’ve got too much to think about as it is” and simply “no.” This systematic self-selection bias was a limitation to this study because the participants that could offer significant insight into the difficulties of managing the most complex disorders were often the least likely to participate; typically due to their current overwhelmed status.
Ex-post facto examination of the research design suggested potential limitations were the use of the RC survey as a tool to measure what the PI was considering as “connectedness.” Although the RC measure has been used in many studies in the past to measure the interplay between teams, it may not have been necessarily appropriate to measure the concept of connectedness from the patient’s perspective. This is not necessarily a reflection on the survey tool itself but more so a reflection on how participants may not have connected the concept of connectedness to the items on the survey tool. This disconnect by participants may reflect the fact that the quantitative RC data did not match the qualitative interview data.

Data results were possibly negatively impacted by the response rate. It was difficult to identify a patient sample that had significant connections with all four categories of team members mentioned on the survey: medical providers, behavioral health provider, care coordinators, and family caregivers. Due to this limitation, the response rate for each category was not consistent, resulting in some missing data fields between categories.

**Practical Implications**

One of the most significant observations in this study was that patients often reported not feeling like part of the team. It is unknown if this was actually an important component in overall patient outcomes and overall team performance. Research has shown that activated and engaged patients have better healthcare outcomes (Lorig et al., 2012; Wasson & Coleman, 2014), yet there is still little known about the patient’s relationship to the team and its impact on patient health. Qualitative data from this study suggested that connectedness to the team increased patient confidence, yet the results were not conclusive enough to show a strong relationship regarding this phenomenon.
A second observation regarding the concept of teamwork and team members related to the patient and their identified family caregiver. RC averages between patient and caregiver were third lowest (Family Care Giver = 3.93) out of the four identified team members (medical provider, behavioral health provider, care coordinator and family caregiver). Furthermore, the data showed that for participants in this population the more complex their illness profile was, the more likely they had a FCG. This suggests that there was a potential gap in communication between the patient and the identified FCG. Additionally, as long-term care of patients living with complex chronic conditions shifts more to the home setting, communications with family caregivers becomes paramount. For example, research from Weinberg et al. (2007) showed improved health outcomes in the home setting, such as reduced pain and improved mental health and function status. Attention must be given to this concept for, as Weinberg et al. showed, when the number of identified team members increased, so did the need for co-production of care amongst those identified team members.

Research (Hudson et al., 2014; Paschalides et al., 2004; Smith et al., 2013) has demonstrated that there is a significant relationship between mental health conditions and medical outcomes. One approach to addressing this complex treatment issue is with integrated behavioral health providers. Although the identified organization in this study employed integrated BHPs, it is not the national standard of care. As suggested by Baird et al. (2014), further expansion and utilization of fully integrated primary care teams is one way to achieve a true patient-centered medical home and subsequent improved health outcomes.

Recommendations for Action

1. **Recommend employing more integrated behavioral health providers (BHP) within the identified FQHC.**
There is a strong connection between mental health conditions and chronic disease. When the results from this study are coupled with the Antioch University study (Fauth & Tremblay, 2011) this organization has significant insight into the nature of their population. Multiple facts gleaned from these two studies led to these conclusions. First, according to the Antioch study, over half of the population with a chronic disease was moderately to extremely distressed, according to multiple indicators, including PHQ-9 and GAD-7 scores (Fauth & Tremblay, 2011). Second, the current study showed that out of the sample population, 100% had a behavioral health condition, ranging from depression and anxiety to alcohol and drug use disorders. Furthermore, almost one-quarter of the sample population were significantly depressed and/or anxious at the time of the study, yet less than half of the sample population had been connected with the on-site BHP. Conversely, although less than 50% had been introduced to the BHP, over 71% were on one or more psychotropic medications of some kind yet not connected with a behavioral health provider.

