A PATH ANALYSIS OF TRUST IN NURSES, SOCIAL SUPPORT, PATIENT SELF-ADVOCACY, PSYCHOLOGICAL DISTRESS, AND PHYSICAL SYMPTOMS IN PATIENTS WITH CHRONIC HEART FAILURE

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A PATH ANALYSIS OF TRUST IN NURSES, SOCIAL SUPPORT, PATIENT SELF-ADVOCACY, PSYCHOLOGICAL DISTRESS, AND PHYSICAL SYMPTOMS IN PATIENTS WITH CHRONIC HEART FAILURE (199 pp.)

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Patients with heart failure participate in care by self-advocating, or speaking up, to their health care providers. By gaining and using health information, assertively communicating, and making decisions, patients are self-advocating. A cross-sectional, path analysis design was used to test two structural models. A convenience sample of 80 HF clinic patients were surveyed using the Adapted Patient Self-Advocacy Scale, Health Care Relational Trust in Clinic Nurses Scale, Medical Outcome Study Social Support Scale, Hospital Anxiety and Depression Scale, and the Symptom Status Questionnaire for Heart Failure.

An analysis was conducted to test the direct and indirect effects of trust in nurses, social support, and self-advocacy, on psychological distress and physical symptoms. Two structural models were created; neither model fit the data as hypothesized. A respecified model focusing on the components of self-advocacy was tested, trimmed, and found to fit the data (chi square 9.452, df 6, p .105; RMSEA .085; CFI .877, IFI .892, NFI .752). Trust in nurses directly affected patient self-advocacy knowledge (β .25, R² .06, p .05). Social support directly affected patient assertiveness (β .26, R² .07, p .05). And social support directly affected depressive symptoms (β -.40, R² .16, p .001). Nursing plays a role in
patient self-advocacy. Educating and encouraging patients to use acquired knowledge in decision making supports patient participation and self-advocacy. Nursing’s encouragement of the supportive role of friends and family members can have a positive influence on patient assertiveness and depressive symptoms.
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CHAPTER I
INTRODUCTION

Background

You must be a humble, polite, persistent squeaky wheel. Fight for your information without alienating the team. Don’t be afraid to be that squeaky wheel so you will get the best care possible.

-Tiffany Christensen, Sick Girl Speaks, 2007

Gone are the days of the passive patient; the sick-role is all but dead (Burnham, 2012). It is work to be a patient and it can seem like a full-time job (Bernhard, 2013; Corbin & Strauss, 1988; Unruh & Pratt, 2008). Most patients want to actively participate in their care even when it can seem overwhelming and time consuming (Deber, Kraetschmer, Urowitz, & Sharpe, 2007; Patel & Bakken, 2010; Say, Murdaugh, & Thomson, 2006). To become more responsive and accountable to consumers, health care organizations and providers are supporting patients’ desire to take a more active and involved role in their care (Bastian, 1998; Madison, 2010). Therefore, not only is there a desire on the patient’s part to actively participate, there is now also pressure from providers and health care organizations for patients to participate and take greater responsibility in their health and health care. Providers encourage patients to participate in many aspects of care including treatment decision-making, self-management activities, and the many routine facets of in-patient and out-patient care (Allen et al., 2012). Patients are being encouraged to contribute to the safety of their care by asking providers to wash their hands prior to examination (R. E. Davis, Sevdalis, Pinto, Darzi, & Vincent,
2011; Duncanson & Pearson, 2005). Some hospitals encourage in-patients and family members to initiate calling a rapid response team if they feel it is necessary (Greenhouse, Kuzminsky, Martin, & Merryman, 2006). Joint Commission ([JC], 2014) has a “Speak Up” initiative, which encourages patients to speak up about many different aspects of their care. We, as providers, are asking patients to participate and contribute in increasingly assertive ways. Patients recognize they need to participate by speaking up for themselves, by being self-advocates (Brashers, Haas, & Neidig, 1999; T. Christensen, 2010; Elder et al., 2008; Freddolino, Moxley, & Fleishman, 1988; Hagan & Donovan, 2013a; Juhila, 2008).

The National Academy of Medicine (NAM), formerly the Institute of Medicine ([IOM], 2001), has identified 10 rules that need to be followed if we are to achieve success in healthcare. Considering the patient as the source of control is one of these rules. Two others that are closely related involve customizing care based on the values and needs of the patient and placing a focus on healing relationships. The American Nurses Association ([ANA], 2001) supports these imperatives within the “Code of Ethics for Nurses” which emphasizes nursing’s role in honoring the patient’s right to self-determination, respecting human dignity, and establishing relationships with patients. These ethical provisions emphasize the need to treat each patient as an individual with individual needs and preferences that should be placed at the center of patient care.

To truly provide patient-centered care, patient participation is necessary. In the current healthcare system, patients are typically the only person coordinating their entire healthcare experience throughout a fragmented system (Coleman, Parry, Chalmers, &
Min, 2006; Unruh & Pratt, 2007). The patient is the only person who can contribute self-knowledge, sustained interest and desire for a positive outcome, and physical and emotional presence throughout the health care experience (Lyons, 2006). Healthcare providers are not able to accurately predict patient preferences (Hamann et al., 2010). Therefore, it is necessary for patients to share information concerning their needs and preferences with a multitude of providers who are planning and providing their care (Davidson, Cockburn, Daly, & Fisher, 2004; Hamann et al., 2010; Ruland, 1999).

Self-advocating is one way that patients share information about their needs, values, and preferences that contributes to patient-centered care. Self-advocating is a health promoting, communication behavior used to enhance participation in care, protect personal integrity, and assert one’s needs. It is done by: (a) gathering and using information; (b) assertively communicating during healthcare interactions; and (c) making healthcare decisions (Brashers et al., 1999).

Self-advocacy is a patient’s contribution to shared decision-making and patient-centered care. By becoming knowledgeable about their health/illness, a patient can integrate what they know about themselves and their circumstances with what they know about their illness in order to contribute to the plan of care (Test, Fowler, Wood, Brewer, & Eddy, 2005). Most patient-centered care models represent what the patient brings to the health care experience as vulnerabilities or needs; yet, patients can come with strengths and life skills as well (Hobbs, 2009; Mead & Bower, 2000). The willingness and ability of a patient to provide the skill of self-advocating to his or her health care experience deserves further investigation. Health care workers are not the only
“providers” and health care providers are not the only “workers.” We need to know more about what patients provide, the work of being a patient, and how we as healthcare providers affect the job of being a patient including the quality of patient-centered care given and received.

We are asking patients to be more assertive and most patients want to participate in their care. The current healthcare environment is demanding both assertiveness and participation from all patients, particularly chronically ill patients such as those with heart failure (HF), yet little is known about what contributes to a patient’s ability to speak up assertively and what impact speaking up has on health outcomes.

**Self-Advocacy**

Self-advocacy is closely linked to self-determination (Nonnemacher & Bambara, 2011). Self-advocating behaviors are employed when someone is attempting to exercise self-determination or autonomy, which promotes a sense of control (Bakitas, 2005). Nurses have long been concerned with patient autonomy and honoring the unique interests of each patient. Nurses have often taken on the role of advocate, speaking up for the patient to protect patient interests when necessary (ANA, 2001). Advocating for someone is different than encouraging someone to speak up for themselves. By encouraging and supporting patients to advocate for themselves, nurses can potentially avoid becoming maternalistic or paternalistic (Bird, 1994; Christensen & Hewitt-Taylor, 2006; Cody, 2003; Gadow, 1983; Kohnke, 1980; Taylor, Pickens, & Geden, 1989; Zomorodi & Foley, 2009). By encouraging and supporting a patient to use his or her own voice, nurses promote problem-focused coping that can help the patient maintain a sense
of control and well-being (Brashers, Haas, Klingle, & Neidig, 2000). This is not to say that a patient will never need his or her nurse to act as an advocate, but the nurse should first consider encouraging the patient to speak up for himself or herself about the concern at hand before “rescuing” the patient (Cody, 2003; Zomorodi & Foley, 2009). According to Gadow (1980), the relationship the nurse has with the patient can enhance the ability for advocacy. Relationships are a defining aspect and central unifying focus of the discipline of nursing (Meleis, 2012). A nurse with a therapeutic patient relationship will see the patient as a unique individual with unique needs and is more likely to be able to help the patient process information and apply it to his or her unique situation while showing confidence in the patient’s ability to manage and advocate for his or her own health care needs (Gadow, 1980; Lynn-McHale & Deatrick, 2000). Nurses can provide advocacy and/or encourage the patient to practice self-determination by expressing himself or herself directly. The nurse can work with the patient to make meaning of his or her current experience. The patient can identify his or her values and needs within the context of that experience and then articulate his or her desires so that the plan of care can reflect individual preferences (Ruland, 1999). When self-advocating, people pair gathered information with contextualized self-knowledge enabling them to convey their desires to health care providers so that their needs can be met (Hagan & Donovan, 2013b; Juhila, 2008; Van Reusen, Bos, Schumaker, & Deschler, 2007). Patients with chronic illnesses, like those with heart failure, who receive on-going, complex, often uncoordinated care will benefit if they practice self-advocating in their health care interactions (Mendelson & Poole, 2007; Rouse, 2011; Ruland, 1999).
Chronic Illness

A person diagnosed with a chronic illness has a disease that is long-lasting, is incurable, and requires on-going adaptations (Improving Chronic Illness Care, n.d.; World Health Organization [WHO], n.d.-b.). Chronic illness involves a lifetime of psychological, physical, social, and environmental adjustment (Bishop, 2005). Individuals with a chronic illness may lack a sense of control over illness progression, so that the desire for control is greater than the actual ability to control (Bastian, 1998; Bishop, 2005). Chronically ill people can use emotion-based and problem-based-focused coping to approach these continual adjustments (Lazarus & Folkman, 1984). Emotion-based coping is used to manage distressing feelings related to a problem that is unresponsive to change. Examples of positive emotion-based coping are prayer, relaxation, and mindfulness (Hughes et al., 2013). Problem-focused coping is used when the issue of concern is potentially responsive to change. Problem-focused or task-based coping centers on identifying the problem, seeking information, considering alternative solutions, choosing the solution, and acting on the solution (Lazarus & Folkman, 1984). Self-advocating is a skill that is problem-focused in nature by the gathering and use of information, assertive communication, and decision-making. Some chronic illness self-management programs include teaching patients self-advocacy skills along-side the typical lifestyle and adherence topics (Coleman et al., 2006; Jonikas et al., 2011; Pickett et al., 2012).

Accessing social support is an adaptive coping strategy that can be both problem-focused (providing tangible support) and emotion-focused (providing emotional support)
(Langford, Bowsher, Maloney, & Lillis, 1997). In the chronic heart failure (HF) patient population, using self-advocating behaviors and accessing social support has been found to increase subjective well-being (Graven & Grant, 2013; Perez-Garcia, Olivan, & Bover, 2014).

**Heart Failure**

HF is a chronic illness that affects an estimated 5.1 million Americans with projections to increase by 25% by 2030 (Go et al., 2013). The failure of the heart to pump adequately causes cardiac and systemic symptoms (Center for Disease Control and Prevention [CDC], n.d.). Fifty percent of those diagnosed with HF will die within five years (Go et al., 2013). The total cost of caring for those with HF was $32 billion in 2013 and this is projected to rise to $70 billion by 2030 (Go et al., 2013). HF is associated with frequent hospitalizations, many of which are potentially preventable (Suter, Gorski, Hennessey, & Suter, 2012; Wakefield, Boren, Groves, & Conn, 2013). With early detection of symptom progression, patients can be treated outside the hospital and further complications may be avoided. Teaching patients how to identify and manage symptoms, access help when needed, and practice health-promoting behaviors are the primary objectives of self-management programs. Self-management programs typically include maintenance topics such as maintaining health promoting lifestyles and management topics such as managing symptoms. Programs that include information on both topics (maintenance and management) can be called a self-care program but are typically referred to as “self-management programs” (Carlson, Riegel, & Moser, 2001). Each patient’s self-management program is founded on the patient’s perceptions of his or
her needs, identification of the typical progression of his or her illness, collaborative communication with healthcare providers, and wellness practices (Udlis, 2011). Patients who self-manage by using health-promoting wellness practices can delay illness progression and/or reduce the severity of illness (Huckstadt, 2013; Riegel et al., 2009).

**Self-Advocacy as a Health Promoting Behavior**

The definition of health has broadened significantly to mean well-being or wellness (Raingruber, 2014). Wellness includes “the patient’s capacity to cope with stress, choose healthy behaviors, recognize their health-related limitations, participate in lifestyle modifications, and manage changes in their health status” (Raingruber, 2014, p. 15). In the past, health was usually referenced as the absence of illness, as such, a person was either healthy or sick (Pender, Murdaugh, & Parsons, 2011). Now with close to 50% of the US population having one or more chronic illnesses, the meaning of health has become relative and subjective (Udlis, 2011). A behavior that leads to a sense of well-being can be said to be a health promoting behavior (Pender et al., 2011). According to Pender et al. (2011), one strives for well-being through “goal-directed behavior, competent self-care, and satisfying relationships with others, while adapting to maintain structural integrity and harmony with the social and physical environments” (p. 22).

Maintaining a sense of control is an important objective of health promotion in patients with chronic illnesses (Sperber, 2010). Self-advocating has been found to have a positive effect on measures of chronically ill patients’ well-being and is associated with enhanced problem-focused coping, and patient self-management skills (Brashers et al., 2000;
Jonikas et al., 2011; Wiltshire, Cronin, Sarto, & Brown, 2006), therefore, increasing a patient’s sense of self-control.

Patient self-advocacy involves an actively participating patient who is assertively using communication to get his or her needs met. Self-advocating behavior can be considered a central part of health literacy (Hagan & Donovan, 2013b; L. T. Martin et al., 2011; Wiltshire et al., 2006), a self-management behavior (Coleman et al., 2006; Jonikas et al., 2011; Pickett et al., 2012), a coping mechanism (Brashers, Haas, Neidig, & Rintamaki, 2002; Mendelson & Poole, 2007), an activation/engagement behavior (Brashers et al., 1999; Sinding, Miller, Hudak, Keller-olaman, & Sussman, 2011; Volk et al., 2008), and/or a self-determination behavior (Goodley, Armstrong, Sutherland, & Laurie, 2003; Juhila, 2008; Nonnemacher & Bambara, 2011; Test, Fowler, Brewer, & Wood, 2005). Self-advocacy is a dynamic multi-faceted concept that can be viewed from different angles or conceptual perspectives. In this study, self-advocacy is a self-management health promoting behavior that will help the chronically ill HF patient to maintain psychological and physical integrity.

**Statement of the Problem**

HF is a highly prevalent chronic illness that currently affects over 5 million Americans (Go et al., 2013). These patients are attempting to cope with a life altering illness while navigating and participating in an uncoordinated health care system. Patients need to communicate with their providers to get the care they feel they need. By accessing the social support of intimate friends/family/others and healthcare professionals, patients are more likely to assertively communicate their needs by self-
advocating as an attempt to maintain a sense of control and enhance their well-being. This study is an attempt to understand the role of supportive relationships in relation to the self-advocating behaviors of chronic HF patients and the effect these relationships and self-advocacy have on psychological distress and physical symptoms. An adaptation of Pender’s Health Promotion Model (HPM) was used to guide this study.

**Purpose of the Study**

There is a gap in empirical knowledge concerning the associations of relationships on self-advocating behaviors, psychological distress, and physical symptoms and the association of patient self-advocating on psychological distress and physical symptoms in patients with heart failure. The purpose of this study was to examine: (a) the direct effects of social support and trust in nurses on self-advocating behaviors; (b) the direct effect of self-advocating behaviors on psychological distress; (c) the direct effect of self-advocating behaviors on physical symptoms; (d) the direct and indirect effects of social support and trust in nurses on psychological distress; and (e) the direct and indirect effects of social support and trust in nurses on physical symptoms. This study attempted to contribute to the understanding of self-advocacy antecedents and outcomes in patients with HF.

**Theoretical Underpinnings**

This study draws from two bodies of nursing theory. The existential advocacy theory explains the importance of the nurse-patient relationship and its role in patient advocacy. The health promotion model depicts the factors that contribute to an
individual’s adoption of health-promoting behaviors. Together this theory and model guided the explanation and depiction of the relationship among study variables.

**Patient Advocacy**

Nursing theorists have described nursing’s foundational involvement in patient advocacy based on the differing aspects of advocating for patients. Kohnke (1980) described the objectives of nurses in patient advocacy as information sharing and decision-making support. Jezewski (1993) proposed the nurse advocacy role as like that of cultural broker, helping the patient bridge his or her own culture and values with the health care system’s culture and values, not unlike what we think of as the role of interpreter. Gadow (1980) and L. L. Curtin (1979) proposed that advocacy, wanting good health for others as we want it for ourselves, should be the way we philosophically define nursing not focusing on nursing’s care responsibilities, but on the larger relational meanings of health and nursing’s affiliation to the health of humans collectively and individually. The nurse experiences each patient as a whole and unique individual, which is a prerequisite for patient advocacy (Gadow, 1980). In the theoretical attempts to define nursing’s role in patient advocacy two concepts are pervasive: patient self-determination and the nurse-patient relationship.

Gadow (1983) referred to the “advocacy partnership” as the nurse’s participation in relationship with the patient to enhance autonomy and not just to protect autonomy. The intention of nursing advocacy is to assist individuals in clarifying their needs and preferences concerning their current situation so that they can then use that clarity to make decisions about their care and advocate for themselves. Establishing a trusting
relationship or partnership in which advocacy can take place requires a sense of belonging, mutuality, synchronicity, and reciprocity (Hagerty & Patusky, 2003; Thorne & Robinson, 1988b). These advocacy theorists describe nursing’s role in patient self-advocacy as a supportive one.

**Conceptual Framework**

Foundational concepts of the HPM are person, environment, nursing, health, and illness. These concepts interact to identify, enhance, or discourage health-promoting behaviors (HPBs). The HPM is an individual-level model of health promotion; therefore, is concerned with the mechanisms that support or deter an individual from adopting identified HPBs. Individual characteristics, prior experiences, patient cognitions, and affect can influence, and therefore potentially predict, the successful or unsuccessful adoption of a specific HPB. Individual characteristics and experiences represent prior related behavior or experiences an individual may have had related to the HPB and personal characteristics that may impact a particular HPB. Behavior-specific cognitions and affect represent patient thoughts and feelings concerning the HPB, as well as interpersonal influences and commitment to a plan of action. The HPB itself is considered the behavioral outcome. According to the theoretical assumptions of the HPM, an individual is more likely to participate in a HPB if there is interpersonal support from significant others including family, friends, and healthcare providers (Pender, 2011). Thus, based on the theoretical assumptions of the HPM, social support and trust in nurses were used to predict the adoption of a particular HPB, self-advocacy. There is evidence that psychological distress can be influenced by patient self-advocacy (Jonikas
et al., 2011). Health promoting behaviors have been shown to influence physical symptoms of heart failure (C. J. Chung & Schulze, 2011; Song, Moser, Dunbar, Pressler, & Lennie 2014; Sun, Buys, & Jayasinghe, 2014). Therefore, the variables of psychological distress and physical symptoms are included as distal outcomes, related to practicing the health promoting behavior of self-advocating, in two separate models. See Figure 1 for the adapted models.

Developing a mutually participative, trusting relationship with nurses is a potential resource that has not been routinely considered as a key component for health promoting activity, yet there is evidence to support that it can be (Beach, Keruly, & Moore, 2006; Bova, Fennie, Watrous, Dieckhaus, & Williams, 2006; Stewart, 1995; Thom, Hall, & Pawlson, 2004). “In a positive model of health, emphasis is placed on strengths, resiliencies, resources, potentials, and capabilities rather than on existing pathologies” (Pender et al., 2011, p. 15). Self-advocating, enhanced through relationships, is a positive coping strategy used to improve well-being by attempting to get one’s needs met.

**Concepts in Conceptual Framework**

Trust in nurses, social support, and self-advocacy were identified and depicted within the adapted HPM. Trust in nurses and social support were considered interpersonal influences that impact the outcome of adopting the HPB of self-advocacy. Psychological distress and physical symptoms were included in the model and tested as the outcomes of self-advocacy.
Figure 1. Adaptation of Health Promotion Model for Patients with HF
Self-Advocacy

Self-advocacy is the ability of one to “communicate, convey, negotiate, or assert his or her own interests, desires, needs, and rights” (Van Reusen et al., 2007). Self-advocacy is operationalized by gathering and using information, assertively communicating needs and preferences, and making decisions and taking action based on identified needs and preferences (Bernhard, 2013; Brashers et al., 1999; Hermansen-Kobulnicky, 2008). Self-advocacy has been studied in chronically ill individuals with cancer, mental illness, and mostly with human immunodeficiency virus or acquired immune deficiency syndrome (HIV/AIDS) in the late 1980s to early 1990s, when HIV/AIDS was considered a death sentence with a heightened sense of urgency for decision-making and its potential outcomes (Brashers et al., 2000). Little is known about self-advocacy among chronically ill individuals with HF.

Social Support

“Providers of social support serve as advocates by motivating and empowering recipients to act on their own behalf and to maintain as much control as possible,” and by providing the resources that may be necessary to maintain a sense of control (Finfgeld-Connett, 2005, p. 6).

Social support consists of the resources provided by others to help the recipient of those resources cope with perceived difficulties (Pender et al., 2011). The types of resources given to provide social support are emotional, instrumental, informational, or appraisal (Langford et al., 1997). Emotional support, the providing of “caring, empathy, love and trust,” tends to be the predominant type of support described as received by
recipients (Langford et al., 1997, p. 96). Instrumental or tangible support is providing physical items and helping with task related needs. Vaglio et al. (2004) found a weaker association between instrumental support and the other types of social support among cardiac patients suggesting that providing goods and services might be considered a separate construct. Informational support consists of information, suggestions, or advice that is given to assist the recipient (Glanz, Rimer, & Viswanath, 2008). Appraisal support is affirmative and esteem-building in nature (Pender et al., 2011).

Cobb (1976) defined social support as a mutual obligation and reciprocal in nature, yet this is not represented in measurements of social support but may be captured qualitatively. The support the participant receives is typically measured and the support the participant offers is not captured (Langford et al, 1997). Cohen (2004) described social support using three categories; instrumental, informational, and emotional, thus combining the categories of emotional and appraisal support. Finfgeld-Connett (2005) reported only two types of social support: emotional (support that is intended to ease uncertainty) and instrumental (support for the provision of goods and services), combining emotional, informational, and appraisal support. Combining the categories of social support to explain the concept may prove to oversimplify. Therefore, each of the four categories of social support defined by Langford al. (1997) were measured and compared in the study. For a more complete examination of social support the category of positive social interaction was added as suggested by Sherbourne and Stewart (1991).
Trust in Healthcare Provider

Patient-centered communication, a key aspect of therapeutic, caring relationships, requires a sense of mutual trust (Fosbinder, 1994; McCabe, 2004; Moyle, 2003; Winsett & Hauck, 2011). To be able to communicate intimate personal details, a trusting relationship is fundamental. For the patient to be able to share their unique perspective that may not match the providers requires a sense of trust and security (McQueen, 2000). “Patients are more likely to express their feelings honestly and disclose personal information with a nurse they feel they can trust to be responsive and discrete” (McQueen, 2000, p. 728). Trust is an integral component of therapeutic, supportive relationships (Bell & Duffy, 2009; Dinc & Gastmans, 2013; Wiersma & Pedlar, 2008). Patient-centered interaction, a key component of therapeutic relationships involves communication, a caring presence, and trust (Meleis, 2012). Theoretically, trust has been defined as “the patient’s confidence that care was appropriate and reliable and would be successful as possible” (Radwin, Washko, Suchy, & Tyman, 2005, p. 93). The vulnerability of the trustee is acknowledged in most definitions of trust (Meyer & Ward, 2013). It is also recognized that trust inside of a relationship is mutual, reciprocal, dynamic, and constantly being negotiated over time (Carr, 2001; Lynn-McHale & Deatrick, 2000; Thorne & Robinson, 1988a). Bova et al. (2012) operationalized the collaborative, relationship-based nature of trust by how well the healthcare provider(s) met patient expectations of interpersonal connection (emotional connection), respectful communication (respect and honesty), and professional partnering (knowledge sharing, professional connection, and partnership). These three aspects of trust are not
independent from one another and therefore together measure trust globally (Thom et al., 2004). Trust in nurses has been positively correlated with satisfaction in care, adherence, symptom control, and negatively correlated with depressive symptoms (Mancuso, 2010; Radwin & Cabral, 2010; Thom et al., 2004). However, trust has not been examined in association with self-advocacy and health outcomes among chronic HF patients.

**Psychological Distress**

Chronically ill patients must make many psychosocial and physical adjustments related to their illness. Needing to make these adjustments can lead to anxiety and depression or psychological distress (Doran, 2011). Anxiety and depression have been categorized separately for conceptual purposes but are viewed together empirically as psychological distress (Dobson, 1985). In the USA, 35% of patients with HF have clinical depression, and 50% -70% reported anxiety (Riegel et al., 2009). Evidence shows that both depression and anxiety hinder self-care (Riegel et al., 2009). Depression in HF has been found to contribute to increased hospitalization, worsening functional status, social isolation, hopelessness, and impaired quality of life (Bunyamin, Spaderna, & Weidner, 2013; Johnson et al., 2012; Riegel et al., 2009). While task-focused coping and social support were positively associated with the subjective well-being of HF patients, avoidance-based coping (a maladaptive emotional-focused coping) has been positively associated with depression in patients with HF (Carels, 2004; Graven & Grant, 2013; Perez Garcia et al., 2014). Coping that is considered acceptance and action-based (strategies that focus directly on the demanding circumstance) was significantly negatively associated with depression in HF patients (Carels, 2004). Despite strong
evidence of the association between social support and depression, no study has examined the effects of social support on depression along with key concepts such as self-advocacy and relational trust among chronic HF patients.

**Physical Symptoms**

Physical symptoms are subjective perceptions by the patient of changes in psychological and/or physical functions or experiences (Doran, 2011). Physical symptoms of HF include but are not limited to: shortness of breath, fatigue, weight gain or edema, and dizziness. Studies have found that heart failure symptoms can be impacted by social support (Heo, Lennie, Moser, & Kennedy, 2014) and by self-management behaviors (Rockwell & Riegel, 2001), thus, physical symptoms as a distal outcome were included in the study model.

**Significance of the Study**

The healthcare environment is not simple. It is not easy to navigate. This complicates the job of being a patient. Most patients do want to participate in their care and participation requires effort. This study generated new knowledge concerned with patient participation, and nursing’s role in enhancing participation. Patient participation is considered patient work. This developing body of knowledge examines what are sometimes invisible or unconsidered patient contributions to care (Unruh & Pratt, 2008). Self-advocating can be seen as a patient contribution to care. This study was one of the first steps to looking at what interpersonal factors may predict a patient’s ability to contribute to care through self-advocating and what resources are needed for this form of patient participation. It has also been inferred that encouraging patient participation
without consideration of the resources necessary for doing that is potentially adding to the growing disparities in healthcare (Sinding et al., 2011). This study identifies what resources are needed for patient participation, through self-advocacy, to occur. Past studies have recommended that the outcomes of self-advocating be examined; hence the distal outcomes of psychological distress and physical symptoms were included in the study (Hagan & Donovan, 2013b; Hermansen-Kobulnicky, 2008; Pickett et al., 2012).

Protecting patient self-determination is one of the core ethical concerns for professional nurses (ANA, 2001). Patients are practicing self-determination when self-advocating. It is our professional responsibility as nurses to assist patients in their attempts to self-advocate. Assessing social forces related to self-advocating will inform our practice so that we may assist patients and their loved ones in positive ways to contribute to their care by removing barriers or by facilitating positive behaviors.

**Summary**

HF is a chronic illness that requires patients to receive on-going care from multiple health care providers in many different environments. The patient carries the common thread throughout this complex healthcare experience. To achieve patient-centered care, the patient must be placed at the center as the source of control (IOM, 2001). To do that the patient must participate in his or her care. Self-advocating is a way patients can participate by sharing their needs, preferences, and concerns assertively with healthcare providers. Theoretically, if patients feel they have social support and a trusting relationship with their healthcare provider they are more likely to self-advocate. By sharing their needs, preferences, and concerns through self-advocating, their physical
symptoms and psychosocial distress can be lessened. See Table 1 for definitions used in this study.
Table 1

Definitions

<table>
<thead>
<tr>
<th>Variable</th>
<th>Theoretical Definition</th>
<th>Operational Definition</th>
</tr>
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<tbody>
<tr>
<td>Self-Advocacy</td>
<td>Ability to “communicate, convey, negotiate, or assert his or her own interests, desires, needs, and rights” (Van Reusen et al., 2007).</td>
<td>A numerical value (18–90) obtained from 18 items ranked on a Likert-type scale ranging from 1–5 and measured by the Adapted Patient Self-Advocacy Scale (APSAS; Brashers et al., 1999; Hermansen-Kobulnicky, 2008). The higher the score, the more likely the patient self-advocates in health care interactions.</td>
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<tr>
<td>Social Support</td>
<td>A perception of an individual concerning the resources (emotional, instrumental, informational, and appraisal), that are provided by others to help the recipient of those resources cope with perceived difficulties (Cobb, 1976; Langford et al., 1997; Sherbourne &amp; Stewart, 1991).</td>
<td>A numerical value (0-36) obtained from 19 items ranked on a Likert-type scale ranging from 0-4 and measured by the Medical Outcome Study- Social Support (MOS-SS; Sherbourne &amp; Stewart, 1991). The higher the score, the more social support one experiences.</td>
</tr>
<tr>
<td>Relational Trust</td>
<td>“The confidence one (the truster) has in the goodwill and honesty of the person (the trustee) they are in relationship with and the belief that the trustee will meet the expectations of the truster” (Hams, 1997; Johns, 1996).</td>
<td>A numerical value (0-52) obtained from 13 items ranked on a Likert-type scale ranging from 0-4 and measured by the Health Care Relational Trust: Clinic Nurses (HCRTrust–CN; Bova et al., 2006). The higher the score, the more trust one experiences their relationship with staff nurses.</td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>An emotional response to a perceived threat and the resulting lack of positive adjustment (Doran, 2011).</td>
<td>A numerical value (0-52) obtained from 14 items ranked on a Likert-type scale ranging from 0-3 and measured by the Hospital Anxiety and Depression Scale (HADS; Zigmond &amp; Snaith, 1983). The higher the score, the more the psychological distress one experiences.</td>
</tr>
<tr>
<td>Physical Symptoms</td>
<td>Patient observed health disturbances (Webster Medical Dictionary, n.d.).</td>
<td>A numerical value (0-84) obtained from 7 contingency format questions. Each question ranging on a scale from 0-12 and measured by the Symptom Status Questionnaire- Heart Failure (SSQ-HF; Heo et al., 2015). The higher the score, the more severe the physical symptoms one experiences.</td>
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CHAPTER II
REVIEW OF THE LITERATURE

Chronic HF patients are typically older adults who have a history of cardiac risk factors or cardiac disease. Frequently involved with the health care system as out-patients and in-patients, they also suffer from other chronic conditions that require care. HF specific information can help patients with HF understand and live with their illness more effectively. Evidence shows that HF patients who assertively communicate with their providers and make informed decisions receive more appropriate care (Allen et al., 2008, 2012; Davidson et al., 2004; J. Wu et al., 2008). The Health Promotion Model ([HPM] Pender, 2011) provides a framework to identify what factors may contribute to a patient’s ability to gain knowledge, assertively communicate, and make decisions, and therefore self-advocate. Little is known about the HF patient experience in relation to patient self-advocacy and trust in nurses. Thus, a more thorough discussion of these concepts is included to provide a sound base from which to develop study objectives related to chronic HF. Literature does exist linking social support, psychological distress, and physical symptoms with chronic HF and as such the discussion is very focused.

Heart Failure

HF is a chronic illness that is usually the result of atherosclerotic heart disease. The dominant risk factors and/or comorbidities related to HF include: ischemic heart disease hypertension, valvular disorders, obesity, diabetes, dyslipidemia, and smoking (Bui, Horwich, & Fonarow, 2011; Mosterd & Hoes, 2007). HF is most prevalent in older adults over 65 years of age and increases in prevalence dramatically with increasing age.
Each age range experiences the following prevalence rate: 20 to 39—0.5%, 40 to 59—3.3%, 60 to 79—14%, and 80—27.5% (Bui et al., 2011). More men are affected than women. Black individuals have a higher prevalence rate and present at younger ages than Whites (Bui et al., 2011). It was reported in 2011 that 30-day mortality after diagnosis was approximately 10%, 20–30% for 1-year mortality, and 45–60% for 5-year mortality (Bui et al., 2011, p. 4). HF has been considered more ‘malignant’ than most cancers (Bui et al., 2011).

The New York Heart Association (NYHA) classified HF patients into four severity levels: no symptoms and ordinary activity (NYHA-I); mild symptoms with physical activity slightly limited (NYHA-II); unable to walk on the flat without symptoms (NYHA-III); short of breath while at rest (NYHA-IV; Mosterd & Hoes, 2007). In 2009, the average length of stay (LOS) related to HF in the USA was 5.3 days with a median LOS of 3.5 days (Chen, Dharmarajan, Wang, & Krumholz, 2013). There are substantial readmission rates for HF patients; 27% at 30 days and up to 29% at 60–90 days (Bui et al., 2011).

Treatments for HF can involve surgery, device implantation, pharmaceuticals, and palliative therapies (Allen et al., 2012). The number and scope of treatments for HF continue to grow. Due to HF comorbidities, multiple professions involved in treatments, and the substantial readmission rates, HF patients need to deal with the health care system and the people that represent those systems on a frequent and continual basis. This requires HF patients, for better outcomes, to self-advocate throughout their health care experience.
**HF and Self-Advocacy**

Patient self-advocacy is a conceptual term and patient self-advocating behaviors are the behaviors that characterize this conceptual term. Gaining and using illness knowledge, assertively communicating, and making decisions, including the decision not to follow the advice of the provider, are the triad of self-advocating behaviors that are integrally related to one another. Although no literature specifically describes the self-advocacy of HF patients as a cohesive concept, there is literature describing individual behaviors of knowledge, communication, and decision-making of HF patients.

HF knowledge is the foundation of HF care. Health care providers provide health information during office visits, at the time of hospital discharge, and in self-management programs (Andiretta, Lopes Moreira, & Bottura Leite de Barros, 2011). Knowledge of HF is one of the most frequently measured factors impacting self-care (Barnason, Zimmerman, & Young, 2011). The vast majority of HF self-management programs include illness specific education (Wakefield et al., 2013). While most HF self-management programs focus on teaching lifestyle and illness information and recognition of symptoms that need attention, most do not teach the problem solving and coping skills necessary to interact with an overwhelming, complicated, and sometimes unresponsive healthcare system (Carlson et al., 2001; Dickson, Buck, & Riegel, 2013; Glasgow et al., 2002). The type of coping used by a patient can affect the patient’s ability to use knowledge of his or her illness to reduce anxiety. J. L. Jackson and Emery (2009) found that it was not only knowledge, but also the type of coping a patient used in conjunction with HF knowledge that affected a patient’s emotional quality of life (QOL); problem-
focused coping incorporating the use of HF knowledge decreased anxiety. A study by Graven et al. (2015) showed that problem solving and social support positively affected the self-care behaviors of HF patients. Self-advocacy, seen as a problem-focused coping skill, includes strategies that involve not only gathering resources, such as information about HF, but also the problem-solving activities of sharing information and making decisions (Lazarus & Folkman, 1984).

Communicating and sharing information with providers assertively is done to get the most benefit out of the encounter and gain some control over one’s situation (Adler, McGraw, & McKinlay, 1998). Communication between providers and patients with HF contributes to: (a) the way patients process and understand information; (b) treatment and adherence; (c) clarification of perceptions and expectations; (d) uncertainty acknowledgement; (e) trust building and value identification (Allen et al., 2008, 2012; Davidson et al., 2004; J. Wu et al., 2008). Trust is enhanced by reciprocal active communication, and vice versa (Lynn-McHale & Deatrick, 2000). With these two-way conversations, the patient tends to get appropriate care that meets his or her set goals and preferences (Allen et al., 2012). Communication problems between provider and patient can cause HF knowledge deficits resulting in non-adherence (J. Wu et al., 2008).

The suggested format for conversation with patients is “ask-tell-ask” (Goodlin, Quill, & Arnold, 2008). In the “ask-tell-ask” format, the focus on communication from the patient is a response. Yet, patients do initiate conversation, an important aspect to consider. Research by Davidson et al. (2004) supports that providers need to capture what the HF patient is saying when patients are offering unprovoked information because
nurses and patients perceive care needs differently. Documenting the patient’s needs in the patient’s own words will help nurses to accurately identify such needs (Davidson et al., 2004). The Carvedilol or Metoprolol European Trial (COMET) found that patient’s self-assessed symptoms were uniquely associated with hospitalization and mortality over 5 years of the study (Ekman, Anderson, Cleland, & Swedberg, 2005). Healthcare providers need to encourage and attend to all communications made by patients to understand the patient’s reality, helping to establish a trusting relationship (Ekman, Cleland, et al., 2005).

Patient knowledge also facilitates informed, involved decision-making. When 544 physicians were asked about their perceptions of non-medical factors that contribute to differential care in cardiac patients, they identified significant health assertiveness behaviors of being highly knowledgeable about the procedure and being involved in treatment decisions. They believed that the people who demonstrate these behaviors were more likely to receive appropriate treatment (Barnhart, Cohen, Wright, & Wylie-Rosett, 2006). In a scientific statement from the American Heart Association (AHA) on decision-making in advanced HF, Allen et al. (2012) supported that the majority of patients want to practice shared decision-making between themselves and their providers and that trust is foundational to that process. Deber et al. (2007) found that out of 384 cardiac patients surveyed, 66.5% preferred a shared decision-making approach. Younger patients overall wanted a more shared approach but overall, both older and younger patients preferred a participatory approach to decision-making (Deber et al., 2007; Say et al., 2006). Kahana and Kahana (2014) reported that older patients approached their
health care interactions more assertively than they used to. Health care providers might improve communication in the decision-making process by learning how to communicate with a more assertive patient as opposed to the predominant notion of communication only as drawing information “out of” patients in the “ask-tell-ask” format. Falk, Ekman, Anderson, Fu and Granger (2013) reported that older patients could learn (with more practical training) when given sufficient time, motivation, and involvement in the learning process. Florin, Ehrenberg and Ehnfors (2005) found that nurses perceived that patients wanted to be very active in clinical decision-making and the level of such desire was moderate. Yet, nurses did not successfully involve patients in clinical decision-making even to the moderate level patients preferred. Therefore, even at a moderate level of desire to participate we, as providers, are not meeting the patient’s needs.

Illness knowledge has a positive impact on HF patient’s self-management. Problem-solving and coping skills (like self-advocating behaviors) are not the focus of HF education in general. Evidence supports HF patient use of these adjustment tools. Studies have shown that illness knowledge and positive coping skills are related and both influence the emotional quality of life in patients with HF. Heart failure patients also benefit from communication that encourages a trusting relationship, which considers the patient’s desire for shared decision-making. Understanding the current antecedents and outcomes of self-advocacy in HF patients can inform future appropriate self-management programs for patients and educational and practice related offerings for healthcare providers.
Choice of Predictors/Variables

Patients are expected to participate in their care by self-advocating and patients recognize the need to self-advocate. To comprehensively learn more about patient self-advocacy, the current and historical literature concerning patient advocacy in all contexts was reviewed. Within the domain of nursing, Gadow’s (1980) theory of existential advocacy proposes that for a nurse to adequately advocate for a patient, a relationship with that patient should be established first. Theory and literature support interpersonal factors, such as relationships with others, can influence advocacy behaviors and that self-advocating as a health promoting self-management behavior can lessen psychological distress and physical symptoms. Therefore, social support and trust in nurses will be included to design a representational path model. Theoretically, relationships with others influence health promoting behaviors, and health promoting behaviors influence illness adaptation. In Figure 2, the theoretical substruction is depicted (McQuiston & Campbell, 1997).
Health Promotion

Health can be described as the “realization of human potential through goal-directed behavior, competent self-care, and satisfying relationships with others, while adapting to maintain structural integrity and harmony with the social and physical environments” (Pender et al., 2011, p. 22). This definition underscores the social and relationship aspects of health as well as the responsibility the individual has to maintain or improve their health using self-care. Health promotion can be defined as “increasing the level of well-being and self-actualization of a given individual or group” (Pender, Murdaugh, & Parsons, 2002, p. 34). The World Health Organization (WHO) includes in their definition of health promotion the “process of enabling people to increase control over, and to improve their health” (WHO website, n.d.-a). According to Maben and
Clark (1995), health promotion is “an approach to care through empowerment, equity, collaboration and participation” (p. 1163).

Health promoting behaviors are actions taken by an individual to maintain or enhance wellness and self-actualization to increase personal control over one’s health through empowerment, equity, collaboration, and participation (Maben & Clark, 1995; Moorhead, Johnson, Maas, & Swanson, 2008; Pender et al., 2002; WHO website, n.d.-a). According to the assumptions related to the HPM, health promoting behaviors are proactive rather than reactive in nature. They are performed because the person believes the behavior is of value and will provide the outcome they are looking for (Pender et al., 2002). The dominant variable of interest in the health promotion model is the health-promoting behavior itself. In this study, the health promoting behavior was patient self-advocacy.

The Health Promotion Model (HPM)

The HPM is used to guide the study to capture the complex nature of factors that contribute to an individual successfully practicing health promoting behaviors. See Figure 3. Not only does the model include individual characteristics and expectations, but it also includes dimensions concerning the thoughts, feelings, beliefs, and confidence in performing the behavior (Pender et al., 2011). Unlike other behavioral models that are avoidance based, the HPM does not include threat or fear as a motivating factor. A supposition of this model is that when the patient is attempting to practice a health-promoting behavior, he or she is attempting to move toward health, and away from illness. Therefore, the behavior will occur if there is “positive personal value and a
desired outcome” (Huckstadt, 2013, p. 430). When patients practice self-advocating, they do so in an attempt to have a need met that will enhance their health and well-being.