A study by Hibbard, Greene, and Overton (2013) showed that patient activation was inversely linked to cost of care. The lower the level of activation, the higher the overall cost of treatment was for that individual. BHPs are employed within integrated primary care clinics to work with patients regarding not only their depression, anxiety, and behavioral health conditions but also with their level of activation regarding their self-care. Therefore it is recommended increasing the number of full-time BHPs within the clinic as well as increased boundary spanners (Gittell, 2011) such as care coordinators and community service workers.

2. Consider using the confidence measure for routine relevant visits for all patients living with chronic medical and co-occurring mental health conditions.
As shown by Wasson and Coleman (2014), the confidence ruler can be instituted into the daily work flow of medical practices. Currently, the only assessment of mood and/or readiness for change during a relevant visit is the PHQ-2; which is a shortened, evidence-based version of the PHQ-9 (Arroll et al., 2010). However, this tool may be adequate for assessing mood but not as much as an assessment of confidence for self-care. For this identified FQHC, using the confidence ruler during routine visits for patients living with complex conditions could prove useful. During the pilot phase of this research study the confidence ruler was utilized to assess patients with diabetes and hypertension. Reports from both patients and providers were positive regarding this intervention.

3. **Provide ongoing Motivational Interviewing training and brief intervention trainings to staff regarding the confidence ruler to maximize outcomes.**

Ongoing training and assessment of effective use of motivational interviewing (MI) would be a useful adjunct to the use of the confidence ruler. Due to the ever-changing state of the patient’s subjective experience, the relationship with the patient and provider must also remain flexible with the provider being vigilant to the patient’s current level of confidence. MI is a communication approach that focuses on increasing the innate motivation that everyone possesses. This provider-directed approach has proven effective in multiple settings (Miller & Rollnick, 2013), including with healthcare organizations (Rollnick, Miller, & Butler, 2012). Patient motivation is in constant flux (Carver & Jessie, 2011)—often linked to the patient’s mental health status (Ciechanowski, Katon, & Russon, 2000; Hudson et al., 2014). Because of this, ongoing assessment of patients’ motivational status (via the confidence ruler) and the subsequent motivation-based conversations (MI) regarding this assessment are paramount to increased motivation for change. In addition to its evidence-based status, MI has shown through multiple
studies to be more effective than the standard of care (Substance Abuse and Mental Health Services Administration, 1999).

4. **Continue using the PHQ-9 and GAD-7 as an assessment tool as well as an ongoing gauge of effective treatment regarding depression care.**

The PHQ-9 and GAD-7 are evidence-based assessment tools (Spitzer et al., 2006) supported by the SAMHSA Center for Integrated Health Solutions for the assessment of depression and anxiety in the primary care setting. The identified organization employed the use of a PHQ-9 and GAD-7 assessment packet for any patient that either (a) scored positive on the PHQ-2 or (b) displayed significant signs and symptoms of a mental health condition. This screening process was part of a standardized protocol for this organization, as was the utilization of integrated behavioral health consultants (see recommendation one above). The results from this research study showed that mental health conditions such as anxiety and depression were frequently associated with patient’s medical conditions. Furthermore, this study showed a significant inverse correlation between confidence and PHQ-9 and GAD-7 scores. The continued use of the PHQ-9 and GAD-7 assessments is strongly recommended not only as an assessment tool but also as a treatment effectiveness tool.

5. **Educate patients regarding their role as team member.**

As discussed earlier in this document, some patients were not aware of their role as team member and the subsequent duties that role entailed. Furthermore, the literature reviewed demonstrated that it takes a lot more than patient engagement to demonstrate positive health outcomes. This could be perfect timing. There is a worldwide expansion of interest in the concept of health literacy and an ensuing conflict over exactly what health literacy may entail (Chinn, 2011). This research suggested that the concept of health literacy could include the
concept of patient as team member. Promoting the patient’s concept of *phronesis* (Rief et al., 2012), or practical wisdom around their own self-care, could improve the co-production of care with all members of the team, including the patient. This could be extended to include the patient’s family caregiver as well.

There is currently patient-education curriculum that exists that incorporates the patient as an active team member within the care team. To accomplish this at the identified health center, focus groups could be utilized to first identify if this is truly an interest of the identified patient population. These focus groups would focus on the “deconstruction and reconstruction of social/cultural knowledge frameworks that generate iniquity, acknowledgment of power, and privilege” (Shields, 2010, p. 563) as a framework for creating a patient education curriculum.

6. *Continue with advanced interpersonal communication and team-building concepts in medical school.*

The literature review showed that many medical providers endorse shared decision-making philosophies but few actually do it (Bernabeo & Holmboe, 2013). Furthermore, research shows that medical patients with mental health conditions often want to engage in shared decision-making regarding their co-occurring disorders but medical providers’ responses vary regarding this intervention (Tai-Seale et al., 2013). This suggests that ongoing interpersonal communication and shared-decision-making skills need to continue to be taught to the upcoming wave of medical providers. Doing so could “ensure an adequate foundation on which greater patient engagement and attentiveness to patient needs can flourish” (Frosch et al., 2012, p. 1035). Ultimately, the shared decision-making process is very patient-specific. Central to this is not only the providers’ knowledge of options and the unique characteristics of the patient and his or
her family (Legare & Witteman, 2013) but also the interplay and exchange of information on the interpersonal level.

7. *Ongoing team based training and assessment in real world situations.*

Teamwork takes practice and there are many different ways to both enhance it and measure its effectiveness (Valentine et al., 2013). According to Gittell (2009), team-based interactions focus on both communication and relationship variables. Additionally, Miller and Cohen-Katz (2010) posited the inclusion of mindful, respectful, diverse, and trusting communication. As fee-for-service interactions begin to fade and measuring competency by outcomes begins to rise, team-based interactions will become increasingly important.

Furthermore, the sizes of the team are growing. As behavioral health providers, care coordinators, practice facilitators, medical assistants, psychiatric nurse providers, and others are added to the teams, co-production of care becomes more complex. Gittell (2011) explained that as the complexity of care and number of team members increases, so does the need for cross-functional boundary spanners and protocols, grounded in cross-functional information systems (see Appendix E). Ongoing experiential team-based trainings may prove to be an effective tool in this co-production process.

**Recommendations for Further Study**

Integrated, team-based care is an established norm within the identified FQHC. This organizational environment allows for ongoing research to be conducted regarding team-based care. One recommendation for further study would be to use a similar research design as employed in this study except gain a larger population sample of both hypertensive patients and patents living with diabetes. This would allow both subgroups to meet sample size criteria.
Continued efforts regarding evaluation and assessment of teamwork and team-based care is paramount. In the US, more than 60% of primary care practices use team-based models (Schoen et al., 2009) and in some countries this percentage reaches 100% (Valentine et al., 2013). As the concept of providing care in teams continues to grow more research has to be conducted regarding effective teamwork. Research continues to suggest that patient activation is a key ingredient in health care outcomes as well as team-based care. Considering the outcomes of this study, regarding the fluctuating nature of confidence relative to mood state, there is much to learn about the dynamic interplay of team-based care when the patient is considered part of the team. It could be possible to create a new or redesign an existing assessment scale such as the Health Literacy Management Scale (Jordan et al., 2013) that would more accurately assess patients’ level of awareness regarding their role. Health literacy should not only entail how to seek, understand, and use health information—it should also encompass the role of the patient within his or her care team.

Patient activation, however, is not the only element relative to team-based care. As shown in this study, researchers have well examined the relationship between mental health and chronic diseases such as hypertension and diabetes. A burgeoning concept in research is how to best treat these co-occurring disorders. Integrated primary care (Blount, 2003) is one solution that has been getting a lot of attention (DeGruy & Etz, 2010; Baird et al., 2014; Peek, 2013). Although there is no universal solution, integrated primary care has proven effective with many different conditions including substance use and mental health (Collins et al., 2010). The Lexicon for Behavioral Health and Primary Care Integration (Peek, 2013) is a useful document detailing such efforts. Continued research efforts focused on integrating behavioral health providers into the
primary care setting is necessary in order to build on the existing research and to identify the best models of integrated care.