**Figure 3.** The Health Promotion Model (Pender et al., 2011)

The HPM has been used to identify determinants of lifestyle behaviors that are health and wellness promoting such as exercising and physical activity in healthy adolescents and adults (McGrath, O’Malley, & Hendrix, 2010; T. Wu & Pender, 2002).
Most recently, the model has been used in chronically ill populations, for instance, to assess outcomes of educational programs for peripheral artery disease and self-management behaviors of chronic kidney disease patients (Enworom, 2014; McCoy & DeBakey, 2011). The theory supporting the HPM considers health as a form of self-actualization. It recognizes the patient can be in control of his or her health and illness management involving symptom recognition and adherence to treatment and participation in care. According to a qualitative study by R. B. Curtin and Mapes (2001), chronically ill patients identified that self-management requires patient engagement with the healthcare system through self-presentation and symptom management, vigilant monitoring of care, treatment suggestions, confrontation with providers, and independent adoption of therapies.

There is a call for nursing to move away from the “medicalized” model of health promotion that focuses on lifestyle and behavior change to move toward a more holistic model that values health promoting needs as identified by patients and their families (Whitehead, 2001). Having knowledge, communicating assertively with providers, and making health decisions, is a group of health promoting behaviors that patients have identified as important to maintaining control over their health and wellness (R. B. Curtin & Mapes, 2001; Mendelson & Poole, 2007; Rouse, 2011; Sinding et al., 2011). The HPM was used to examine these elements of health promotion in this study. Many studies used the HPM to investigate interpersonal factors affecting individual’s health promoting behavior. However, prior to this study, no study had focused on self-advocacy using this model. Also, previous studies examined the impact of social support on health
promoting behaviors, but none included the healthcare provider as a source of relational support (E. S. Jackson, Tucker, & Herman, 2007). This study will broaden and build upon current health promotion theory.

Central Concept of Self-Advocacy: Identification, Definition, and Research

Self-advocacy is the conceptual term used to describe the most personalized level of advocacy. When one practices self-advocacy, one is said to be self-advocating. The most common term for self-advocating is “speaking up” (Bastian, 1998; JC, 2014). To self-advocate or “speak up” with healthcare providers, three things need to be accessed or practiced by the patient, the first being personal and illness related knowledge. Questions, concerns, and even preferences are based on some form of knowledge. Second, there needs to be verbal or physical communication of those needs. And third, there is a decision that is made and action taken by the patient based on their knowledge and identified needs even if it is inaction or if it goes against professional advice. This aspect of decision-making in self-advocacy has been termed mindful non-adherence. Mindful non-adherence is consciously making the decision not to adhere (Donovan & Blake, 1992).

According to Earp, French, and Gilkey (2008), there are four ecological levels of patient advocacy. Patient self-advocacy (individual advocacy) is at the center (See Figure 2). The next influencing level of advocacy is interpersonal advocacy, when a health care provider, or family, or friend speaks up or presents the desires of the patient. This is followed by organizational advocacy, the organization representing the patient by ensuring access and safety. The policy level of patient advocacy is where laws and rules
are made to enhance care and protect patients (Earp et al., 2008). Interestingly, T. Christensen (2010), a patient who has written several books on chronic care patient life, discussed “The Four Circles of Advocacy” (p. 10). She proposed that the inner circle is personal advocacy; it is followed by system advocacy, community advocacy, and political advocacy, respectively (See Figure 4). In her description of personal advocacy, patients, families, and friends are at the center and they all are the providers of self-advocacy for patients. This illustrates that there might be some differences in how providers and patients see self-advocacy. Test, Fowler, Wood, Brewer, and Eddy (2005) have developed a conceptual framework of self-advocacy used for students with disabilities. This framework includes the four components of knowing oneself, knowing one’s rights, communicating, and leading. The current study focuses on the communication aspect of self-advocacy and incorporates information about those in the individual, interpersonal, and organizational or system levels of advocacy.

**Key Statements and Definitions Concerning Self-Advocacy**

Theoretically, self-advocacy is a person’s ability to “communicate, convey, negotiate, or assert his or her own interests, desires, needs, and rights” (Van Reusen et al., 2007). Self-advocacy is operationalized when the patient gathers and uses information, assertively communicates her needs and preferences, and makes decisions and/or takes action based on identified needs and preferences (Brashers, 1999; Hermansen-Kobulnicky, 2008).
Assumptions of patient self-advocacy in the context of this study were:

1. The patient was able to communicate.
2. The patient had a need, preference, or desire.
3. The patient wanted to participate in his/her own health and wellness.

Several qualitative and quantitative studies related to patient self-advocacy exist among populations ranging from those with more acute illnesses to chronic mental health problems. However, several studies examined self-advocating behaviors of patients with chronic medical illnesses and only a few investigated patient self-advocacy from the nursing perspective. Most importantly, none examine self-advocacy among chronic HF patients.
Self-Advocacy: Qualitative Studies

Sinding et al. (2011) identified the typical focus of research when investigating patient involvement as internal personal attributes such as self-efficacy, values, and decision-making preference. The results of their study with 10 cancer patients revealed that external contextual factors such as financial resources, time, effort, skill, and support also significantly impacted patient participation and therefore, self-advocacy (Sinding et al., 2011). In support of this finding, Hagan and Donovan (2013a) discovered that most attempts to enhance self-advocacy in patients with cancer are concerned with external factors without considering the internal needs, beliefs, and goals of the patient.

Focus groups of women with scleroderma and ovarian cancer agree that having a “strong” support system and having high quality, timely information is important to their self-advocacy efforts (Hagan & Donovan, 2013a; Mendelson & Poole, 2007, p. 1500). Illness knowledge and knowledge of medical terms and healthcare processes are valuable assets to the self-advocating patient (Sinding et al., 2011). As a result of Rouse’s (2011) case study involving sickle cell patients, the ability of patients to participate in their care increases when they have knowledge about the healthcare system itself and when patients are taught how to respectfully practice mindful non-adherence. A significant portion of chronic dialysis patients practice mindful non-adherence, which they considered a self-management strategy (R. B. Curtin & Mapes, 2001). Brashers et al. (2000) discovered that HIV/AIDS patients considered having knowledge, assertively communicating, and mindfully non-adhering collectively represent their ability to self-advocate.
Entwistle et al. (2010) found that patients assess the potential consequences of speaking up, the positive consequence of having their need met or the potential negative consequence of being perceived negatively or being neglected because of their speaking up. Relational factors that helped patients speak up were staff confidence in patient abilities and encouragement to participate in care (Entwistle et al., 2010). The patient-provider relationship is the key factor influencing self-advocacy in several studies (Brashers et al., 2000; Entwistle et al., 2010; Rouse, 2011). Brashers et al. (2000) found that HIV/AIDS patients who self-advocated with providers experienced two-way dialogue and, as a result, forged partnerships with providers.

Having personal or self-knowledge, illness knowledge, and healthcare system knowledge is advantageous when self-advocating. Informational, tangible, emotional, and appraisal support as well as the support found in the patient-provider relationship, has been found to enhance patient participation and self-advocacy.

**Self-Advocacy: Quantitative Studies**

Brashers et al. (1999) designed the Patient Self-Advocacy Scale (PSAS) based on qualitative findings with HIV/AIDS patients. Three strongly correlated factors reflecting the qualitative themes were identified: (a) illness knowledge; (b) assertive communication; and (c) mindful non-adherence. Acceptable reliability and validity were reported. Self-advocacy was strongly correlated with the desire for control, preference of behavioral involvement and information seeking, and the desire for autonomy. Self-advocacy did not correlate with internal locus of control as was hypothesized but negatively correlated with external locus of control. Brashers et al. (2002) also found that
patient self-advocacy is strongly associated with problem-focused coping and negatively associated with emotion-focused coping. Those patients involved in support groups experienced helpful support from group members. This social support reduced the isolation and harm from being stigmatized.

Anthony (2007) studied the self-advocacy of elderly African Americans who felt stigmatized by healthcare providers. In this population men and those who had higher scores on the Powerful Others Locus of Control were less likely to self-advocate. Wiltshire et al. (2006) studied women and the impact of racial differences in the use of health information. A national sample of 3,960 women who obtained health information was accessed. The number of sources of information was documented. Two self-advocacy behaviors identified as the patient sharing information with the provider and the provider ordering a procedure or treatment based on the shared information were noted. Twenty-eight percent of the women shared information they had gathered from various sources with their doctor. Forty-seven percent of those women reported receiving a treatment or procedure as a result of the information they gave the doctor. Black women had lower odds of mentioning information to the healthcare provider when compared with White women. The combined effect of poverty and race was significant at the .001 level. Kahana et al. (2010) also found that patient assertiveness increased the number of cancer screening tests ordered for elderly patients that physicians would have overlooked.

Hermansen-Kobulnicky’s (2008) used the Adapted PSAS (APSAS) to measure self-advocacy in cancer patients and found that younger patients did not have higher APSAS scores than older patients as hypothesized. Highly educated patients who desired
involvement in decision-making and actively self-monitored were found to have higher levels of self-advocacy. This study also identified a gap in the patients desire to actively participate in decision-making and the realized involvement in decision-making, even for those with high levels of self-advocacy. This suggests that a high level of self-advocacy does not guarantee involvement in decision-making. Unfortunately, the act of speaking up does not guarantee an active listener or action taken on the information that was shared. Hermansen-Kobulnicky (2008) suggested an expansion of APSAS item pool to include both the acquisition of illness information and the use and management of that information including items that reflect seeking a second opinion, treatment alternatives, and symptom management.

Venetis, Robinson, and Kearney (2015) discovered that participation behaviors such as patient question asking and patient assertion of treatment preference were associated with an increase in fighting spirit and a decrease in anxious preoccupation in breast cancer patients. Three randomized control trials reported on the outcomes of self-advocacy interventions in those with chronic mental illness and chronic lung disease (Coleman et al., 2006; Jonikas et al., 2011; Pickett et al., 2012). These self-advocacy programs increased self-advocacy, measured pre-intervention, six-weeks, and six months post intervention. Participants experienced an increase in hope, quality of life (QOL), and empowerment and a decrease in psychiatric symptoms.

Patients who desire control, prefer to participate in their care, and are knowledgeable are more likely to self-advocate. Self-advocacy has led to an increase in hopefulness, fighting spirit, QOL, empowerment, and a decrease in anxious
preoccupation and psychiatric symptoms. Not all patient groups experience self-advocacy at the same level. Race, culture, and gender influence patient self-advocacy. Knowing the level of self-advocacy of HF patients and knowing how certain patient characteristics impact self-advocacy will inform evidence based interventions created to increase patient self-advocacy. This information will also help healthcare providers to support patients when they attempt to self-advocate. Both qualitative and quantitative studies support the importance of personal and health knowledge to patient self-advocacy as well as social support, assertiveness, and decision-making desire and ability.

**Education Research Concerning Student Self-Advocacy**

Research in self-advocacy is not limited to the healthcare environment. Students interact with educational providers that have a long-standing history of research in student self-advocacy. Education self-advocacy research considers how educators can affect this set of behaviors. This translates into provider influences on student self-advocacy, which might be similar to provider influences on patient self-advocacy and thus was explored. Self-advocacy skills taught to students with learning disabilities include participation in planning and problem-solving, knowledge of self and rights, leadership, and assertive communication—the most frequently taught skill (Test, Fowler, Brewer, & Wood, 2005). Twenty-three out of 25 studies showed an increase in one or more self-advocacy behaviors with intervention (Test, Fowler, et al., 2005). Students themselves consider speaking out and being in charge as self-advocacy (Nonnemacher & Bambara, 2011). Students identified being given options, help with accessing people of power, being accessible and approachable while withholding judgment, and follow
through as staff behaviors supporting self-advocacy. Having a supportive relationship with professionals encourages student self-advocacy (Chapman et al., 2011). Four student advocacy groups identified a concern that service-based advocates represent the organization in which they work and therefore, may not be the best choice to represent the student (Goodley et al., 2003). This concern is echoed by nurse ethicists when implying that nurses are the “best” provider of patient advocacy (Bird, 1994).

Because patients may not feel the nurse is the best person to advocate for them, it is crucial to know what nursing behaviors influence patient self-advocacy both negatively and positively. Relationship with provider, trust, social support, and acknowledging the context of self-advocacy are important to consider in any service setting as demonstrated by the research in both education and healthcare settings as well as documenting what the potential distal outcomes of self-advocating, such as reducing psychological distress and physical symptoms, may be. Thus, these variables have been included in this study.

**Trust: Identification, Definition, and Research**

Nurses, being the constant care providers, have one of the best opportunities to forge relationships with patients. Not only is having a relationship an opportunity for nurses and patients, it is a necessity for quality nursing care (Koloroutis, 2004; Watson, 2002). Relationships can be a coping resource that can augment or facilitate coping strategies (Thoits, 1995). Trust is a key component of relationships, including the relationships between nurses and patients (Morse, 1991). According to Johns (1996), trust is a central component of the nurse-patient relationship.
Trust has been defined as the confidence one (the truster) has in the goodwill and honesty of the person (the trustee) they are in relationship with and the belief that the trustee will meet the expectations of the truster (Hams, 1997; Johns, 1996). Trust requires the acceptance of an element of risk because of circumstantial uncertainty (Gilbert, 1998; Hams, 1997). There is a recognition of the vulnerability on the truster’s part. Johns (1996) described trust as a process and an outcome. Most theoreticians agree that trusting is based on deciding to trust and that “blind trust” should be considered dependence and not necessarily trust. Therefore, trusting is seen as a cognitive process (Castlefranchi & Falcone, 2001). Trust “seems even foundational for the notion of agency and for its defining relation of acting on behalf of” (Castlefranchi & Falcone, 2001, p. 55). Thus, trust is important in relating to others and being able to exert one’s own power or act on one’s own behalf.

Trust is also seen as reciprocal. For a relationship to be successful, each party must give and receive trust. Giving trust may not be based solely on the behavior of the other, but is also based on past experience (Dinc & Gastmans, 2013; Lynn-McHale & Deatrick, 2000; Pask, 1995). Optimally, both patient and nurse receive and give trust in a reciprocal manner (Thorne & Robinson, 1988b). Patients want their nurses to have confidence in them. Trust “is essential to patient empowerment as responsibilities for care are shifted more towards the patient” (Johns, 1996, p. 76; Hams, 1997). Patient participation and trust in provider are important for the decision-making process and self-management (Longtin et al., 2010). Patients reflect that it is important that their providers have confidence in them when making decisions and providing self-care as
well (Thorne & Robinson, 1988b). Hams (1997) pointed out that reciprocal trust empowers both parties in the relationship. Trust in providers and oneself can help to manage the complexity and uncertainty that go hand in hand with chronic illnesses (T. Gilbert, 1998; Pask, 1995).

Trust is needed to help patients maintain a sense of control. When patients experience trust in their nurse, they may be able to access coping skills they may not have been able to access otherwise (Hams, 1997; Pask, 1995). Studies have shown a relationship between psychological well-being and interpersonal trust (Johns, 1996). De Raeve (2002) identifies that distrust can lead to anxiety and poor health outcomes.

Time is an important factor that can facilitate trust in relationships (Dinc & Gastmans, 2013; Pask, 1995). The past, present, and future can affect one’s ability to trust and one’s trustworthiness (Dinc & Gastmans, 2013). Trust is built over time (Hupcey, Penrod, Morse, & Mitcham, 2001). Nurses can correct for a lack of time by demonstrating competence and by fully engaging with the patient as soon as the patient is in their care (Hams, 1997; Pask, 1995).

Delmar (2012) discussed the asymmetry of power between nurse and patient and concluded that relationship-based care is one of the ways to avoid an excess of power falling to the nurse; relationship-based care where trust and caring are central objectives (Koloroutis, 2004). According to a study of African Americans and their experiences with health care providers by Semmes (1991), a relationship can have an imbalance of power, but if there is no coercion, trust can exist.
Qualitative and quantitative studies examined what trust is, what is needed to encourage trust, and how trust affects patient outcomes. Most of these studies revolve around the relationship between patient and provider, some were more competency focused, considering the patient perception of nursing skills as the major contributor to a trusting relationship. Most studies included concern the chronically ill. However, none are directly focused on the HF patient population.

**Trust: Qualitative Research**

Thorne and Robinson (1988a, 1988b) explored the healthcare experiences of the chronically ill. Trust within the patient-provider relationship was identified as the dominant theme. Three stages of trust were identified as naïve trust, disenchantment, and guarded alliance. These stages reflect the growing relationship between patient and provider/organization. In the last stage, the patient “assumes responsibility for making their needs known in an assertive and unequivocal manner” (Thorne & Robinson, 1988b, p. 783). Patients identified the need to not only trust their provider but to be trusted by their provider, hence the term, reciprocal trust used by Thorne and Robinson (1988b). Because the patient’s competence varied over time and circumstances, creating trust with his or her provider gave him or her the necessary foundation to be open and honest with his or her provider and share information he or she might not have otherwise. The trust he or she had with the provider allowed the patient to assertively communicate with the provider.

Fosbinder (1994) and Radwin (2000) recognized trust in the provider as an outcome of care related to the confidence the patient has in the provider to give
competent care. While Kirschbaum and Knafl (1996), Courtenay, Stenner, and Carey (2010) described trust in provider as it relates to the quality of relationship as opposed to quality of services. Acute and chronic care patients described their decision-making preferences impacted relational trust more than the amount of time with provider (Kirschbaum & Knafl, 1996). Hood, Hart, Belgrave, Tademy, and Jones (2012) found that African American men’s trust in their providers determined the patient’s interest in participation in decision-making. Mutual respect enhanced trust and patient participation. Nygardh, Malm, Wikby, and Ahlstom (2011) interviewed 20 chronic dialysis patients and they identified that trust was affected by the influence the patient could have on the provider thus supporting the mutuality of trust.

Meyer and Ward (2013) investigated risk, as it relates to trust (See Figure 5) by having two groups of cardiac patients: one low risk group \((n = 18)\) who have been prescribed one cardiovascular drug only, and one high risk group \((n = 19)\) who have a history of a cardiac event (such as heart attack or cardiac surgery). Semi-structured interviews were designed to encourage patients to talk about their relationship with their doctors. The results of this study showed that time with provider and perceived health risk could affect level of trust in that provider and that dependence and trust could coincide. If one is in an emergency situation (high risk) one depends on the providers, yet trusts the medical system. Some of the trust for the medical system is placed in the doctors even though the patient has not developed a relationship with those doctors. See Figure 5. Since nurses are the most trusted profession, according to the latest Gallop Poll findings, this trust may enhance or make possible a level of trust in a particular nurse or
nurses before the nurse(s) has had time to establish a relationship with the patient (Williamson, 2016). The authors also felt, as a result of this study, that overall, people trust until given a reason to distrust (Meyer & Ward, 2013). Evidence shows that a relationship exists between provider and the organization they represent. The patient may trust the facility and then extend trust to the nurses because they work for that facility. Or the opposite may be true: when the patient trusts the nurses at a facility and therefore develops a trusting attitude toward the facility (De Raeve, 2002; Dinc & Gastmans, 2013).

![Figure 5. The Risk and Trust Continuum according to Meyer and Ward (2013)](image)

According to a systematic review of qualitative studies on patient-provider trust, nurses who are engaged, open, communicative, concerned, control sharing, confident, interested, competent, and practical are considered trustworthy (Rortveit et al., 2015). Rortveit et al. discussed that for one group of post myocardial infarction patients, trust in provider led to a sense of complacency about assuming care for oneself as it related to the belief in the powerful others (locus of control) over their (patient) outcomes. Yet for other chronically ill patients, trust meant being able to open up about issues, “they might not have revealed to others” (Rortveit et al., 2015, p. 203).
In sum, this body of qualitative research demonstrates that trust in provider can lead to patient participation and that patient participation can lead to trust in provider. If trust is established, patients are more willing to share information and participate in their care. If patient’s desire for participation is being realized, he or she is more likely to trust his or her provider. The risk of the illness to the patient’s life, as perceived by the patient and represented by the NYHA staging, may also affect the level of trust. Provider competence and relationship skills can affect a patient’s level of trust. The Healthcare Relational Trust in Clinic Nurses (HCRTrust–CN) focuses on the relationship skills of the nurse and includes an item indicator of competency (Bova et al., 2006).

Contradictory evidence exists related to the importance of the amount of time with provider as it relates to trust.

**Trust: Quantitative Research**

Trust in physicians, as a process of care, has been considered and measured for two decades (Thom et al., 2004). However, only recently has trust in other health care providers, including nurses, been studied. Radwin et al. (2005) tested a scale, for measuring trust in nurses as the outcome of care provided. The 4-item Likert-type scale was found reliable and valid (Radwin & Cabral, 2010). Bova et al. (2006) also created and tested a scale measuring trust. They defined trust as part of the relational process of care. The intent of the researchers was to create a scale that could be used with any healthcare provider such as Medical Doctor (MD), Physician’s Assistant (PA), and Advanced Practice Nurse (APN). The scale was reduced to 15 items and was found reliable and valid. The second study by Bova et al. (2012) found the HCR Trust scale to
be reliable and valid in 431 primary care patients. In this study, the scale was reduced to 13 items with three domains including interpersonal connection, professional partnering, and respectful communication were described although in a principal component factor analysis only one factor was identified. In both studies by Bova et al. (2006, 2012) social desirability was tested and the HRC Trust Scale was found to have low social desirability bias. Moderate ceiling effects were identified in both studies.