Being able to accurately assess teamwork is critical (Valentine et al., 2013). The RC measure could be used for this; however, a study would have to be designed to allow for all members of the care-team (both medical and non-medical) including but not limited to the patient, their informal caregivers, nurses, medical assistants, physicians, behavioral health providers, and others.

However, there is one concern regarding the use of the RC measure in integrated PCMH settings. Gittell (2011) stated that RC was based on role-based coordination that has a practical advantage over coordination that is based on personal ties. She continued by saying that this feature allows for interchangeability of employees, allowing employees to come and go without a beat, an important consideration for organizations that strive to achieve high levels of performance while allowing employees the scheduling flexibility to meet their outside commitments (p. 17).

This dynamism works in the airline industry as well as in hospital and operative settings. Patient Centered Medical Homes, however, resource the fundamental concept of relationship enhancement by having one physician be at the center of a provider team. The “interchangeability” in this case may be contradictory to the core of the PCMH philosophy, for relationships in the PCMH are about continuity and maintaining personal relationships (Assurance, 2014).

Regarding this issue, Gittell (2011) suggested that, according to RC theory, ties between teams tend to weaken as more diverse members, groups, and roles are created within a team (i.e., including the patient as a member of the care team). These ties continue to weaken unless
boundary spanner roles, team meetings, and shared protocols are expanded to counteract the increased diversity within the groups. Further research could investigate how these interventions play a role when considering a patient as team member, and as well, what other considerations may be needed to accommodate for this additional team member. Gittell (2011) posited this conflict as she questioned whether

general role relationships even count as relationships? Can role relationships serve as a basis for effective coordination and at the same time as a source of positive connection at work? Or must relationships be supplemented by personal concern for individual people as specific human beings? If so which proceeds which? (p. 406)

Gottlieve, Sylvester, and Eby (2008), from the South Central Foundation in Alaska, stated that “all customers [patients] deserve to have a health care team they know and trust (p. 4). Knowing and trusting a care team provider requires enrichment of interpersonal relationships as well as continuity of care. Further research regarding how to assess patients’ level of connectedness and interoperability and ability to function within the entirety of the team would benefit the health care community. This becomes increasingly important as we continue to work towards integrated teams that focus not just on delivering care to a patient but also include the active and engaged patient as member of the whole-health care team.
REFERENCES


*Health care that revolves around you.* Retrieved from

www.ncqa.org/Porals/o/Programs/Recognition/2011 PCMHbroughure_web.pdf

National Institute of Mental Health. (2013). *National Institute of Mental Health.* Retrieved from

http://www.nimh.nih.gov/health/publications/the-numbers-count-mental-disorders-in-america/index.shtml#CensusBureauTable2


doi:10.1097/HMR.0b013e3182497262


APPENDIX A

CRITERIA FOR PATIENT SAMPLE

To be participant in this study you must:

• Be 18 years of age or older
• Have been diagnosed with a chronic illness that satisfies our organizations Important Conditions (hypertension and/or Diabetes Mellitus)
• Be a patient at Families First Health and Support Center
• Have taken the PICCS survey
• Identified as an active patient and have had an appointment in the past two years
THANK YOU FOR TAKING THIS SURVEY. YOU ARE HELPING US IMPROVE PATIENT CARE FOR ALL OF OUR PATIENTS!

PLEASE INDICATE THE EXTENT TO WHICH EACH STATEMENT IS TRUE FOR YOU.