Evidence shows that trust in providers is associated with positive patient outcomes. Mancuso (2010) used the 15-item HCR Trust Scale to measure trust in provider as a predictor of glycemic control in 102 urban diabetic patients. Eighty percent of those patients were of African American descent. Trust in provider, primarily nurses or advanced practice nurses, significantly negatively correlated with glycemic control. Patient trust was also weakly negatively correlated with depressive symptoms. Gilbert and Hayes (2009) examined how NP relationship-related communication of expressing concern and encouraging participative decision-making affected patient trust and receptivity with 31 NP’s and 155 of their older primary care patients. Practicing both relationship-related communications resulted in an increase patient satisfaction and self-management behaviors (Heisler, Cole, Weir, Kerr, & Hayward, 2007; Paasche-Orlow & Roter, 2003). Gilbert and Hayes (2009) found that improved physical health was related to greater trust and receptivity and higher rates of patient sharing medical information with the provider.
The current study treats trust as a relational process of care, theoretically supportive of patient self-advocacy. Trust has been found to affect patient participation and patient outcomes, therefore, direct and indirect paths of trust were measured.

**Social Support: Identification, Definition, and Research**

Unlike the concepts of self-advocacy and trust, social support is better understood in HF patients (Minicucci, Azevedo, Polegato, Paiva, & Zornoff, 2011). Social support is the support individuals receive through positive relationships they have with people such as family, friends, and others. People who provide tangible, emotional, informational, and/or appraisal encouragement or assistance are said to be providing social support (Cobb, 1976; Langford et al., 1997; Sherbourne & Stewart, 1991). Many quantitative studies examined social support and its effects on HF self-care, which combines self-maintenance (diet, exercise, medication) and self-management (decision-making, problem solving) behaviors (Graven & Grant, 2014; Riegel & Carlson, 2004). Strong evidence confirms that social support is associated with optimal patient outcomes. Friedman and Quinn (2008) found that family support has a positive effect on self-management behaviors among 148 HF patients. In a study by Sayers, Riegel, Pawlowski, Coyne, and Samaha (2008) social support had a positive association with self-care confidence, medication, and dietary adherence in patients with HF. Sayler, Schubert, and Chiaranai (2012) found that self-care confidence leads to self-care behaviors. In their study with 97 HF patients, social support was measured with the Medical Outcome Study-Social Support scale (MOS-SS). The Self-Care of HF Index was used to measure self-care confidence and self-care behaviors (maintenance and management). Results
showed that supportive relationships had a direct effect on self-care behaviors and an indirect effect through self-care confidence on self-care management. The authors also found that through social support, HF patient’s problem solving and decision-making skills were improved resulting in better self-care management (Sayler et al., 2012).

In their longitudinal study, Bennett et al. (2001) measured social support and found that an increase in social support was associated with an increase in HRQOL in 227 HF patients and contributed 3–8% of the change in HRQOL. Baseline social support was also negatively related to heart-failure-related admissions, in-line with results from M. L. Chung, Lennie, Dekker, Wu, and Moser (2011), showing that social support predicted hospitalization and mortality in patients with HF. Moreover, Chung et al. also found that perceived social support was negatively related to depressive symptoms. Patients who experienced both less social support and more depressive symptoms were more likely to experience shorter event-free survival times (M. L. Chung et al., 2011).

Evidence shows that a lack of social support is linked to depression (Park, Fenster, Suresh, & Bliss, 2007). Enhancing Recovery in Coronary Heart Disease (ENRICHD), a study involving 196 patients hospitalized for myocardial infarction (MI), found that social support during hospitalization decreased depression two weeks post discharged (Barefoot et al., 2003). Social conflict was also found to have a negative relationship with depressive symptoms.

Graven and Grant’s (2014) integrative review summarized social supports’ positive role in HF self-care behaviors. However, a few studies found that social support could be associated with negative patient outcomes. For instance, one qualitative study
found that a large social network could distract the patient from healthy behaviors and encourage dependency, affecting HF patients’ self-care confidence and reducing their desire to initiate self-care behaviors (Strachan, Currie, Harkness, Spaling, & Clark, 2014). Albert, Forney, Slifak, and Sorrell (2015) reported mixed findings. In their study, some participants reported that friends, family, and health care providers were dismissive, negative, and not helpful at all, whereas others voiced that they found support from friends and family very positive and meaningful. Those that found they lacked support had a lower motivation to exercise, and those that found they had support felt they had a higher motivation to exercise. Some even had family or friends participate with them in the exercise activity (Albert et al., 2015).

Social support from friends, family, and health care providers can be a barrier or a facilitator to self-management behavior (Audulv, Norbergh, Asplund, & Hornsten, 2009). Audulv et al. interviewed 26 chronically ill people, some of which had cardiac diseases, and found that the process of self-management begins with the patient considering their personal beliefs concerning illness and health, the risks they associate with the illness, and assessing their various competing role-requirements. Participants felt that social support did affect their ability to self-manage. Nurses recognize the value of social support and report that they include family members to encourage the self-care behaviors of medication adherence and symptom recognition in patients with HF (Jaarsma, Nikolova-Simons, & Van der Wal, 2012).

According to Riegel, Dickson, Kuhn, Page, and Worall-Carter (2010), men \( (n = 19) \) and women \( (n = 8) \) with HF experience social support differently, but both groups did
find social support very important. Male participants reported receiving more tangible support, whereas female participants reported receiving more emotional support. Women reported more sadness, whereas men reported more anxiety. Both forms of psychological distress affected the self-management of the participants.

Social support is related to HF self-care and self-management behaviors. Self-advocating can be conceptualized as a self-care behavior. Therefore, social support may affect a HF patient’s ability or desire to self-advocate. Social support also affects HRQOL. In general, emotional health is assessed as part of HRQOL. Therefore, if social support has a positive impact on HRQOL in HF patients it may have a positive effect on psychological distress (depression and anxiety) as well. In fact, evidence shows that social support is negatively correlated with depression in various populations (R. Ross, Sawatphanit, & Zeller, 2009; R. Ross, Warner Stidham, Saenyakul, & Creswell, 2015; R. Ross et al., 2014; R. Ross et al., 2005).

**Psychological Distress: Identification, Definition, and Research**

Psychological distress is an emotional response to a perceived threat and the resulting lack of positive adjustment (Doran, 2011). The lack of positive adjustment, or successful coping, can lead to depression and/or anxiety as well as other mood disturbances or adjustment issues (Lazarus & Folkman, 1984). According to the Anxiety and Depression Association of America (ADAA), anxiety is the worry or tension related to known or unknown causes. It is manifested through symptoms of restlessness or jitteriness, fatigue, difficulty concentrating, insomnia or lethargy, irritability, and other individualized symptoms (ADAA, 2015a). Depression is a mood disorder characterized
by symptoms of: feelings of sadness, feelings of hopelessness, loss of interest or pleasure in activities, fatigue, lack of energy, low appetite or overeating, irritability, and other individualized symptoms (ADAA, 2015b). When someone experiences stressors and does not employ the necessary coping mechanisms, skills, or tools, anxiety and/or depressive symptoms can occur. Chronic illness is a stressor that requires adjustment using coping skills and other important self-care skills. Depression and anxiety are seen frequently in those suffering from a chronic illness like HF. Park et al. (2007) found that active coping related to lower depressive symptoms and perceiving one’s illness as threatening was a strong predictor of depression in HF patients.

In their meta-analysis of depression in HF, Rutledge, Reis, Link, Greenberg, and Mills (2006) reported that approximately 21.5 % (range 9%–60%) of HF patients experienced depressive symptoms that are of clinical significance. Between the four NYHA classes, the biggest jump in depressive symptoms was between class II and class III, although patients in class IV significantly suffered from depressive symptoms as well. Younger and female patients were more likely to experience depressive symptoms (Rutledge et al., 2006). Also, those with HF suffered from depression two to three times the rate of the population in general. Finally, HF patients with depressive symptoms experienced an increased risk of mortality and hospitalization and a reduction in event-free survival, when compared with HF patients without such symptoms (Johnson et al., 2012; Rutledge et al., 2006; J. Wu, Lennie, Dekker, Biddle, & Moser, 2013). Johnson et al. (2012) found that depression predicted rehospitalization of HF patients at a ratio of 1.45 to non-depressed HF patients among 784 patients in the HF and Retention Trial.
In a study of 216 patients with HF, those who suffered with depression were less adherent with medications, had higher anxiety, were younger, and were NYHA class III or IV when compared to their non-depressed peers (J. Wu et al., 2013). Physiologic changes as a result of HF are linked to depression; neurohormonal functioning, coagulability, autonomic neurocardiac function, and the cytokine system are negatively impacted by depression, thereby collectively increasing the potential injury to the heart (McGowan, 2013; J. Wu et al., 2013).

In a secondary analysis of U.S. Medicare beneficiary data \( (n = 21,429) \), Sayers et al. (2007) found that depression and anxiety were the most frequently diagnosed psychiatric comorbidities among HF benefactors, contributing to an increase in rehospitalization and higher health care costs.

Jackson and Emery (2011) investigated the relationship between coping styles, illness knowledge, and quality of life among women with HF. In their intervention study, 35 women with HF participated in an 8-week social support intervention. At baseline, participants who reported an anger-in (denial-based) coping approach and more illness knowledge were more likely to have lower emotional quality of life (QOL) and were more likely to suffer from psychological distress. Also, having little illness knowledge was associated with psychological distress. Thus, it is crucial to individualize the care for our patients. The more the patients tell us about themselves and their preferences, the better the opportunity there is to individualize their care.

Heo (2012) reported that depressive symptoms were related to a decrease in heart failure self-care when controlling for socio-demographic variables. Self-care in African
Americans with HF is hindered by depression according to a study by Dickson, McCarthy, and Katz (2013). Thirty African American adults participated in a mixed methods study looking at the relationship between self-care, heart failure, and depression. The qualitative results showed that depressive symptoms, coping mechanisms, and social support affected the ability to self-care. Of extreme interest is the participant revelation that when they “feel blue,” they just “wait it out” until heart failure symptoms get to the point where they must be emergently hospitalized. This supports the notion that it may be hard for patients to acknowledge the urgency of their symptoms when suffering from depression. It also supports the need to recognize that communicating with a health care provider is important. This corroborates the findings mentioned earlier of Sinding et al. (2011) that requiring participation without full knowledge of patient needs, preferences, and circumstances may encourage disparities. Dickson et al. (2013) also found that social isolation, as accounted for by HF symptoms and depression, contributed to a decreased ability for self-care and for accessing the things that could help, including social support, and coping strategies. Friedmann, Son, Thomas, Chapa, and Lee (2014) found that poor social support is linked with depression but not anxiety in HF outpatients. As part of The Psychosocial Factors Outcome Study (PFOS), social support, depression, and anxiety were studied over two years in 108 HF patients, roughly half of who received Implantable Cardiac Defibrillator (ICD) device treatment. Social support did not significantly impact the level of anxiety at baseline or overtime. Changes in anxiety were not related to NYHA class, ICD intervention, or age. The authors found there was no difference over time in depression between the ICD group and the placebo group. For all
patients, depression increased over time if social support was low at baseline, an
indication of a significant link between social support and depressive symptoms in HF
patients (Friedmann et al., 2014). Thus, it was important to include social support in the
study.

Physical Symptoms: Identification, Definition, and Research

The physical symptoms of HF are well documented and are positively associated
with depressive symptoms, hospitalization, and mortality in HF patients (Heo, Moser,
Pressler, et al., 2014a). However, they are negatively associated with social support, self-
care management, and self-care behaviors (J. Wu et al., 2008). According to a study by
Albert, Trochelman, Li, and Lin (2010) out of 276 heart failure patients, 100% had
symptoms of shortness of breath or trouble breathing. Sixty percent of those patients had
exercise intolerance, 43% experienced profound fatigue and dizziness or lightheadedness
while over 20% percent had nausea or loss of appetite, restlessness or confusion, and
difficulty breathing at night. Eighteen percent had right-sided abdominal discomfort,
severe cough, and chest pain. As expected, symptoms intensified or grew in number as
functional class increased (NYHA I, II, III, IV). More symptoms were being experienced
by the hospitalized patients when compared with outpatients at a ratio of 2:1 respectively
(Albert et al., 2010). The results of this study mirror the current symptom information
shared with patients by the Mayo Clinic and WebMD Internet sites (Mayo Clinic, n.d.;
WebMD, 2016). Schiff, Fung, Speroff, and McNutt (2003) found that symptoms that
brought HF patients to the hospital included shortness of breath walking (89%), shortness
of breath lying flat (81%), edema (77%), cough (69%), weight gain (41%), and shortness of breath at rest.

Health responsibility is one aspect of a health promoting lifestyle. Health responsibility, as assessed by the Health Promotion Lifestyle Questionnaire involves behaviors such as asking questions of providers, discussing health concerns, and reading books about health, among other items (Walker, Sechrist, & Pender, 1987).

Mohsenipouya et al. (2016) found that having poor health responsibility increased the risk of a positive exercise stress test by 1.622 times. Symptoms related to a positive stress test are chest pain, shortness of breath, and lightheadedness (AHA, 2015).

Literature suggests that HF patients self-advocate by communicating with their healthcare providers and participating in decision-making (Allen et al., 2012). However, self-advocacy, a new and important concept, has not been studied for its unique contribution to physical and psychological symptoms in relationship with other concepts such as social support and trust in nurses. In this study, structural models specifying these theoretical relationships have been tested, along with the direct and indirect effects each variable had on each other. Variables included in the model were social support, trust in nurses, self-advocacy, psychological distress, and physical symptoms.

**Implications of the Study**

Literature has shown HF patients desire to receive illness-related information (Andiretta et al., 2011). HF patients do communicate with providers and participate in decision-making (Allen et al., 2012). By practicing these behaviors HF patients are self-advocating. These behaviors have been studied individually in the HF patient population
but not considered together as the unique concept of self-advocacy. Relationships patients have with family, friends, and health care providers can lessen the impact of a chronic disease like HF (Bennett et al., 2001; Graven & Grant, 2013). The lessening of impact on illness may result in a decrease in psychological distress and physical symptoms. The study models have tested these theoretical relationships and the direct and indirect effects each variable had on each other.
CHAPTER III

METHODOLOGY

The purpose of this study was to examine the direct and indirect effects of self-advocacy and its predictors on psychological distress and physical symptoms in patients with heart failure. This chapter describes the study hypotheses and the methodology used to test them.

Research Hypotheses

H1: Social support and trust in nurses have a positive, direct effect on self-advocating behaviors.

H2: Self-advocating behaviors have a negative, direct effect on psychological distress.

H3: Self-advocating behaviors have a negative, direct effect on physical symptoms.

H4: Social support and trust in nurses have a negative, direct and indirect effect on psychological distress.

H5: Social support and trust in nurses have a negative, direct and indirect effect on physical symptoms.

H6: The proposed models fit the data well.

Phenomena that are psychological and social in nature have an objective reality according to research paradigms using quantitative methods such as path analysis. This objective reality can be reduced to numerical values to perform statistical analysis (Gelo, Braakmann, & Benetka, 2008). If the theoretically defined variables of a phenomenon or
concept align with an identified conceptual framework and can be operationalized and measured with observable numerical indicators, quantitative methods are employed to study the phenomenon (Waltz, Strickland, & Lenz, 2005). Generalizable causal effects can be predicted based on these theoretical relationships (Gelo et al., 2008). When variables in a framework have a relationship pattern that can be identified a priori using previous research or theory, a structural model can be tested using path analysis (Byrne, 2010). Therefore, a path analysis methodology was chosen for this study.

**Design of Current Study**

As a result of the literature review in Chapter 2, both theory and research have established the importance of forming a relationship with supportive persons and nurses for patients when self-advocating. The Health Promotion Model presents the framework in which to predict factors affecting self-advocacy, of which interpersonal influences are one potential predictor category. Research has also supported that potential outcomes of self-advocating are a reduction in psychological distress and physical symptoms. Based on these theoretical conjectures and research findings, paths of predictors and outcomes can be modeled and tested, therefore, path analysis was used in the quantitative strand to test two specified models of prediction. Self-advocating behaviors, psychological distress, and physical symptoms are outcome variables. Model 1 (See Figure 6) represents the path that culminates in the distal outcome of psychological distress which has been found to be reduced by self-advocacy (Jonikas et al., 2011). Model 2 (See Figure 7) represents the path that culminates in the distal outcome of physical symptoms. Although evidence has not been established supporting self-advocacy influencing
physical symptoms, there is evidence that health promoting, self-management behaviors influence HF physical symptoms (Sun et al., 2014). Therefore, the second model has been added.

**Figure 6.** Hypothesized HF Self-Advocacy Path Models – Diagram 1

**Figure 7.** Hypothesized HF Self-Advocacy Path Models – Diagram 2

Path analysis is a structural equation modeling technique that is used to test theory with directional relationships using observable variables (Grace & Bollen, 2005). A path model is specified, identified, estimated, and tested for fit. Specification of the study models was developed using the HPM. The paths were defined and one directional
arrows were drawn according to the relationship of descriptive categories within the HPM. Existential advocacy theory and current HF literature was used to identify the specific variables used in the models and the paths were diagramed. Self-advocacy and psychological distress and physical symptoms are considered endogenous outcome variables and as such, the uncorrelated disturbance terms of each variable have been measured. Healthcare relational trust and social support are considered exogenous variables; therefore, the covariance between the two variables has been measured. Because all arrows or effects being measured are one directional, the model is considered recursive. Identification calculation is done so that the number of parameters (unknowns) can be compared to the observations (known values) successfully (Kenny, 2011; Tabachnick & Fidell, 2007). In structural modeling techniques “there is a limit to the number of paths that can be analyzed in any one diagram” (Ramirez, 2017, p. 156). The number of parameters is determined by the sum of the number of paths, variances of exogenous variables, covariances, and disturbance terms. Both of the study models have 10 parameters. “Parameters are used to predict the correlation or covariances between measured variables and predicted correlations or covariances are compared to the observed correlations or covariances” (Kenny, 2011, para. 24). Both models are just-identified or saturated. Models that are just-identified have an equal number of parameters and observations. The formula for calculating identification is the number of observations \[v(v+1)/2\] minus the number of parameters. In this study \(4(4+1)/2 = 10\) observations – 10 parameters = 0 df. With a just-identified model (df = 0) there is only one solution, the structural equation model will perfectly fit the data (Kline, 2016).
Trimming the model to better represent the data will increase the likelihood of having more than one solution thus making hypothesis testing more interesting (Tabachnick & Fidell, 2007). Model fit indices measured were Chi-square, Comparative Fit Index (CFI), Incremental Fit Index (IFI), Normed Fit Index (NFI), Root Mean Squared Error of Approximation (RMSEA). Path coefficients, both direct and indirect were estimated.

**Target Population and Sample**

The target population for this study consisted of patients who have been diagnosed with HF for at least three months. HF is a chronic disease, but on occasion HF can be a temporary condition related to a medication side effect or another disease process (Maxwell & Jenkins, 2011). To avoid selecting a patient with transient HF, only patients experiencing HF for at least three months were included. The sample was drawn from one mid-western health care organization serving a small city and its outlying areas. The sampling frame was 80% White, 15% African American, 3% Asian, 2% other, 57% female, and 94% English speaking in the home (United States Census Bureau, 2015). The study setting was one nurse managed heart failure out-patient clinic that serves 500 patients annually (Akron General Medical Center [AGMC], 2013).

**Criteria for Selection**

Participants included in this study were English speaking adult patients with a HF diagnosis for at least three months who had at least two visits at the out-patient care at the sampling facility. Evidence shows that, in general, relational trust in provider has been historically measured after at least two healthcare visits (Bova et al., 2006). Also, transient HF is treated and relieved within 3 months (Maxwell & Jenkins, 2011), and
patients with HF begin practicing health promoting behaviors around three months after diagnosis (Rockwell & Riegel, 2001). Exclusion criteria include the inability to perform interviews due to physical or cognitive disabilities such as speech and hearing impediment and/or a history of dementia.

**Sample Size**

This study used convenience sampling. Path analysis was used to determine if the hypothesized models fit the data well (goodness of fit). According to Kline (1998, 2011), the number of participants is related to the number of parameters being estimated in the path model. In this study, there were 10 estimated parameters, which reflected 10 pieces of information being sought (Streiner, 2005). With parameters estimated the models were identified (Byrne, 2010). An ideal sample size is 20 participants for every parameter \(n = 200\). For harder to access populations like this study, a sample size of 5–10 participants per parameter \(n = 50-100\) is acceptable (Kline, 1998, 2011; Tabachnick & Fidell, 2007). The sample size for this study with 10 parameters was 80 participants.

**Variables and Their Measures**

In this study, interpersonal influences potentially contributing to patient self-advocacy are social support (from family, friends, and significant others) and health care relational trust in healthcare providers. The potential outcomes of patient self-advocacy are psychological distress (anxiety and depression) and physical symptoms. Following this line of reasoning, psychological distress and physical symptoms may be influenced by self-advocacy, which is influenced by the interpersonal influences of social support
and health care relational trust. Each variable was measured and tested for model fit. See Table 2 for variables and their accompanying measures.