1. HOW IMPORTANT IS IT TO MANAGE YOUR HEALTH AND WELLBEING? (PLEASE PLACE AN "X" ON THE CORRECT NUMBER. "0" BEING NOT IMPORTANT AT ALL AND "10" BEING VERY CONFIDENT)

   0  1  2  3  4  5  6  7  8  9  10

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2. HOW CONFIDENT ARE YOU THAT YOU CAN MANAGE YOUR HEALTH AND WELLBEING? ("0" BEING NOT AT ALL CONFIDENT AND "10" BEING VERY CONFIDENT)

   0  1  2  3  4  5  6  7  8  9  10

   0  0  0  0  0  0  0  0  0  0  0

3. DO YOU HAVE A NON-MEDICAL CARE GIVER [SUCH AS A FAMILY MEMBER, LOVED ONE, FRIEND OR NEIGHBOR] WHO HELPS YOU WITH YOUR HEALTHCARE SUCH AS PICKING UP MEDICATIONS, TALKING TO DOCTORS, TAKING YOU TO APPOINTMENTS OR ASSISTING IN OTHER WAYS? ☐ Yes ☐ No
THE FOLLOWING QUESTIONS ARE ABOUT **HOW YOU COMMUNICATE WITH THE PEOPLE HELPING YOU MANAGE YOUR HEALTHCARE**, INCLUDING FAMILY MEMBERS OR FRIENDS THAT ARE ASSISTING WITH YOUR CARE.

WHEN ANSWERING THIS QUESTION BE SURE TO **CONSIDER ALL FORMS OF COMMUNICATION INCLUDING IN-PERSON/FACE TO FACE, PHONE CALLS, EMAILS, TEXTS, ETC.**

4. **Frequent Communication**

**HOW FREQUENTLY DO PEOPLE IN EACH OF THESE GROUPS COMMUNICATE WITH YOU ABOUT MANAGING YOUR HEALTHCARE?** PLEASE MARK AN “X” IN THE BOX THAT BEST REPRESENTS HOW YOU FEEL.

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5. **Timely Communication**

**DO PEOPLE IN THESE GROUPS COMMUNICATE WITH YOU IN A TIMELY WAY ABOUT MANAGING YOUR HEALTHCARE?**

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6. Accurate Communication

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7. Problem Solving Communication

WHEN THERE IS A PROBLEM WITH MANAGING YOUR HEALTHCARE, DO PEOPLE IN EACH OF THESE GROUPS BLAME OTHERS OR WORK WITH YOU TO SOLVE THE PROBLEM?

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8. Shared Goals

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9. Shared Knowledge

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10. Mutual Respect

AT YOUR DOCTOR’S OFFICE, DO PEOPLE IN EACH OF THESE GROUPS RESPECT THE WORK YOU DO MANAGING YOUR HEALTHCARE?

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IF YOU WOULD LIKE TO BE PART OF IMPROVING OUR HEALTHCARE SERVICES BY TAKING PART IN AN INTERVIEW, PLEASE FILL IN THE FOLLOWING INFORMATION AND A STAFF MEMBER WILL CONTACT YOU. IF YOU DECIDE TO PARTICIPATE IN AN INTERVIEW YOU WILL BE REIMBURSED FOR YOUR TIME WITH A $10 GIFT CARD AND ALSO ENTERED INTO A RAFFLE FOR A LARGER GIFT CARD. WE THANK YOU FOR YOUR TIME AND EFFORT.

NAME: ___________________________ DATE OF BIRTH: ___________________________

SIGNATURE: ___________________________ CONTACT NUMBER: ___________________________
Project Title: Confidence, and Connectedness: A Mixed Methods Study on Patients Managing Co-occurring Physical and Behavioral Health Conditions

Principal Investigator: Peter Fifield M.S. LCMHC, MLADC, Manager of Behavioral Health Services, Families First Health, and Support Center.

Faculty Advisor: Carey Clark Ph.D. Adjunct Professor of Education, College of Arts & Sciences.