Table 2

*Quantitative Variables and Their Measures*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Measure</th>
<th>Present study’s alpha</th>
</tr>
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<tbody>
<tr>
<td>Social Support</td>
<td>Medical Outcome Study (MOS) Social Support Survey</td>
<td>.95</td>
</tr>
<tr>
<td>Trust in Nurses</td>
<td>Health Care Relational Trust: In Clinic Nurses (HCRTrust–CN)</td>
<td>.87</td>
</tr>
<tr>
<td>Adapted Patient Self-Advocacy</td>
<td>Adapted Patient Self-Advocacy Survey (APSAS)</td>
<td>.74</td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>Hospital Anxiety and Depression Scale (HADS)</td>
<td>.87</td>
</tr>
<tr>
<td>Physical Symptoms</td>
<td>Symptom Status Questionnaire-HF (SSQ-HF)</td>
<td>.93</td>
</tr>
</tbody>
</table>

*Quantitative Instrumentation*

Five instruments were used in this study: the Adapted Patient Self-Advocacy Scale (APSAS; Brashers et al., 1999; Hermansen-Kobulnicky, 2008), the Health Care Relational Trust—In Clinic Nurses Scale (HCRTrust–CN; Bova et al., 2006), the Medical Outcome Study—Social Support Survey (MOS-SS), the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), Symptom Status Questionnaire–HF (SSQ-HF; Heo et al., 2015).
**Patient Self-Advocacy Scale**

The Patient Self-Advocacy Scale (PSAS) is currently the only reliable and valid tool available for measuring patient self-advocacy. It captures three dimensions of self-advocacy: being educated about one’s illness, assertiveness, and mindful non-adherence. The higher the PSAS score, the greater the self-advocacy.

**Description.** The PSAS is a 12-item tool that incorporates three self-advocacy dimensions. It is a self-report, Likert-type scale with responses ranging from one to five: 1–*strongly disagree*, 2–*disagree*, 3–*undecided*, 4–*agree*, 5–*strongly disagree*. Example questions include: “I believe it is important for people [with HF] to learn as much as they can about their illness and treatments,” “I am more assertive about my health care needs than most U.S. citizens,” and “sometimes I think I have a better grasp of what I need than my nurses do.”

**Reliability.** Initial alphas for the overall PSAS were reported at 0.78 in two separate populations. Alphas of the three dimensions or factors ranged from 0.60–0.82 (Brashers et al., 1999). In subsequent studies using the PSAS, the alphas of factors ranged from 0.67 to 0.75 and the overall scale from 0.75 to 0.81 (Frain, Tschopp, & Bishop, 2009; Hermansen-Kobulnicky, 2008; Pickett et al., 2012). Although the factor of health education consistently generated the lowest alpha among the three dimensions, researchers continue to include this factor. Theoretically, when being assertive and making health care decisions, it is necessary to have knowledge about the subject one is being assertive and making decisions about. Additional items added to the education/knowledge dimension that reflect the use of information/knowledge in health
care interactions have strengthened the reliability in this study. See Appendix A for a comparison of the original items to the adapted items.

**Validity.** Construct validity “is concerned with the extent to which a particular measure relates to other measures consistent with theoretically derived hypotheses concerning the hypothesis” (Carmines & Zeller, 1979, p. 23). Theoretically, patient self-advocacy is linked to the patient’s desire for participation, desired control in decision-making, and desire for autonomy. To substantiate construct validity of the PSAS, these other related constructs were measured with the initial testing of the PSAS (Brashers et al., 1999). It was found that the desire for control in decision-making (Desire for Control Scale), desire for autonomy (Desire for Autonomy Scale), and behavioral involvement (Health Opinion Survey Instrument) were highly correlated with the PSAS. An external locus of control (negatively; Health Locus of Control Scale) and information seeking (Health Opinion Survey Instrument) were moderately correlated with the PSAS. These findings substantiate the theoretically proposed links between self-advocating and the patient’s desire for participation. A principal component factor analysis resulted in three factors education, assertiveness, and mindful non-adherence (Waltz et al., 2005).

Criterion validity is, “the degree of correspondence between the test and the criterion [and] is usually estimated by the size of their correlation” (Carmines & Zeller, 1979, p. 17). The criterion of “do you consider yourself an activist?” was asked of the HIV positive sample in the initial PSAS testing. The group of “yes” respondents was compared with those who answered “no” and it was found that the “yes” group had significant differences in mean scores on the PSAS. Therefore, the criterion of
considering one’s self an activist does correlate with higher scores on the PSAS (Brashers et al., 1999). This finding supports the criterion-related validity of the PSAS.

**Readability.** The PSAS as written for this study has a Flesch-Kincaid score of 4.4 or 4th grade reading level.

**Questionnaire adaptation.** The PSAS has been adapted in this study based on prior studies’ suggestions for future use to reflect the current study population (HF) and provider (nursing). One question was broken down into two questions by Hermansen-Kobulnicky (2008): If my physician prescribes something I don’t understand or agree with, I question it . . . If my doctor prescribes something I don’t understand I ask; If my doctor prescribes something I don’t agree with, I question it. These two questions were retained in the current study. The Hermansen-Kobulnicky (2008) adapted questions were used in this study and were adapted to pertain to the HF patient population and provider population of nursing. To increase scale reliability five test questions were added to the original 13 questions for a total of 18 questions. Two questions were added based on Hermansen-Kobulnicky’s (2008) use of the tool. Suggestions from this study included the addition of questions based on information use and management. Two questions were also added concerning the sharing of personal information. This reflects educational research findings that having and sharing self-knowledge is important when articulating one’s needs and desires (Test, Fowler, Wood, et al., 2005). The education subscale is referred to as the knowledge subscale reflecting the attempt to broaden the subscale to include obtaining and using knowledge and self-knowledge. The last additional question is added in attempt to capture the acceptable practice of asking for a
second opinion or of changing providers. According to Reed, the Center for Studying Health System Change (2000), 40% of people who change health care providers do so related to personal preference as opposed to health insurance or other reasons (Reed, 2000). In the structure of nursing care the way to ask for a second opinion concerning nursing care or to change nurses is accomplished by accessing the nursing supervisor. The last question added reflects this reality. See Appendix B for complete patient version. The Health Promoting Lifestyle Profile is a measurement tool that includes items pertaining to health responsibility. Some of those items reflect items in the PSAS. The health responsibility subscale is not measuring self-advocacy as an independent and complete construct. Therefore, the PSAS was chosen to measure self-advocacy as an independent health promoting behavior.

**Health Care Relationship Trust Scale**

The Health Care Relationship Trust in Clinic Nurses (HCRTrust–CN) is a self-report instrument used to measure the trust a patient has with his or her healthcare provider. It was originally intended to measure relational trust in one healthcare provider although after conferring with the authors of the scale, it has been adapted to measure the trust of a group of health care providers, specifically nurses, for the current study (C. Bova, personal communication, February 25, 2014). See Appendix C for a comparison between the original items and adapted items.

**Description.** The HCRTrust–CN Scale was designed to capture the collaborative aspects of trust such as: knowledge sharing, professional connection, emotional connection, honesty, respect, and partnership (Bova et al., 2006). The tool was
developed with HIV-positive individuals using focus groups and individual interviews. It is a Likert-type scale with responses ranging from zero to four: 0—none of the time, 1—some or a little of the time, 2—occasionally or a moderate amount of the time, 3—most of the time, 4—all of the time. Example items include: “my nurses are sincerely interested in me as a person,” “my nurses accept me for who I am,” and “my nurses tell me the complete truth about my health-related problems.”

Other instruments attempt to capture perceived trust between patient and nurse (Radwin et al., 2005; Watson, 2002). One tool designed by Radwin et al. (2005) does not focus on the relational aspects of trust as comprehensively as the NCRTrust–CN and tends to focus on the direct care aspects of nursing; for example, two out of the six items included in the tool are: “how often were your nurses there when you needed them?” and “how often did your nurses do what they said they would do?” While these aspects of care can lead to trust in one’s provider as an outcome of quality nursing care, what the current study is concerned with is how trust in provider leads to a social environment or relationship that enhances the ability of patients to self-advocate. Instruments designed to measure caring weave conceptual aspects of trust throughout the tools. However, they are not concentrated into one factor for easy use. Because caring is such an all-encompassing concept with many measurable aspects, the caring tools are burdensome to use when the concentration of concern is only a partial, albeit important, aspect of caring (Watson, 2002).

**Reliability.** The initial 15-item instrument had a Cronbach alpha of 0.92 (Bova et al., 2006). Subsequent studies demonstrated acceptable alphas with a revised 13-item
scale of 0.96 with a sample size of 431 primary care participants and second study with 102 diabetic participants with an alpha of 0.92 (Bova et al., 2012; Mancuso, 2010).

**Validity.** The HCRTrust–CN, when initially tested with 99 HIV positive individuals, was found to have three underlying factors: interpersonal connection, respectful communication, and professional partnering (Bova et al., 2006). Upon further testing, the scale was found to be unidimensional (Bova et al., 2012).

The initial testing of the HCRTrust–CN was administered face-to-face. Social desirability (measured by Marlowe-Crowne Social Desirability Scale), adult literacy (measured by Rapid Estimate of Adult Literacy in Medicine), and depressive symptoms (measured by Center for Epidemiologic Studies in Depression Scale) were included with the initial testing (Bova et al., 2006). Social desirability is the tendency to respond to questions in a socially desirable way (Spector, 2004). Adult literacy is measured to ascertain readability level of a tool by measuring the influence of literacy on item response (T. C. Davis et al., 1993). According to Bova et al. (2006), depressive symptoms were negatively correlated with trust in provider in a randomized controlled trial (RCT) studying the effects of a nursing intervention to increase adherence to highly active antiretroviral therapy (HAART). The HCRTrust–CN was found to be negatively correlated with depressive symptoms and did not correlate with the social desirability or the adult literacy measure (Bova et al., 2006).

**Readability.** The Flesch-Kincaid score for readability of the tool as adjusted for this study is 4.2 or at the fourth-grade reading level.
**Questionnaire Adaptation.** Changes in wording by the principal investigator were approved by the original authors. See Appendix B for complete patient version.

**Hospital Anxiety and Depression Scale**

The Hospital Anxiety and Depression Scale (HADS) is a 14 item self-report scale used to help identify medical patients that might be experiencing psychological distress (Zigmond & Snaith, 1983).

**Description.** There are two subscales within the larger scale, one assessing anxiety symptoms, the other assessing depressive symptoms with the overall scale measuring symptoms of psychological distress. Example questions include: “I still enjoy the things I used to enjoy,” 0—*definitely as much*, 1—*not quite so much*, 2—*only a little*, 3—*hardly at all*; “I can sit at ease and feel relaxed,” 0—*definitely*, 1—*usually*, 2—*not often*, 3—*not at all*. Each of the 14 questions has a unique corresponding Likert-type scale answer ranging from 0-3. The scale has been used to identify normal (total score of 0–7), borderline (total score of 8–10), and abnormal amounts (total score of 11–21) of psychological distress (Snaith, 2003). The HADS has been used with cardiac patients and found to be reliable and valid in this patient population (Gallagher & McKinley, 2009; Gallagher, McKinley, & Dracup, 2003; Lewin & Robertson, 1992; C. R. Martin, Lewin, & Thompson, 2003).

The advantage of using the HADS is that while other scales used to measure anxiety and depression incorporate items that may be confused with the physical symptoms of the patient’s disease process, the HADS does not. Physical symptoms such as racing heart, shortness of breath, and fatigue, symptoms of anxiety and depression, can
also be symptoms of HF. Since the HADS does not contain items that may confuse the issue of psychological or physical distress, it is the most appropriate psychological distress scale to use with this study population.

**Reliability.** Full-scale Cronbach coefficients have been found to range from 0.81–0.91 (Herrmann, 1997; C. R. Martin et al., 2003; Woolrich, Kennedy, & Tasiemski, 2006). The HADS Anxiety (HADS–A) subscale alpha coefficients ranged from 0.80–0.93 (Herrmann, 1997; Woolrich et al., 2006). The HADS Depression (HADS–D) subscale alpha coefficients ranged from 0.79–0.90 (Herrmann, 1997; Woolrich et al., 2006).

**Validity.** The HADS was found to have a two-factor dimensionality (Bjelland, Dahl, Haug, & Neckelmann, 2002; Woolrich et al., 2006). The two factors are split into the anxiety and depression subscales (Zigmond & Snaith, 1983). Whereas the anxiety and depression subscales are highly correlated with each other as expected, “there is sufficient evidence that both subscales differ in a clinically meaningful way” (Herrmann, 1997, p. 20).

Studies have found strong correlations between the HADS–D subscale with the Beck’s Depression Inventory (BDI) and the Symptom Checklist 90 (SCL–90) subscales of depression (Bjelland et al., 2002).

**Readability.** The HADS has a Flesch-Kincaid of 8, which equates to an 8th grade reading level. See Appendix B for complete patient version.
**Symptom Status Questionnaire-HF**

The Symptom Status Questionnaire–HF (SSQ–HF) is a seven-item self-report tool presented in a contingency question format used to measure the presence and severity of physical symptoms in HF (Heo et al., 2015; Trochim, 2006).

**Description.** An example question is, “Did you have shortness of breath when you lay down?” 0–no (if your answer is no, please go to question3), 1–yes (if your answer is yes, please fill out 2a, 2b, 2c), 2a. “How often?” and “How severe?” and “How much did it distress or bother you?”

The SSQ-HF assesses symptoms specific to HF while other measures concerned with physical symptoms in capturing a broader range of generalized chronic illness symptoms including some psychological symptoms and specific to the most common physical symptoms of HF (Heo et al., 2015).

**Reliability.** The SSQ-HF has achieved a Cronbach alpha of 0.80 in two studies and 0.93 in one other study (Heo, Moser, Lennie, et al., 2014; Heo, Moser, Pressler, et al., 2014; Heo et al., 2015).

**Validity.** In a common factor analysis, the SSQ-HF generated one factor (Heo et al., 2015). All items are inter-correlated between 0.30–0.70. Construct validity was supported by correlating the SSQ-HF with depressive symptoms and health related quality of life (HRQOL), both of which have been found to be related to HF symptoms in other studies (Heo et al., 2015). The SSQ-HF was found to positively correlate with depressive symptoms and negatively correlate with HRQOL, confirming its construct valid (Heo et al., 2015).
Readability. The SSQ-HF has a Flesch-Kincaid score of 1.9, and thus is at a second-grade reading level (Readability-Score, n.d.). See Appendix B for complete patient version.

Medical Outcomes Study- Social Support Survey

The Medical Outcomes Study Social Support Survey (MOS-SS) was developed to measure perceived functional social support. Social support that meets patient’s needs is considered functional in nature (Cohen, Mermelstein, Kamarck, & Hoberman, 1985). Social support functions identified by Sherbourne and Stewart (1991) are: emotional, instrumental, information, appraisal, and social companionship.

Description. The MOS-SS has been used extensively with chronically ill patients and in particular with chronically ill HF patients (Bennett et al., 2001; Cene et al., 2013; Kao, Tseng, Lin, & Cheng, 2014). It incorporates a multidimensional view of functional support that is useful when looking at how various aspects of social support may affect a patient’s level of self-advocacy. Example questions include: “Someone you can count on to listen to you when you need to talk,” and “someone who shows you love and affection.” Each question is followed by Likert-type scale responses ranging from zero to four: 0–none of the time, 1–some or a little of the time, 2–occasionally or a moderate amount of the time, 3–most of the time, 4–all of the time.

Reliability. The original scale reliability was 0.97 with a sample of 2,987 primary care patients (Sherbourne & Stewart, 1991). Subsequent studies with HF patients demonstrated the tool’s reliability alpha coefficients of 0.94 (Kao et al., 2014) and 0.96 (Cene et al., 2013). In one longitudinal study involving 150 HF patients, the
reliability was measured each time the survey was given, and the alpha coefficient varied from 0.80 to 0.97 (Bennett et al., 2001).

**Validity.** Initial item scale correlations were 0.72–0.90. Confirmatory factor analysis yielded four discernable factors or subscales (Sherbourne & Stewart, 1991). The subscales discriminated well from, “measures of loneliness or feelings of belonging, mental health, current health perceptions and other aspects of family and social functioning” (Sherbourne & Stewart, 1991, p. 709). The four factors that reflect the five components of functional support are: emotional/informational, tangible, positive interaction, and affection.

**Readability.** The MOS-SS has a Flesch-Kincaid score of 5.7, suggesting the 5th grade reading level. See Appendix B for complete patient version.

**Demographic and Diagnosis Related Characteristics**

Descriptive data were collected to allow for a comprehensive description of the sample (Grove, Burns, & Gray, 2013).

**Demographic characteristics.** Demographic characteristics that were measured include age, gender, ethnicity, education, employment, marital status, and income. These demographic characteristics have been measured in previous studies concerning the self-advocating behaviors, psychological distress, and physical symptoms of patients and may enhance the generalizability of study findings while addressing potential biases (Anthony, 2007; Hermansen-Kobulnicky, 2008; Jonikas et al., 2011). See Appendix D.

**Diagnosis related characteristics.** Certain HF related characteristics have been measured to give a more in-depth perspective of how outcome variables are represented
in patients with HF. This study used the New York Heart Association (NYHA) classification system for the functional status of patients with cardiac disease, a system with four categories used to describe how well a patient with heart disease feels during physical activity (American Heart Association, 2017). The categories are: Class I–no limitation, no symptoms with exercise; Class II–slight limitation, some symptoms with exercise; Class III–marked limitation, marked symptoms with exercise; and Class IV–severe limitation, severe symptoms with exercise. The American Heart Association (AHA) and the American College of Cardiology Foundation (ACCF) also have a functional status scale that is routinely documented and has been collected. The ACCF/AHA Stages of HF are: Stage A–at high risk for HF but without structural heart disease or symptoms of HF; Stage B–structural heart disease by without signs or symptoms of HF; Stage C–structural heart disease with prior or current symptoms of HF; and Stage D–refractory HF requiring specialized interventions (Yancy et al., 2013). Number of comorbidities, number of lifestyle factors, family history of heart disease, presence of obstructive sleep apnea (OSA), left ventricular ejection fraction, and the presence of diastolic and/or systolic heart dysfunction were also collected. Health-related support groups do exist and membership may have some impact on patient self-advocacy, psychological distress, and physical symptoms. Therefore, the participants will be asked if they have attended any health-related support group meetings in the last year and how many meetings they attended in that time period. See Appendix D.
Protection of Human Subjects

The healthcare facility in which the clinic is located, Akron General Medical Center (AGMC), granted permission to conduct the study through the Institutional Review Board (IRB) as the institution of record. See Appendix E. Kent State University IRB accepted the review and continuing oversight of this study in conjunction with AGMC. See Appendix F. The purpose of the study was explained and any questions answered prior to signing a consent agreeing to participate. See Appendix G. Potential risks of this study were participant fatigue, given the nature of the HF. The researcher offered to read and scribe for each participant and stopped for breaks as necessary. The medical center is the Institution of Record and therefore the medical center Institutional Review Board requirements have been complied with and Collaborative Institutional Training Initiative (CITI) training was completed and documented.

Study Procedures

Participant Recruitment

The investigator was on site 3–4 days a week. On those days, clinic patients were screened according to inclusion and exclusion criteria by the nurse caring for them. If the patient met the criteria the nurse would approach them for potential participation. A total of 90 patients were asked to participate. Eighty of those 90 consented to participate for a response rate of 89%. Reasons for non-participation were split evenly between those who gave no reason and those where were too tired or in a rush.
Data Collection

Data were collected from October 2016 thru April 2017. At the end of a clinic visit the patient was informed by the nurse that an investigator was conducting a survey study. The nurse gave the patient a recruitment letter. See Appendix H. After the recruitment letter was read by the participant the nurse asked if they would like to hear more about the study. If the patient indicated interest, the nurse informed the investigator. The investigator then approached the patient and reviewed the recruitment letter together with the patient. If the patient agreed to participate, the investigator read the consent with the participant and after signing offered to read the survey to the participant. If the participant wanted the investigator to read the survey, the survey was read exactly as written. Questions concerning survey items were answered but all other discussion was held until after the completion of the survey to maintain procedural fidelity. The participant received the associated gift card and a blank copy of the consent form after the survey was complete. The surveys were filled out in a private room or at the back of the patient care area where privacy could be maintained.

It is important to capture participant information at all levels of HF severity because it has been suggested that the more time one has spent dealing with their illness and the healthcare system, the more experiences or opportunities they may have had to self-advocate (Hagan & Donovan, 2013b; Sinding et al., 2011). Due to the fatiguing nature and severity of chronic HF, the principal investigator (investigator) offered to assist by reading each question and circling the answer indicated by the participant (American Heart Association, 2017). The percentage of participants who requested the
survey be read to them was 62.5%, with 37.5% choosing to read and respond to the survey themselves. There were no significant differences found in the results of both groups based on this factor (based on Levene’s Test for Equality of Variances; $F = .137$, $p = .712$).

Completed surveys were assigned a number in order of participation. A list tracking the name of the participant and the corresponding ID number was kept in a password protected file on the investigator’s laptop. The completed surveys and consents were kept in a locked file cabinet in the investigator’s home. Survey data were entered in a password protected SPSS file at the end of each week.

**Pre-analysis data management.** SPSS™ version 22 software was used. All data were screened to assess accuracy. Missing data points were identified and Little’s MCAR performed confirming that all of the 19 missing data points were completely at random. Those data points were imputed using predicted values by Expectation Maximization Algorithm. The only other missing data point was replaced using the case mean of the factor being measured (anxiety). Because path analysis uses regression to establish structural modeling, the assumptions of regression must be met or managed (Mertler & Vannatta, 2017).

Univariate and multivariate descriptives demonstrated normality, linearity, and homoscedasticity. All but one assumption was met. Trust in nurses was substantially negatively skewed and leptokurtic. A log10 transformation was performed. A new variable of HCRT_LOG was used in all analyses as well as the non-transformed variable HCRTTOT for comparison. There were no significant differences in statistical
outcomes; therefore, the original variable was reported throughout the analyses. Outliers were identified using Mahalanobis Distance (df 3, \( p < .001 \), chi-square 16.2662). One outlier was identified. Analyses were performed with and without the outlier with no significant difference. Therefore, the outlier was retained for all analyses. Mulitcollinearity of variables was ruled out via tolerance \( \geq .2 \) and, VIF < 10 (Mertler & Vannatta, 2017).

**Exploratory Factor Analysis of the APSAS**

A principal component factor analysis was performed to explore the structure of the APSAS. The originally adapted scale had 13 items. It was suggested to add more items to further support the structure of the tool (Hermansen-Kobulnicky, 2008). The investigator added five items to strengthen the tool. The items were: “I use the information I have learned about my illness when talking with my nurse,” “I use the information I have learned about my illness when making decisions about my health,” “I consider my overall needs, preferences, and responsibilities when making health care decisions,” “I tell my nurse my needs, preferences, and responsibilities when discussing my plan of care,” and “I would ask to speak to a supervisor if not satisfied with my nursing care.” These items were added to reflect the dimensions of not only gaining knowledge but using knowledge for self-advocacy. Knowledge was extended to knowledge of one’s self and the use of that knowledge in health care decisions and plan of care. And lastly, it has become more acceptable and encouraged to seek a second opinion; therefore, the question concerning accessing a nursing supervisor was added. Varimax rotation was used with a fixed three factor solution. The originally adapted 13
item tool had a Cronbach’s alpha of .68 in this study. The factor analysis on the newly adapted 18 item tool resulted in the removal of two items (“I believe it is important for people with heart failure to learn as much as they can about their illnesses and treatments,” and “I tell my nurse my needs, preferences, and responsibilities when discussing my plan of care”). See Table 3 for rotation results. The Cronbach alpha of the now 16 item tool was .74. Thus, the questions did strengthen the tool for this sample.

**Reliability**

Study instruments were tested for internal consistency using Cronbach’s alpha to measure scale reliability. Internal consistency measures how well items are correlated with one another (Nunnally & Bernstein, 1994). A Cronbach’s alpha of .70 is an acceptable level for scale reliability with efforts in further scale development to reach .80 (Burns & Grove, 2009). A low alpha may be related to an inadequate number of items or items that have little in common (Nunnally & Bernstein, 1994). Table 4 provides a summary of scale internal consistency analyses.
## Table 3

*Principal Component Analysis of the APSAS*

<table>
<thead>
<tr>
<th>#</th>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I believe it is important for people with heart failure to learn as much as they can about their illnesses and treatments.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>I actively seek out information on heart failure.</td>
<td>.536</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>I have enough knowledge about the health problems that come from having heart failure.</td>
<td>.603</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>I think I am more educated about my health than most US citizens.</td>
<td>.704</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I use the information I have learned about my illness when talking with my nurse.*</td>
<td>.534</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>I use the information I’ve learned about my illness when making decisions about my health.*</td>
<td>.690</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>I am more assertive about my healthcare needs than most US citizens.</td>
<td>.761</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>If my nurse asks me to do or take something I don’t understand I ask questions.</td>
<td></td>
<td>.628</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>I don’t get what I need from my nurse because I am not assertive enough.**</td>
<td></td>
<td>.582</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>I frequently make suggestions to my nurse about my health care needs.</td>
<td></td>
<td>.685</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>If my nurse asks me to do or take something I don’t agree with, I question it.</td>
<td></td>
<td>.589</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>I consider my overall needs, preferences, and responsibilities when making health care decisions.*</td>
<td></td>
<td>.591</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>I tell my nurse my needs, preferences, and responsibilities when discussing my plan of care.*</td>
<td></td>
<td>.550</td>
<td>.480</td>
</tr>
<tr>
<td>14</td>
<td>Sometimes I think I have a better grasp of what I need than my nurse does.</td>
<td></td>
<td></td>
<td>.658</td>
</tr>
</tbody>
</table>
Table 3 (continued)

*Principal Component Analysis of the APSAS*

<table>
<thead>
<tr>
<th>#</th>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>15</td>
<td>Sometimes there are good reasons not to follow the advice of a nurse.</td>
<td>0.681</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>If I am given a medicine by my nurse that I don’t agree with, I am likely not to take it.</td>
<td>0.730</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>I don’t always choose to do what my nurse has asked me to do.</td>
<td>0.684</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>I would ask to speak to a supervisor if not satisfied with my nursing care.*</td>
<td>0.546</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Reverse coded item, *item added to scale for evaluation, Principal component analysis, Varimax rotation, 3 loadings.**

Table 4

*Internal Consistency Results Using Cronbach’s Alpha*

<table>
<thead>
<tr>
<th>Instruments</th>
<th>Number of Items</th>
<th>N</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare Relational Trust: Trust in Clinic Nurses</td>
<td>14</td>
<td>80</td>
<td>0.87</td>
</tr>
<tr>
<td>Medical Outcome Study: Social Support Scale</td>
<td>19</td>
<td>80</td>
<td>0.95</td>
</tr>
<tr>
<td>Symptom Status Questionnaire: Heart Failure</td>
<td>21</td>
<td>80</td>
<td>0.93</td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety Subscale</td>
<td>14</td>
<td>80</td>
<td>0.87</td>
</tr>
<tr>
<td>Depression Subscale</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Self-Advocacy Scale- Original Items</td>
<td>13</td>
<td>80</td>
<td>0.70</td>
</tr>
<tr>
<td>Adapted Patient Self-Advocacy Scale</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge Subscale</td>
<td>16</td>
<td>80</td>
<td>0.74</td>
</tr>
<tr>
<td>Assertiveness Subscale</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mindful Non-Adherence Subscale</td>
<td>7</td>
<td>80</td>
<td>0.75</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>80</td>
<td>0.66</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>80</td>
<td>0.70</td>
</tr>
</tbody>
</table>
Summary

A convenience sampling of 80 out-patients with heart failure were surveyed to examine two path models depicting the relationships between trust in nurses, social support, self-advocacy, and physical symptoms and psychological distress. The patients recruited for this study have had heart failure for at least three months, have had at least two visits to the clinic in the last year, are English speaking, and have no history of dementia or difficulties that would interfere with survey completion. The five instruments used in this study were all found reliable with alpha coefficients ranging from .74 to .95. Sample characteristics were described and path analysis was used to evaluate the hypothesized models.
CHAPTER IV
RESULTS

The purpose of this study was to examine the association between self-advocacy and its antecedents of trust in nurses and social support on and psychosocial distress and physical symptoms in patients with heart failure. Evidence shows that patient self-advocacy can be affected by relationships with others and that patient self-advocacy can affect HIV/AIDS, cancer, and mental health patient outcomes. There has been no documented literature studying how relationships affect self-advocacy and how that in turn affects outcomes in patients with HF. Therefore, the goal of this study was to investigate the following hypotheses in patients with HF:

H1: Social support and trust in nurses have a positive, direct effect on self-advocating behaviors.

H2: Self-advocating behaviors have a negative, direct effect on psychological distress.

H3: Self-advocating behaviors have a negative, direct effect on physical symptoms.

H4: Social support and trust in nurses have a negative, direct and indirect effect on psychological distress.

H5: Social support and trust in nurses have a negative, direct and indirect effect on physical symptoms.

H6: The proposed models fit the data well.
This study used a cross-sectional, path analysis design with a sample of 80 out-patient HF clinic patients from one Midwestern medical center. The five instruments used in this study were the Adapted PSAS (Brashers et al., 1999; Hermansen-Kobulnicky, 2008), HCRTrust–CN (Bova et al., 2012), MOS-SS (Sherbourne & Stewart, 1991), HADS (Zigmond & Snaith, 1983), SSQ-HF (Heo et al., 2015). Demographic variables collected were age, gender, ethnicity, education, employment, marital status, and income. Diagnosis-related variables collected were the NYHA classification, ACCF/AHA Stages, number of comorbidities, presence of obstructive sleep apnea (OSA), left ventricular ejection fraction (EF), the presence of diastolic and/or systolic heart dysfunction, and health-related support group participation.

Pre-Analysis of Data

Pre-analysis data cleaning and screening were performed using SPSS 24 software. Univariate and multivariate normality, linearity, and homoscedasticity were tested. Trust in nurses score was treated for its negative skew and leptokurtic distribution; there were no significant differences in comparative analyses. Therefore, the original data were used throughout. One outlier was identified using Mahalonobis Distance and analyses were performed with and without the outlier to compare. The investigator chose to include the outlier in all analyses. Path analysis was used to model and test the hypotheses. SPSS 24 AMOS software was used to analyze the model.

Sample Characteristics

The participants in this study were current patients of a nurse managed and staffed out-patient heart failure clinic. All participants met the inclusion criteria: HF for three
months and had at least two visits to the HF clinic in the year prior to completing the survey. None had documented dementia or sensory difficulties that would preclude them from participation. The investigator did offer to read and scribe for each patient to decrease the burden with 62.5% choosing to accept and 37.5% choosing to read and respond to the survey independently. Data from 80 participants were used for analysis. See Table 5 for a description of the demographic and diagnosis related sample characteristics.

Table 5

*Demographic and Diagnosis Related Sample Characteristics*

<table>
<thead>
<tr>
<th>Demographic/Diagnosis Related Characteristics</th>
<th>M</th>
<th>SD</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-25</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>25-49</td>
<td>9</td>
<td>11</td>
<td>9</td>
<td>11%</td>
</tr>
<tr>
<td>50-64</td>
<td>24</td>
<td>30</td>
<td>24</td>
<td>30%</td>
</tr>
<tr>
<td>65-79</td>
<td>26</td>
<td>33</td>
<td>26</td>
<td>33%</td>
</tr>
<tr>
<td>80+</td>
<td>20</td>
<td>25</td>
<td>20</td>
<td>25%</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>39</td>
<td>49</td>
<td>39</td>
<td>49.0%</td>
</tr>
<tr>
<td>Female</td>
<td>41</td>
<td>51</td>
<td>41</td>
<td>51.0%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>49</td>
<td>61</td>
<td>49</td>
<td>61%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>27</td>
<td>34</td>
<td>27</td>
<td>34%</td>
</tr>
<tr>
<td>American Indian</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td>4%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grades 1-8</td>
<td>5</td>
<td>6</td>
<td>5</td>
<td>6%</td>
</tr>
<tr>
<td>Grades 9-11</td>
<td>7</td>
<td>9</td>
<td>7</td>
<td>9%</td>
</tr>
<tr>
<td>Graduated High School</td>
<td>27</td>
<td>34</td>
<td>27</td>
<td>34%</td>
</tr>
<tr>
<td>1-3 years of College</td>
<td>27</td>
<td>34</td>
<td>27</td>
<td>34%</td>
</tr>
<tr>
<td>Demographic/Diagnosis Related Characteristics</td>
<td>$M$</td>
<td>$SD$</td>
<td>N</td>
<td>Percent</td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td>-----</td>
<td>------</td>
<td>-----</td>
<td>---------</td>
</tr>
<tr>
<td>4 years of College</td>
<td>4</td>
<td>7</td>
<td>7</td>
<td>7%</td>
</tr>
<tr>
<td>Graduate School</td>
<td>8</td>
<td>10</td>
<td>10</td>
<td>10%</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed for wages</td>
<td>11</td>
<td>14</td>
<td>14</td>
<td>14%</td>
</tr>
<tr>
<td>Self-employed</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>4%</td>
</tr>
<tr>
<td>Out of work for more than 1 year</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Out of work for less than 1 year</td>
<td>5</td>
<td>6</td>
<td>6</td>
<td>6%</td>
</tr>
<tr>
<td>Homemaker</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>4%</td>
</tr>
<tr>
<td>Retired</td>
<td>44</td>
<td>55</td>
<td>55</td>
<td>55%</td>
</tr>
<tr>
<td>Unable to Work</td>
<td>12</td>
<td>15</td>
<td>15</td>
<td>15%</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
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<td></td>
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<tr>
<td>Married</td>
<td>30</td>
<td>38</td>
<td>38</td>
<td>38%</td>
</tr>
<tr>
<td>Divorced</td>
<td>12</td>
<td>15</td>
<td>15</td>
<td>15%</td>
</tr>
<tr>
<td>Widowed</td>
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<td>16</td>
<td>16</td>
<td>16%</td>
</tr>
<tr>
<td>Separated</td>
<td>5</td>
<td>6</td>
<td>6</td>
<td>6%</td>
</tr>
<tr>
<td>Never been married</td>
<td>8</td>
<td>10</td>
<td>10</td>
<td>10%</td>
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<tr>
<td>Single</td>
<td>9</td>
<td>11</td>
<td>11</td>
<td>11%</td>
</tr>
<tr>
<td>A member of an unmarried couple</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>4%</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 10,000</td>
<td>18</td>
<td>23</td>
<td>23</td>
<td>23%</td>
</tr>
<tr>
<td>10,000-19,999</td>
<td>20</td>
<td>25</td>
<td>25</td>
<td>25%</td>
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<tr>
<td>20,000-29,999</td>
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<td>8</td>
<td>8</td>
<td>8%</td>
</tr>
<tr>
<td>30,000-39,999</td>
<td>10</td>
<td>12</td>
<td>12</td>
<td>12%</td>
</tr>
<tr>
<td>40,000-49,999</td>
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<td>5</td>
<td>5</td>
<td>5%</td>
</tr>
<tr>
<td>50,000-74,999</td>
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<td>9</td>
<td>9%</td>
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<tr>
<td>75,000-99,999</td>
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<td>8</td>
<td>8</td>
<td>8%</td>
</tr>
<tr>
<td>100,000-150,000</td>
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<td>3</td>
<td>3</td>
<td>3%</td>
</tr>
<tr>
<td>150,000+</td>
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<td>2</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Unknown</td>
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<td>5</td>
<td>5</td>
<td>5%</td>
</tr>
<tr>
<td>Attended support group</td>
<td>12</td>
<td>15</td>
<td>15</td>
<td>15%</td>
</tr>
<tr>
<td>Came alone to visit</td>
<td>56</td>
<td>70</td>
<td>70</td>
<td>70%</td>
</tr>
<tr>
<td>Brought someone to visit</td>
<td>24</td>
<td>30</td>
<td>30</td>
<td>30%</td>
</tr>
<tr>
<td>Total # visits to Clinic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-4</td>
<td>47</td>
<td>59</td>
<td>59</td>
<td>59%</td>
</tr>
<tr>
<td>5-7</td>
<td>20</td>
<td>25</td>
<td>25</td>
<td>25%</td>
</tr>
<tr>
<td>8-10</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>3%</td>
</tr>
<tr>
<td>&gt;11</td>
<td>10</td>
<td>13</td>
<td>13</td>
<td>13%</td>
</tr>
<tr>
<td>Number of Comorbidities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2</td>
<td>6</td>
<td>8</td>
<td>8</td>
<td>8%</td>
</tr>
<tr>
<td>3-5</td>
<td>28</td>
<td>35</td>
<td>35</td>
<td>35%</td>
</tr>
<tr>
<td>Demographic/Diagnosis Related Characteristics</td>
<td>M</td>
<td>SD</td>
<td>N</td>
<td>Percent</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-----</td>
<td>----</td>
<td>-----</td>
<td>---------</td>
</tr>
<tr>
<td>6-8</td>
<td>35</td>
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<td>35</td>
<td>44%</td>
</tr>
<tr>
<td>9-11</td>
<td>10</td>
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<td>12%</td>
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<tr>
<td>12-14</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Sleep Apnea</td>
<td>31</td>
<td></td>
<td>31</td>
<td>40%</td>
</tr>
<tr>
<td>Absence of Sleep Apnea</td>
<td>49</td>
<td></td>
<td>49</td>
<td>60%</td>
</tr>
<tr>
<td>Ejection Fraction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-20%</td>
<td>8</td>
<td></td>
<td>8</td>
<td>10%</td>
</tr>
<tr>
<td>20-30%</td>
<td>14</td>
<td></td>
<td>14</td>
<td>17%</td>
</tr>
<tr>
<td>30-40%</td>
<td>12</td>
<td></td>
<td>12</td>
<td>14%</td>
</tr>
<tr>
<td>40-50%</td>
<td>15</td>
<td></td>
<td>15</td>
<td>19%</td>
</tr>
<tr>
<td>50+%</td>
<td>31</td>
<td></td>
<td>31</td>
<td>40%</td>
</tr>
<tr>
<td>ACCF/AHA Functional Scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>B</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>C</td>
<td>78</td>
<td></td>
<td>78</td>
<td>98%</td>
</tr>
<tr>
<td>NYHA Functional Scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>II</td>
<td>70</td>
<td></td>
<td>70</td>
<td>88%</td>
</tr>
<tr>
<td>III</td>
<td>8</td>
<td></td>
<td>8</td>
<td>10%</td>
</tr>
<tr>
<td>IV</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Ventricular Dysfunction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systolic dysfunction</td>
<td>16</td>
<td></td>
<td>16</td>
<td>20%</td>
</tr>
<tr>
<td>Diastolic dysfunction</td>
<td>44</td>
<td></td>
<td>44</td>
<td>55%</td>
</tr>
<tr>
<td>Systolic and diastolic dysfunction</td>
<td>20</td>
<td></td>
<td>20</td>
<td>25%</td>
</tr>
</tbody>
</table>

**Descriptive Statistics of Study Variables**

The variable, patient self-advocacy, modeled as a predictor and outcome variable, is discussed first followed by the predictor variables, trust in nurses and social support. And lastly, the outcome variables, psychological distress and physical symptoms will be discussed. See summary of variable descriptives in Table 6.
Patient Self-Advocacy

The APSAS measured the level of self-advocacy that described a participant’s current behavior or behaviors they would practice if found necessary. The total mean score was 58 ($SD = 6.17$). The higher the score, the higher the propensity to self-advocate (Brashers et al, 1999). Means for subscales were 27.84 for knowledge, 19.60 for assertiveness, and 10.51 for mindful non-adherence or decision-making. The three subscales of the APSAS had Cronbach’s alphas that ranged from .66 to .75 and the full scale demonstrated an alpha of .74. See Table 6.

Table 6

Adapted Patient Self-Advocacy Descriptives

<table>
<thead>
<tr>
<th>Scale</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>(SD)</th>
<th>CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adapted Patient Self-Advocacy (16 items)</td>
<td>40</td>
<td>73</td>
<td>57.95</td>
<td>6.12</td>
<td>56.58-59.32</td>
</tr>
<tr>
<td>APSAS-K: Knowledge (7 items)</td>
<td>19</td>
<td>35</td>
<td>27.84</td>
<td>3.48</td>
<td>27.06-28.61</td>
</tr>
<tr>
<td>APSAS-A: Assertiveness (5 items)</td>
<td>12</td>
<td>25</td>
<td>19.60</td>
<td>2.66</td>
<td>19.00-20.19</td>
</tr>
<tr>
<td>APSAS-M: Mindful Non-Adherence (4 items)</td>
<td>5</td>
<td>17</td>
<td>10.51</td>
<td>2.88</td>
<td>9.87-11.15</td>
</tr>
</tbody>
</table>

Trust in Nurses

The NCRTrust–CN scale measured the level of trust a participant has in his or her nurses. The total mean score was 45.64 ($SD = 3.89$) with a minimum score of 24 and a maximum score of 52. The higher the score the higher the trust in clinic nurses the participant reports. The demonstrated Cronbach’s alpha was .87.
Social Support

The MOS-SS scale measured the amount and type of support participants felt they have. The total possible score ranged from 0–76. The total mean score was 57.66 \((SD = 15.25)\) with a minimum score of 10 and a maximum score of 76. The higher the score the more social support the participant reported they experienced. The demonstrated Cronbach’s alpha was .95.

Psychological Distress

The HADS measured the amount and type of psychological symptoms participants self-reported. The total mean score was 32.08 \((SD = 6.97)\). The higher the score, the higher the psychological distress. The mean score for the anxiety symptom subscale was 6.91 \((SD = 3.88)\). The mean score for the depressive symptom subscale was 5.77 \((SD = 3.83)\).

Table 7

*Hospital Anxiety and Depression Scale Descriptives*

<table>
<thead>
<tr>
<th>Scale</th>
<th>Min</th>
<th>Max</th>
<th>Mean (SD)</th>
<th>CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Anxiety and Depression Scale (16 items)</td>
<td>1</td>
<td>33</td>
<td>12.68</td>
<td>6.99</td>
</tr>
<tr>
<td>HADS-A: Anxiety (7 items)</td>
<td>0</td>
<td>16</td>
<td>6.91</td>
<td>3.88</td>
</tr>
<tr>
<td>HADS-D: Depression (7 items)</td>
<td>0</td>
<td>17</td>
<td>5.78</td>
<td>3.83</td>
</tr>
</tbody>
</table>
Physical Symptoms

The SSQ-HF was used to quantify the heart failure symptom status for participants. The higher the score, the more severe the symptoms. The total mean score was 32.08 ($SD = 18.61$) with a minimum score of 0 and a maximum score of 78. See summary of variable descriptives in Table 8.