Introduction:

- Please read this form, you may also request that the form is read to you. The purpose of this form is to provide you with information about this research study, and if you choose to join, it will assist with informing you how to record your decision.
- You are encouraged to ask any questions that you may have about this study, now, during or after the project is complete. You can take as much time as you need to decide whether you want to participate. Your participation is voluntary.

Why is this study being done?

- This study is being done to learn more about how to improve the care coordination with our patients that are living with both a medical and a mental health condition.
- The reason we want to know more about how to improve patient care is because care coordination is always difficult. We know that people living with a long-term illness often have many doctors that they have to see. Different doctors often give many medications with different care plans. Also, there are often other non-medical providers involved in patient care such as care coordinators, and therapists. We would like to know how we could better serve patients by coordinating all of these service providers with in the patient’s medical record at Families First.
- Families First wants to survey and interview both patients, their informal caregivers and the primary care team members. This information will be used to inform potential changes in the care delivery processes for all Families First patients.
Who will be in this study?

- Group 1:
  - Patients at Families First:
  - That are 18 years or older
  - Live with a long term medical condition such as Diabetes and high blood pressure.
  - Live with a mental health diagnosis such as Depression and Anxiety
  - Have a caregiver; such as a family member, neighbor, or friend, in their lives that is not a medical professional who helps you manage your health.

- Group 2:

What will I be asked to do?

- If you agree to be in this study, we will first fill out the short survey in this packet.
- On the last page, it will ask if you would like to participate in the interviews.
- Please check either “yes” or “no”
- If you check “yes,” please check the box for “group” or “individual” interview.
- If you chose “yes” we will then call you and set up a time for the interview.
- For patients, the interview will have questions about your condition, how you manage it, what are the barriers to getting care, and how we could improve our care coordination efforts regarding your care.
- For provider team members, the interview will include questions about how your healthcare management is impacted by barriers to care, and care coordination concerns that impact the team coordination of care.
- The interviews will take about 30 minutes to complete.
- We would also like to tape-record the interview.
- If you do an interview you will receive a gas card for fuel and a lottery ticket to the NH state Megabucks for your participation.

What are the possible risks of taking part in this study?

- There are no likely risks associated with this study.

What are the possible benefits of taking part in this study?

- There are no direct benefits to you. We will use the information that you give us, to improve the care of our patients.

What will it cost me?

- There will be some travel time for you to get to the location of the interview held at Families First
- If you are a patient and decided to participate in the interviews, you will receive a gas card worth $10 to pay for this travel time.
How will my privacy be protected?

- All Surveys will be completed during medical visits.
- Interviews will take place at Families First Health and Support Center.
- Group interviews will have less confidentiality because there are other people in the interview with you. If you do not want to do a group interview please chose, “Individual” and you will be given more privacy.
- Your answers will be confidential and all records of this study will be kept private and secure by locking all documents and data up in the office.
- For patients the key researcher will have access to the patient’s medical information within their electronic medical record
- In any sort of report that is made public, all information that will make it possible to identify you will be removed.
- Research records will be kept in a locked file; only the researchers will have access to the records.
- The recorded interviews will be destroyed after they have been transferred to the computer.

How will my data be kept confidential? Although there is always, chance that confidentiality will be lost, the Primary Investigator will take all precautions to make sure that this does not happen. Below are the ways that the Primary Investigator will assure your privacy.