Table 8

*Summary Variable Descriptives*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>(SD)</th>
<th>Score</th>
<th>Possible Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trust in nurses (14 items)</td>
<td>45.64</td>
<td>3.89</td>
<td>24-52</td>
<td>0-56</td>
</tr>
<tr>
<td>Social Support (19 items)</td>
<td>57.66</td>
<td>15.25</td>
<td>10-76</td>
<td>0-76</td>
</tr>
<tr>
<td>Self-Advocacy (16 items)</td>
<td>57.95</td>
<td>6.12</td>
<td>40-73</td>
<td>16-80</td>
</tr>
<tr>
<td>Knowledge (7 items)</td>
<td>27.84</td>
<td>3.48</td>
<td>19-35</td>
<td>7-35</td>
</tr>
<tr>
<td>Assertiveness (5 items)</td>
<td>19.60</td>
<td>2.66</td>
<td>12-25</td>
<td>5-25</td>
</tr>
<tr>
<td>Mindful Non-Adherence (4 items)</td>
<td>10.51</td>
<td>2.88</td>
<td>5-17</td>
<td>4-20</td>
</tr>
<tr>
<td>Psychological Distress (14 items)</td>
<td>12.68</td>
<td>6.99</td>
<td>1-33</td>
<td>0-42</td>
</tr>
<tr>
<td>Anxiety (7 items)</td>
<td>6.91</td>
<td>3.88</td>
<td>0-16</td>
<td>0-21</td>
</tr>
<tr>
<td>Depression (7 items)</td>
<td>5.78</td>
<td>3.83</td>
<td>0-17</td>
<td>0-21</td>
</tr>
<tr>
<td>Physical Symptoms (21 items)</td>
<td>32.08</td>
<td>18.61</td>
<td>0-78</td>
<td>0-84</td>
</tr>
</tbody>
</table>
Preliminary Data Evaluation

Path analysis is rooted in multiple regression; therefore, meeting the assumptions of multiple regression for this analysis is discussed. Missing data were imputed in pre-analysis therefore, there was no missing data for data analysis. Univariate normality, linearity, and homoscedasticity assumptions were met with one exception. Trust in nurses was negatively skewed and leptokurtic. A log10 transformation was applied (Grande, n.d.). Both transformed and non-transformed variables were used in the following tests of multivariate assumptions and there were no significant differences between the two; therefore, for ease of translation, the non-transformed variable was used throughout the rest of the analyses. The single outlier, as a result of a low trust score, was included in the analyses. Multivariate tests for normality, linearity, and homoscedasticity were met with the same exceptions as the univariate analysis. Non-transformed trust scores were used and the outlier was retained. Variables were assessed for multicollinearity. Patient self-advocacy, trust in nurses, and social support demonstrated bivariate correlation of $\leq .50$ and tolerances of $\geq .2$ (Mertler & Vannatta, 2017). Therefore, these independent variables are not multicollinear in nature.

Path Analysis

Total scores were transformed into standardized $z$ scores. Models were created, reflecting the hypothesized models, using SPSS and AMOS version 24. Model coefficients and fit indices were generated. Hypothesized model 1 had one significant path coefficient at the .001 level between social support and psychological distress. The covariance between trust and social support of .23 was significant at the .05 level. This
covariance was demonstrated in hypothesized model 2 as well although there were no significant path coefficients in the second hypothesized model. Both models were just-identified models; therefore, the chi-squared statistic is 0 related to 0 degrees of freedom. Model fit statistics for both models are estimated at 1.0 (CFI, IFI, NFI) due to the identification of the model. Figures 8 and 9 show the hypothesized models with standardized coefficients. Tables 9 and 10 show the hypothesized model estimates.

Figure 8. Hypothesized Model 1: Psychological Distress Path Coefficient Estimates and $R^2$ Estimates (in gray)

Figure 9. Hypothesized model 2: Physical Symptoms Path Coefficient Estimates and $R^2$ Estimates (in gray)
Table 9

*Hypothesized Model 1: Psychological Distress Estimates*

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Unstandardized Estimate</th>
<th>SE</th>
<th>CR</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Advocacy ←---- Trust in nurses</td>
<td>.022</td>
<td>.114</td>
<td>.195</td>
<td>.846</td>
</tr>
<tr>
<td>Self-Advocacy ←---- Social Support</td>
<td>.150</td>
<td>.114</td>
<td>1.312</td>
<td>.189</td>
</tr>
<tr>
<td>Psychological Distress ←---- Social Support</td>
<td>-.357</td>
<td>.019</td>
<td>-3.272</td>
<td>.001</td>
</tr>
<tr>
<td>Psychological Distress ←---- Self-Advocacy</td>
<td>.056</td>
<td>.106</td>
<td>.529</td>
<td>.597</td>
</tr>
<tr>
<td>Psychological Distress ←---- Trust in nurses</td>
<td>-.009</td>
<td>.108</td>
<td>-.084</td>
<td>.933</td>
</tr>
<tr>
<td>Trust in nurses ←-- Social Support</td>
<td>.228</td>
<td>.114</td>
<td>1.997</td>
<td>.046</td>
</tr>
</tbody>
</table>

*Note.* Chi –square = .000, df = 0
Table 10

_Hypothesized Model 2: Physical Symptoms Estimates_

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Unstandardized Estimate</th>
<th>SE</th>
<th>CR</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Advocacy</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust in nurses</td>
<td>.022</td>
<td>.114</td>
<td>.195</td>
<td>.846</td>
</tr>
<tr>
<td>Social Support</td>
<td>.150</td>
<td>.114</td>
<td>1.312</td>
<td>.189</td>
</tr>
<tr>
<td>Trust in nurses</td>
<td>-1.377</td>
<td>2.100</td>
<td>-.655</td>
<td>.512</td>
</tr>
<tr>
<td>Social Support</td>
<td>-2.407</td>
<td>2.122</td>
<td>-1.134</td>
<td>.257</td>
</tr>
<tr>
<td>Self-Advocacy</td>
<td>-2.311</td>
<td>2.068</td>
<td>-1.117</td>
<td>.264</td>
</tr>
<tr>
<td>Social Support</td>
<td>.228</td>
<td>.114</td>
<td>1.997</td>
<td>.046</td>
</tr>
</tbody>
</table>

_Note_. Chi –square = .000, df = 0

_Hypothesized Model Fit_

The hypothesized models were consistent with theory and evidence. Model 1 (psychological distress) had only one standardized regression coefficient or path coefficient and one covariance that met significance at the ≤ .05 level and model 2 (physical symptoms) had none. Therefore, the model fit, using Maximum Likelihood Estimation, of both models is poor or non-existent. “If the fit of the model is poor, then the model needs to be re-specified and the researcher returns to step 1” (Kenny, 2011). The model was respecified to reflect the empirical evidence presented in chapter 2. Patients with heart failure have experience in each of the three subscales of self-
advocacy: knowledge, assertiveness, and decision making. Therefore, the subscales were used to capture the parts of self-advocacy this sample of HF patients has reported. Depression, which evidence shows affects major outcome variables in HF, has been considered the outcome variable. Each of the self-advocacy subscales was independent with Cronbach alphas of .75, .70, and .66 respectively. Variable level data were analyzed for multivariate normality, linearity, homoscedasticity, and multicollinearity. Errors were found to be normally distributed as shown in Figure 10 as well as homoscedasticity of the data. The variances of the residuals were constant.

**Figure 10.** Scatterplot of Regression Residuals: HADS Depression, Trust in Nurses, Social Support, SA Knowledge, and SA Assertiveness
Linearity has been substantiated. See Figure 11. A scatterplot with IVs and DV shows elliptical shapes demonstrating normality and linearity. The normality of the trust data has been discussed and although skewed and leptokurtic has been retained in its raw form. Multicollinearity of dependent variables was dismissed based on the tolerance and VIF findings as seen in Table 11 (Mertler & Vannatta, 2017).

Figure 11. Scatter Plot: HADS Depression, Trust, Support, SA Knowledge, SA Assertiveness
Table 11

**Multicollinearity of Dependent Variables**

<table>
<thead>
<tr>
<th>Model</th>
<th>Correlations</th>
<th>Collinearity Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Zero-order</td>
<td>Partial</td>
</tr>
<tr>
<td>(Constant)</td>
<td>-.157</td>
<td>.045</td>
</tr>
<tr>
<td>Trust</td>
<td>-.398</td>
<td>-.379</td>
</tr>
<tr>
<td>Support</td>
<td>-.099</td>
<td>-.082</td>
</tr>
<tr>
<td>SA Knowledge</td>
<td>-.064</td>
<td>.064</td>
</tr>
<tr>
<td>SA Assertiveness</td>
<td>-.064</td>
<td>.064</td>
</tr>
</tbody>
</table>

A new model reflecting these underlying factors of self-advocacy was re-specified. See Figure 12. Identification was completed [6(6+1)/2-18 free parameters = 3df]. The model was over identified. Estimation with Maximum Likelihood Estimation was performed. See Figure 13. See Table 12 for model estimates. Because trust in nurses was leptokurtotic and the model was over identified Bollen Stine bootstrapping procedures were applied (Kline, 2016). The model as presented did meet significance (p .020) with bootstrapping procedures therefore the null, the model is correct, was rejected.
Figure 12. Respecified Model

Figure 13. Respecified Model with Path Coefficient Estimates and $R^2$ Estimates (in gray)
Table 12

**Re-Specified Model Estimates**

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Unstandardized Estimate</th>
<th>SE</th>
<th>CR</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>SA Knowledge ←---- Trust in nurses</td>
<td>.253</td>
<td>.112</td>
<td>2.262</td>
<td>.024</td>
</tr>
<tr>
<td>SA Assertiveness ←---- Trust in nurses</td>
<td>-.057</td>
<td>.112</td>
<td>-.512</td>
<td>.608</td>
</tr>
<tr>
<td>SA Mindful Non-Adherence ←---- Trust in nurses</td>
<td>-.205</td>
<td>.113</td>
<td>-1.812</td>
<td>.070</td>
</tr>
<tr>
<td>SA Knowledge ←---- Social Support</td>
<td>.003</td>
<td>.112</td>
<td>.030</td>
<td>.976</td>
</tr>
<tr>
<td>SA Assertiveness ←---- Social Support</td>
<td>.271</td>
<td>.112</td>
<td>2.432</td>
<td>.015</td>
</tr>
<tr>
<td>SA Mindfulness ←---- Social Support</td>
<td>.066</td>
<td>.113</td>
<td>.585</td>
<td>.558</td>
</tr>
<tr>
<td>Depressive Symptoms ←---- Social Support</td>
<td>-.399</td>
<td>.108</td>
<td>-3.695</td>
<td>≤.001</td>
</tr>
<tr>
<td>Depressive Symptoms ←---- Trust in nurses</td>
<td>-.012</td>
<td>.109</td>
<td>-.114</td>
<td>.909</td>
</tr>
<tr>
<td>Depressive Symptoms ←---- SA Knowledge</td>
<td>-.086</td>
<td>.104</td>
<td>-.819</td>
<td>.413</td>
</tr>
<tr>
<td>Depressive Symptoms ←---- SA Assertiveness</td>
<td>.021</td>
<td>.105</td>
<td>.205</td>
<td>.848</td>
</tr>
<tr>
<td>Depressive Symptoms ←---- SA Mindful Non-Adherence</td>
<td>.162</td>
<td>.103</td>
<td>1.574</td>
<td>.115</td>
</tr>
<tr>
<td>Trust in nurses ←---- Social Support</td>
<td>.228</td>
<td>.114</td>
<td>1.997</td>
<td>.046</td>
</tr>
</tbody>
</table>

Chi–square = .13.836, df = 3, p = .003

The respecified model was trimmed to reflect the data, keeping paths that met significance. See Figure 14. Trimmed model estimates show that each path maintains significance. See Table 13 for trimmed model estimates. Based on Bollen Stine
bootstrap procedures, the null hypothesis that the model is correct, was accepted ($p = .405$; Crowson, 2016). No further trimming was necessary. See Figure 15 for the trimmed model with path coefficients and $R^2$ estimates.

*Figure 14. Trimmed Model*
Table 13

Trimmed Model 2: Final Model Estimates

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Unstandardized Estimate</th>
<th>SE</th>
<th>CR</th>
<th>p</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>SA Knowledge</td>
<td>0.254</td>
<td>0.109</td>
<td>2.332</td>
<td>0.020</td>
<td>0.0638 (small)</td>
</tr>
<tr>
<td>Trust in nurses</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>SA Assertiveness</td>
<td>0.258</td>
<td>0.103</td>
<td>2.374</td>
<td>0.018</td>
<td>0.07527 (small)</td>
</tr>
<tr>
<td>Social Support</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Depressive Symptoms</td>
<td>-0.398</td>
<td>0.103</td>
<td>-3.857</td>
<td>≤0.001</td>
<td>0.19048 (medium)</td>
</tr>
<tr>
<td>Social Support</td>
<td>0.228</td>
<td>0.114</td>
<td>1.997</td>
<td>0.046</td>
<td>-</td>
</tr>
</tbody>
</table>

Note. Chi-square=9.452, df = 6, p = 0.150
* estimated using free statistics calculator (Soper, n.d.)

Figure 15. Trimmed Model with Path Coefficients and $R^2$ Estimates (in gray)
Respecified Trimmed Model Fit

Two model fit indices for small sample size studies (75–200 cases) are suggested by Kenny (2015). They include the chi square statistic and Root Mean Square Error of Approximation (RMSEA). If the chi square p value is >.05 the model is considered a good fit to the data. If RMSEA is < .10 the model can be said to “fit” the data although here are no absolute qualifiers for whether the fit is excellent, good, or mediocre (Kenny, 2015). The trimmed model had a chi-square value of 9.452 with 6 df and a p value = .105. The RMSEA was .085. For reporting completeness CFI = .877, IFI = .892, and NFI = .752. Effect sizes are reported in Table 13. The trimmed model fit the data.

Hypotheses Testing

The purpose of this study was to examine the impact of patient self-advocacy and its antecedents on psychological distress and physical symptoms in those with chronic heart failure. This was accomplished by examining the association between relationships with others and self-advocacy and how self-advocacy impacts psychological distress and physical symptoms. The following section discusses the outcome of hypotheses testing these associations.

H1: Social support and trust in nurses have a positive, direct effect on self-advocating behaviors. Social support had a positive, direct effect on the assertiveness aspect of patient self-advocacy. Trust in healthcare provider had a direct, positive effect on the knowledge aspect of self-advocacy.
H2: Self-advocating behaviors have a negative, direct effect on psychological distress. This study did not support the hypothesis that self-advocating behaviors have a negative, direct effect on psychological distress.

H3: Self-advocating behaviors have a negative, direct effect on physical symptoms. This study did not support the hypothesis that self-advocating behaviors have a negative, direct effect on physical symptoms.

H4: Social support and trust in nurses have a negative, direct and indirect effect on psychological distress. Social support was found to have a negative, direct effect on psychological distress. There is no evidence in this study that social support indirectly effects psychological distress through self-advocacy. Trust in nurse did not demonstrate having a negative direct, or indirect effect on psychological distress in this study.

H5: Social support and trust in nurses have a negative, direct and indirect effect on physical symptoms. This study did not support the hypothesis that social support and trust in healthcare provider did not have a negative, direct and indirect effect on physical symptoms.

H6: The proposed models fit the data well. This study did not support that the model fit the data well. Therefore, a new model was formed. The new model did fit the data well and did partially support H1 and H4.

Summary
This study used path modeling and analysis to test two models. A diverse sample of 80 patients with heart failure receiving care at an out-patient nurse managed HF clinic
participated in completing surveys testing the association between self-advocacy and its antecedents on psychological distress and physical symptoms. Data collected were cleaned and analyzed for normality, linearity, homoscedasticity, and multicollinearity. All data met parametric standards except trust in nurses. These data were negatively skewed and leptokurtic. A log10 transformation was applied and statistical tests were performed using both transformed and non-transformed data throughout data analysis. Differences were not significant; therefore, raw data were used for report. One outlier was retained.

Initial path analysis with hypothesized models did not demonstrate model fit as proposed. A new model was respecified, identified, estimated, and tested for fit. The trimmed model fit the data. Both trust in nurses and social support predict aspects of patient self-advocacy and social support is a predictor of psychological distress. Trust in nurses and social support were covariates. Trust in nurses and patient self-advocacy did not predict psychological distress or physical symptoms.
CHAPTER V
DISCUSSION

Heart failure is a chronic disease that has a 50%, 5-year mortality rate (Go et al., 2013). Patients see clinicians for heart failure related symptoms anywhere from 2–3 times a year to once a month or more (WebMD, 2015). HF is the most prevalent admitting diagnosis in people 65 and over (Go et al., 2013).

Having heart failure requires on-going adaptation and coping. Interactions with an array of health care providers is typical. The patient is commonly the only person involved throughout the process of care who is responsible for managing and organizing his or her care experiences. Therefore, self-management is key to maintaining health and integrity. Health promoting behaviors are a crucial part of self-management.

Maintaining control is a primary motivating consideration in self-management and health promotion (Pender et al., 2011; Riegel & Carlson, 2002). Self-advocacy is one tool used to maintain control and actively participate in the health care experience. Self-advocating involves gaining and using information, assertively communicating, and making decisions even when the decision goes against provider advice. Patients recognize that they need to self-advocate (Brashers et al., 1999; T. Christensen, 2010; Elder et al., 2008; Freddolino et al., 1988; Hagan & Donovan, 2013a, 2013b; Juhila, 2008). The HPM illustrates how interpersonal factors can influence health promoting behaviors (Pender, 2011). Evidence shows that trusting relationships with others influence patient self-advocacy (Hagan & Donovan, 2013a). According to Jonikas et al. (2011) self-advocacy
in the chronically ill can positively influence hopefulness while negatively influencing psychological distress.

Evidence shows that the personal factors of desire for control, preference for behavioral involvement, and desire for autonomy influence patient self-advocacy (Brashers et al., 1999). This study investigated interpersonal influences that might influence patient self-advocacy. Nurses contribute to patient interpersonal influences. The nursing profession has defined supporting patient self-determination as one of its fundamental goals. In an effort to understand how to help patients maintain a sense of control and personal integrity, there is a clear need to understand the contributors and outcomes of patient self-advocacy. There is a professional obligation to understand nursing’s role in patient self-advocacy. The aim of this study was to examine the predictive role of trust in nurses and social support on patient self-advocacy and the predictive role of self-advocacy on psychological distress and physical symptoms.

Eighty HF out-patient clinic patients were accessed for this study. Participants had HF for at least three months and had at least two clinic visits prior to taking part in this study. Just over half were women (51%), over 65 years old (59%), White (61%), retired (55%), with an ejection fraction of 40% or more (59%), and 6 or more comorbidities (57%). The majority were high school educated or above (85%), in class II of the NYHA functional class (88%) and stage C in the ACCF/AHA functional stage (98%). Close to half of the participants had incomes below $20,000 yearly (48%) and 42% were in committed relationships. Sleep apnea was documented in 40% of participants.
Data were collected using five survey instruments: the APSAS (Brashers et al., 1999; Hermansen-Kobulnicky, 2008), HCRT-trust–CN (Bova et al., 2012), MOS-SS (Sherbourne & Stewart, 1991), HADS (Zigmond & Snaith, 1983), SSQ-HF (Heo et al., 2015). The combined survey also included demographic questions used to describe the sample. This chapter provides a summary of findings, interpretation of findings, context of findings, implications of findings, study limitations, and future directions.

**Summary of Findings**

Two hypothesized models were tested for direct and indirect effects of trust in nurses and social support on patient self-advocacy and psychological distress and physical symptoms in patients with heart failure. One path showed effects that achieved statistical significance; social support influences psychological distress in patients with HF. Thirteen percent of the variation in psychological distress is related to social support ($\beta = .40, p = .001, R^2 = .13$). This relationship is supported by literature (Graven & Grant, 2013; Graven, Martorella, Gordon, Grant Keltner, & Higgens, 2017). That no other effects were shown was a curious result given the findings of previous research. A new model was formed that more closely aligned with the literature as it related to the components of self-advocacy in heart failure with depressive symptoms as the outcome. Each of these attributes of self-advocacy, knowledge, assertiveness, and the mindful non-adherence aspect of decision-making were investigated independently as predictors and outcomes. The results showed that trust in nurses predicted self-advocacy related knowledge ($\beta = .25, p = .05, R^2 = .06$) and social support predicted assertiveness ($\beta = .26, p = .05, R^2 = .07$). None of the three attributes of self-advocacy predicted depression or
physical symptoms. The mindful-nonadherence of decision making was removed from the model as it was not predicted by trust in nurses and social support and did not predict depression or physical symptoms. Also, as a result of respecification the variation explained by social support on depression was 16% ($\beta = -.40, p = .05, R^2 = .16$).