- We will use the survey part of this study to see how you relate to your caregiving team.
- We will keep all of your information private but if you are part of the interview focus group we can not guarantee that others in the focus group will keep your information private
- We will have a discussion with all participants requesting that they keep all information regarding the other members of the group private.
- Paper research records will be kept in a locked file in the locked office of the person doing the research.
- Data will be stored on an Ironkey thumbdrive and locked in the office of the person doing the research
- Individually identifiable data will be destroyed after the study is complete
- All information that would assist in identifying each patient will be removed from the data
- Data will be encrypted using industry standards.
- Please note that regulatory agencies, and the Institutional Review Board may review the research records.
- A copy of your signed consent form will be kept by the principal investigator for at least 3 years after the project is complete. It will then be destroyed.
- The consent forms will be stored in a secure location that only members of the research team will have access to and will not be connected with any data gotten during the project.
Focus group members will be asked not to repeat what is discussed in the sessions, but the researcher cannot ensure that they will respect other people’s privacy. All audio tape recordings will be destroyed within 12 months of completion of the research study. Recordings are optional so please see the provided checkbox at the end of this form. All use of this data will be used to improve care coordination efforts. If the participants requests, all analyses of audio data will be shown to them before use. At this time, the participant will have the ability to cancel their involvement in the study or ask their data to be either corrected or deleted from the study. A copy of the final publication can be provided to all participants upon request.

What are my rights as a research participant?

- Your participation is voluntary. Your choice to participate will not affect your current or future relationship with Families First Health.
- You may skip or refuse to answer any question for any reason.
- If you choose not to participate, there is no penalty to you and you will not lose any benefits you already have. You are free to withdraw from this research at any time, for any reason.

Whom may I contact with questions?

- The person conducting this study is Peter Fifield (Principal Investigator). If you have any questions or concerns you can contact him at: pfifield@familiesfirstseacoast.org or at (603) 422-8208 x 150
- If you participated in this study and believe you may have suffered a research related injury, please contact Carey Clark, Ph.D. Professor of Education, at the University of New England at (540)-631-5548 or cclark14@une.edu

If you have any questions or concerns, you may call Olgun Guvench, M.D. Ph.D., Chair of the UNE Institutional Review Board at (207) 221-4171 or irb@une.edu.

Will I receive a copy of this consent form?

You will be given a copy of this consent form

Participant’s Statement

I understand the above description of this research and the risks and benefits associated with my participation as a research subject. I agree to take part in the research and do so voluntarily.

Participant’s signature or Legally authorized representative

Date

Printed name
Researcher’s Statement

The participant named above had sufficient time to consider the information, had an opportunity to ask questions, and voluntarily agreed to be in this study.

_________________________________________  __________________________
Researcher’s signature                                      Date

_________________________________________
Printed name

*May we use the audio recording of your interview for this study?  ☐ ☐

Yes No
APPENDIX D

PATIENT INTERVIEW QUESTIONS

Families First is trying to improve the way we work as a team. We know that teamwork takes effort from both medical provider and patients. You have been asked to participate in this interview because we think you could help us improve how we work as a team. Before we get started, could you tell me a little bit about your family medical and mental health history as well as your own medical and mental health history?

1. We use care teams to provide care for patients. Who at Families First do you believe is a part of your team? Role examples?

2. On a scale from 1-10 (1 being not at all and 10 being very) how confident are you that you can manage your health?

3. How does your confidence regarding your own health care influence how you interact with your team?

4. What improves your confidence

5. What decreases your confidence

6. How does your depression and/or anxiety change how you care of yourself?

7. How does your depression and/or anxiety influence your confidence?

8. How would something like depression and anxiety influence how you interact with your team?

9. When was the last time you felt like part of the team regarding your overall health care? Why?

10. What advice would you give your medical team to improve how they operate as a team?
[Prompts: Could you provide examples? Do you remember how you felt when that happened?

    How would that help? What allows you to feel safe within the team?]
APPENDIX E

RELATIONAL COORDINATION MODEL

Relational work practices
- Selection for cross-functional teamwork
- Cross-functional conflict resolution
- Cross-functional performance measurement
- Cross-functional rewards
- Cross-functional meetings
- Cross-functional boundary spanners
- Cross-functional protocols
- Cross-functional information systems

Relational coordination
- Shared goals
- Shared knowledge
- Mutual respect
- Frequent comm.
- Timely comm.
- Accurate comm.
- Problem-solving comm.

Quality outcomes

Efficiency outcomes

Contingency factors
- Reciprocal interdependence
- Input or task uncertainty
- Time constraints