**Interpretation of Findings**

Self-advocacy is a complex phenomenon. The three components of self-advocacy are influenced by different predictors. This study found that high trust in nurses positively influences only the knowledge aspect of self-advocacy in the sample. Patients do rely on nurses to educate them about their illnesses (Garbacz et al., 2015; Ross, Ohlsson, Blomberg, & Gustafsson, 2015). Knowledge is integral to their assertiveness and decision making. When looking at the items that comprise the knowledge subscale (See Table 3) they use assertive language such as: “I actively seek out…,” “I have enough…,” “I think I am more educated…,” “I use the information…,” “I am more assertive….” The language of the items captures more than just patient knowledge acquisition and use. The items convey an assertive attitude about knowledge, a confidence in their knowledge. If the patient highly trusts his or her providers maybe he or she does not feel the need to be assertive; therefore, a relationship between high trust and assertiveness might not be detectable. Distrust has been measured in patients concerning distrust in physicians and health care systems (Gupta, Bell, Schildcrout, Goggins, & Kripalani, 2014). For the last 15 years the public, according to the Gallup Poll, have listed nursing the leading profession for ethics and honesty both of which are closely related to trust (Williamson, 2016). One of the difficulties in measuring trust in
nurses is that in most studies to date the results have been skewed toward highly positive scores (Bova et al., 2006, 2012). Without variation, it is difficult to know the full extent of the influence trust in nurses has on another phenomenon such as patient self-advocacy. Questions concerning low trust are essentially unanswerable. For example, does low trust or distrust in nurses have an impact on assertiveness or decision making of the mindful non-adherence type? This would make logical sense but if low trust is not experienced (in the aggregate) then these relationships are not measurable and not imperative to measure.

This study found that social support positively influences patient assertiveness in the study sample. Evidence shows that social support influences self-management behaviors in patients with heart failure (Graven & Grant, 2014; Riegel & Carlson, 2004). There is also evidence that social support impacts self-advocacy in patients with cancer (Hagan & Donovan, 2013a). According to Shahrbabaki, Nouhi, Kazemi, and Ahmadi (2016) adequate social support facilitates coping in patients with HF just as inadequate social support is a major hindrance to coping for patients with HF. This study shows that social support positively influences assertiveness in patients with HF. The higher the reported social support the higher the reported assertiveness of the patient. According to T. Christensen (2007, 2010), an author, advocate, and patient with a chronic illness from birth, she considers herself and her family as a unit. When writing about patient self-advocacy she considers herself and her family as the “self”-advocates on her behalf. This may be reflected in this study’s findings. Social support is comprised of positive social interaction, and support that is emotional, informational, tangible, and affectionate. If a
patient with heart failure has social support they have someone who is supporting his or her positive self-image (Towey, 2016). Social support itself is used as a coping mechanism that in turn enhances or promotes the use of other effective coping mechanisms (Ivarsson, Rådegranb, Hesselstrandc, & Kjellströmd, 2017). In a study conducted with hospitalized cardiac patients social support predicted health care system distrust and physician distrust (Gupta et al., 2014). This study showed a positive covariance between social support and trust in nurses.

Mindful non-adherence was not predicted by trust or social support in this sample. When looking at the items of the APSAS, the first subscale of knowledge suggests self-confidence about the knowledge the patient has. The assertiveness items seem to consider the interaction of patient with nurse. The mindful non-adherence items refer to interactions of patient against the advice of the nurse, that is, “sometimes I think I have a better grasp of what I need than my nurse does,” “sometimes there are good reasons not to follow the advice of a nurse,” “if I am given a medicine by my nurse that I don’t agree with I am likely not to take it,” “I don’t always choose to do what my nurse has asked me to do.” The mean of this subscale (10.51) was below the center of the possible total score (12); 66% had a score below 12. Something to consider with capturing mindful non-adherence is the potential for social desirability bias. Self-administered questionnaires are one way of combating social desirability bias. Another way of combating social desirability when performing structured interviews is to have a task-oriented interview (Nederhof, 1985). When the survey was read to the participants who requested such, all questions were read as written and all discussion was held until after the questionnaire
was completed. When comparing those who had the survey read to them and those that read it themselves, equal variances can be assumed (Levene’s test for equality of variances, \( F = .137, p = .712 \)). If we consider the scores of the mindful non-adherence subscale without the influence of social desirability the scores tell us that patients may be more assertive in acquiring and using knowledge and interacting with nurses but not as assertive when acting against nurses. It was surprising that there was not a negative relationship between trust in nurses and mindful non-adherence. Possibly with a larger sample size this relationship would be substantiated as this path in the current model had a p value of .07 (β=-.21).

**Context of Findings**

The intake visit at the recruiting HF clinic is scheduled for one and a half hours. That time is devoted to history and physical, patient education, and medication reconciliation. The nurses educate the patient concerning signs and symptoms of heart failure and their treatments, which includes medication education. They also spend a significant amount of time on the importance of dietary choices of which can have a tremendous impact on HF outcomes (M. L. Chung, Park, Frazier, & Lennie, 2017). They review the patient’s current dietary habits down to the brands of foods they eat and discuss the sodium content of those foods. They also teach and practice reading food labels and searching for sodium content of typical foods eaten out by the patient. The teaching is very individualized.

Having read the surveys and scribed for over half of the participants came with some unintended research benefits. One of them was that participants would talk to
themselves out loud about how to answer a question. The question, “I actively seek out information on heart failure” was a question many people talked to themselves about, questioning the word actively. For example, some participants said things like, “I don’t seek out information from other people or the library or anything, but I do ask a lot of questions when I’m here, that seems active.” It seemed like some participants got most or all their HF related information from the nurses at the HF clinic. The thoroughness of the teaching may be responsible for that. Also, if a patient had repeated visits to the HF clinic and had symptoms that could be attributed to diet, the nurses would recommend and schedule an appointment with the cardiac dietitian so that an even more individualized education plan could be created. It could be with the emphasis, amount, repetition, and individualization of patient education the HF clinic nurses provide, patients are empowered to be assertive about the knowledge they have.

The mean social support score was 57.66 with a standard deviation of 15.25. This represents participants reporting a very wide range of social support with an overall average that is in the top quarter of possible scores. Assertiveness subscale average was 19.60 ($SD = 2.66$), which was approaching the top quarter of possible scores. On average, participants experienced moderate to high social support and assertiveness. Support did not necessarily come in the form of a support person being present. The majority of patients came to their appointment alone (70%). The relationship between having support persons present and level of assertiveness is interesting to consider. Having a support person present did not predict assertiveness ($F = 2.916, p = .092$). Overall accessibility of social support was measured and not just support related to this
one clinic experience. According to this study’s results, social support does impact assertiveness, which means social support, whether physically present or not, impacts patient assertiveness. The HF clinic nurses contribute to the strengthening of patients’ social support systems by referring patients to cardiac rehabilitation. Eleven of the 12 patients who answered yes to the support group question were referring to cardiac rehabilitation. The HF clinic also offers a weekly “check-in” to monitor weight and vital signs for their patients. This provides another opportunity for interpersonal contact by the nurses.

**Implications of Findings**

The results of this study have implications to theory, research, and practice. The implications of research findings on the discipline of nursing is discussed.

**Theory**

The HPM is a comprehensive model that illustrates the personal and interpersonal motivators to the adoption of health promoting behaviors. The model was useful in bridging research evidence to behavior. Social support has been studied as an interpersonal influence that impacts health promoting self-management behaviors in HF (Graven & Grant, 2014). This relationship was corroborated by this study. This study considered relationships with health care providers as a predictor of establishing a health promoting behavior. Doing this expands the model to look at health promoting behaviors and their antecedents in a more holistic manner that attempts to capture what patients prioritize for their health and well-being. It also attempted to capture nursing’s role in promoting or inhibiting patient self-advocacy.
Considering self-advocacy as a health promoting behavior is innovative and timely. The National Academy of Medicine (NAM; IOM, 2001) has prioritized acknowledging the patient as the source of control, customizing care based on the values and needs of the patient, and placing a focus on healing relationships. By achieving these goals, it is hoped that the plan of care will be individualized to the patient. And as a result of shared communication and planning, the patient is more likely to adopt the behaviors that have been mutually crafted and thereby improve his or her health. On average, this sample of patients is receiving and using knowledge and are assertive in asking questions with their nurses and are sharing information with their nurses.

This study also relied on the existential advocacy theory to define relationships with provider as a potential antecedent to patient self-advocacy. The nurse-patient relationship influences self-advocacy knowledge, which is important in enabling the patient to advocate on their own behalf.

**Research**

Up until this point internally focused constructs such as desire for control, desire for autonomy, preference for behavioral involvement, and locus of control have been investigated as predictors of patient self-advocacy. This study investigated how things external to the patient may affect his or her level of self-advocacy. Investigating how relationships with nurses contribute to patient health and wellness is essential for disciplinary validation. This study shows that having a trusting relationship with nurses can have a positive impact on knowledge attainment and use related to patient self-
advocacy. The outcomes of patient self-advocacy need to be further defined and investigated.

**Practice**

Trust in nurses and social support both affected aspects of self-advocacy to a small degree. It is of use to know that trust in nurses can support patient confidence in knowledge attainment and use. In a study with older adults, Ruggiano, Whiteman, and Shtompel (2016) found that when older adults were self-assured in their knowledge and assertive communication skills they were more persistent in getting their needs met. Nurses need to continue their educational efforts not only for the substantial reason of affecting patient awareness and levels of knowledge for its own sake but also to help patients support their own voice so that they can get their needs met (Oermann, Harris, & Danmeyer, 2001; Ruggiano et al., 2016). Sharing knowledge with patients can therefore assist in helping patients be more participative in their health and healthcare. Assessing and encouraging social support is also of value in supporting the goal of increasing patient self-advocacy.

This study sample does represent the outpatient HF population at large (age, ethnicity, functional limitation); therefore, the findings are generalizable to other outpatient HF patients. These findings may also be generalizable to older chronically ill patients who are served by education intensive outpatient clinics.

**Study Limitations**

There were several limitations of this study. There are limitations inherent in the self-report method of data collection. Social desirability, acquiescent responding, and
extreme responding are all potential limitations of self-report surveys (Nederhof, 1985). The ways in which this study attempted to maintain internal validity regarding these potential limitations were: reading exactly what is written on the survey and withholding any discussion until after the survey was completed, having reverse scored scale items, and emphasizing the confidentiality of responses and survey results.

Sample size was a potentially limiting factor. Although theoretically adequate, the sample size was at the lower end of the range of acceptable. Outliers may have a large impact on small sample sizes (Tabachnick & Fidell, 2007). Analyses were completed with and without the one outlier, identified using Mahalanobis Distance and chi-square statistics, but there were no differences in results and so the outlier was retained. The outlier was also retained because it was a legitimate observation. The small sample size could have affected the significance or rather lack of significance in path coefficients and therefore, hypothesized model fit.

Based on the final model, patient self-advocacy could be considered a latent variable. Latent variables are constructs that are represented by a combination of observed variables (Schumacker & Lomax, 2016). The respecified final model with the three indicators of patient self-advocacy as observable variables is very similar to considering self-advocacy a latent variable. All indicators had disturbance terms associated with them as they would if considered part of a latent variable. But the model initially was not hypothesized using self-advocacy as a latent variable. Doing this would have clearly necessitated a larger sample size.
The APSAS had a full-scale reliability alpha coefficient of .74. The three subscales—knowledge, assertiveness, and mindful non-adherence—had alphas of .75, .70, .66 respectively. The reliability of these scales could be improved. To improve the scale more questions could be added and/or the scale could be modified to fit the HF population using results from qualitative data concerning self-advocacy in the HF population (Brown, 1997).

Self-advocacy is a complex phenomenon. This complexity would be served well with a mixed methods design. Collecting qualitative data that could clarify and enhance quantitative results would be advantageous in providing a more complete explanation and description of patient self-advocacy in patients with heart failure.

**Future Directions**

Self-advocacy in patients with HF needs to be investigated further. Qualitative research that will provide more context to the phenomenon within the HF population might help clarify these quantitative findings. A grounded theory study would help describe how patients conceptualize their self-advocacy efforts.

According to Heydari and Khorashadizadeh (2014), improving QOL has been identified by the WHO as a desirable outcome of health promoting behaviors. Adams (2010) found that patient education has a positive effect on QOL. Practicing successful coping mechanisms and health-promoting behaviors have been defined by HF patients as things that increase their QOL (Heo, Lennie, Okoli, & Moser, 2009). Ruggiano et al. (2016) reported on a study they completed with older adults concerning their experiences with self-determination and self-advocacy. The reason most participants gave for
needing to self-advocate was to improve their quality of life (QOL). If a decrease in QOL is what contributes to older adults self-advocating, and QOL is potentially affected by aspects of self-advocacy, QOL should be considered a measurable patient outcome of self-advocacy in the future. In a study by Naastrom, Jaarsma, Idvall, Aerstedt, and Stromberg (2014), the outcomes of patient participation in patients with HF receiving structured home care revealed that patient participation influenced self-care behavior. Patient participation was measured with scales pertaining to patient definition of involvement, health knowledge, question asking, and being treated with respect. Self-care was measured with the European Heart Failure Self-Care Behavior scale (EHFScB-9). Since self-advocacy is a participation behavior, self-care behavior might be a proximal outcome to measure in the future.

Different models guiding the investigation of patient self-advocacy could capture other predictors of self-advocating that may have more impact. Combining aspects of the HPM and The Health Belief Model (HBM) might be helpful in accomplishing this. The HPM includes internal and external motivating forces and the HBM includes perceived threats and cues to action. If conceptualizing self-advocacy as a coping mechanism, coping theory and stress models may more adequately depict potential factors that might influence patient self-advocacy.

Continuing to support patients in their efforts to participate through gaining and using knowledge, assertively communicating, and making decisions is important to obtain the goal of patient-centeredness. One aspect that needs investigating further is how encouraging patient participation and self-advocacy may affect different groups of
patients in different ways. Also, what does patient participation require? It calls for a desire, trust in nurses, social support, and many other things that still need to be identified.

**Summary**

Heart failure is a chronic disease that requires patients to interact with many aspects of the healthcare system and its providers. Self-advocacy is one way in which patients communicate their desires and needs to providers. Self-advocacy involves gaining and using knowledge, assertively communicating, and making decisions. Relationships with others impacts patient self-advocacy. Trust in nurses has a positive influence on the knowledge aspect of self-advocacy. Social support has a positive influence on the assertiveness aspect of self-advocacy. Social support also influences psychological distress in patients with HF.

By creating trusting relationships with patients, nurses facilitate patient acquisition and use of knowledge that is necessary for patient self-advocacy. Nurses can also recognize the importance of social support’s impact in patient self-advocacy by encouraging family and friend involvement so that patients can assertively communicate in order to get their needs met.

Patient self-advocacy has been conceptualized as a health-promoting behavior in this study. The understanding of self-advocacy for patients with heart failure could be strengthened by utilizing qualitative methods. Once conceptualized for this particular patient population, specific predictors and outcome measures can be identified and tested.
My goal as a nurse researcher is to find ways to relieve some of the burden of being a patient. This involves considering the role of the healthcare system, health care providers, and the patients themselves. What does each have to offer to relieve the burden and what does each have that stands in the way of relieving the burden. My work will be never done.
APPENDICES
APPENDIX A

PATIENT SELF-ADVOCACY SCALE (PSAS) ORIGINAL

AND ADAPTED ITEMS
Appendix A

Patient Self-Advocacy Scale (PSAS) Original and Adapted Items

<table>
<thead>
<tr>
<th>Original Items</th>
<th>Adapted Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe it is important for people [people with HIV or AIDS] to learn as much as they can about their illnesses and treatments.</td>
<td>I believe it is important for people [people with HF] to learn as much as they can about their illness and treatments.</td>
</tr>
<tr>
<td>I actively seek out information on my illnesses.</td>
<td>I actively seek out information on my illnesses.</td>
</tr>
<tr>
<td>I am more educated about my health problems of people like myself [people with HIV or AIDS].</td>
<td>I am more educated about my health problems of people like myself [people with HF].</td>
</tr>
<tr>
<td>I am more educated about my health than most citizens.</td>
<td>I am more educated about my health than most citizens.</td>
</tr>
<tr>
<td>I have full knowledge of the health problems of people like myself [people with HIV or AIDS].</td>
<td>I have full knowledge of the health problems of people like myself [people with HF].</td>
</tr>
<tr>
<td>I don’t get what I need from my physician because I am not assertive enough.</td>
<td>I don’t get what I need from my nurse because I am not assertive enough.</td>
</tr>
<tr>
<td>I am more assertive about my health care needs than most U.S. citizens.</td>
<td>I am more assertive about my health care needs than most U.S. citizens.</td>
</tr>
<tr>
<td>I frequently make suggestions to my physician about my health care needs.</td>
<td>I frequently make suggestions to my nurse about my health care needs.</td>
</tr>
<tr>
<td>If my physician prescribes something I don’t understand or agree with, I question it.</td>
<td>If my nurse asks me to do or take something I don’t agree with, I question it.</td>
</tr>
<tr>
<td>Sometimes there are good reasons not to follow the advice of a physician.</td>
<td>Sometimes there are good reasons not to follow the advice of the nurse.</td>
</tr>
<tr>
<td>Sometimes I think I have a better grasp of what I need medically than my doctor does.</td>
<td>Sometimes I think I have a better grasp of what I need than my nurse does.</td>
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<tr>
<td>If I am given a treatment by my physician that I don’t agree with, I am likely to not take it.</td>
<td>If I am given a medication by my nurse that I don’t agree with, I am likely to not take it.</td>
</tr>
<tr>
<td>I don’t always do what my physician or health care worker has asked me to do.</td>
<td>I don’t always do what my nurse has asked me to do.</td>
</tr>
<tr>
<td></td>
<td>I use the information I have learned about my illness when talking with my nurse.</td>
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<tr>
<td></td>
<td>Items added</td>
</tr>
<tr>
<td>I use the information I’ve learned about my illness when making decisions about my health.</td>
<td></td>
</tr>
<tr>
<td>I consider my overall needs, preferences, and responsibilities when making health care decisions.</td>
<td></td>
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<tr>
<td>I tell my nurse my needs, preferences, and responsibilities when discussing my plan of care.</td>
<td></td>
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<tr>
<td>I would ask to speak to a supervisor if not satisfied with my nurse care.</td>
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Appendix B

Participant Survey

**Demographic Questions**

Please check the box the best describes you.

<table>
<thead>
<tr>
<th>1) How old are you?</th>
<th>2) How do you describe yourself?</th>
<th>3) What is your gender?</th>
<th>4) What is the highest grade or year of school you completed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 18-24 years</td>
<td>Non-Hispanic White</td>
<td>1. Male</td>
<td>Never attended school</td>
</tr>
<tr>
<td>2. 25-49 years</td>
<td>Black or African American</td>
<td>2. Female</td>
<td>Grades 1 through 8</td>
</tr>
<tr>
<td>3. 50-64 years</td>
<td>Hispanic or Latino</td>
<td>3. Grades 9 through 11</td>
<td>Grade 12 or GED (high school graduate)</td>
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<tr>
<td>4. 65-79 years</td>
<td>Asian or Asian American</td>
<td>4. College 1-3 years</td>
<td>College 1-3 years (Some college or technical school)</td>
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<tr>
<td>5. 80+ years</td>
<td>Hawaiian or Other Pacific Islander</td>
<td>5. College 4 years</td>
<td>College 4 years (College graduate)</td>
</tr>
<tr>
<td>6. Would rather not say</td>
<td>American Indian or Alaska Native</td>
<td>6. Graduate school</td>
<td>Graduate school</td>
</tr>
<tr>
<td>7. Multiracial</td>
<td></td>
<td></td>
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<tr>
<td>8.</td>
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</tr>
</tbody>
</table>
5) What is your current employment status?

- 1 □ Employed for wages
- 2 □ Self-employed
- 3 □ Out of work for more than 1 year
- 4 □ Out of work for less than 1 year
- 5 □ A homemaker
- 6 □ A student
- 7 □ Retired
- 8 □ Unable to work

6) What is your current household income?

- 1 □ Under $10,000
- 2 □ $10,000-$19,999
- 3 □ $20,000-$29,999
- 4 □ $30,000-$39,999
- 5 □ $40,000-$49,999
- 6 □ $50,000-$74,999
- 7 □ $75,000-$99,999
- 8 □ $100,000-$150,000
- 9 □ Over $150,000

7) What is your marital status?

- 1 □ Married
- 2 □ Divorced
- 3 □ Widowed
- 4 □ Separated
- 5 □ Never been married
- 6 □ Single
- 7 □ A member of an unmarried couple

8) Have you attended any health-related support groups in the last year?

- 1 □ Yes
- 2 □ No

If yes, how many times did you attend in the last year?

__________
Adapted Patient Self-Advocacy Scale

Directions:

Circle the words that best describe your response.

1. I believe it is important for people with heart failure to learn as much as they can about their illnesses and treatments.
   Strongly disagree  Disagree  Undecided  Agree  Strongly agree

2. I actively seek out information on heart failure.
   Strongly disagree  Disagree  Undecided  Agree  Strongly agree

3. I have enough knowledge about the health problems that come from having heart failure.
   Strongly disagree  Disagree  Undecided  Agree  Strongly agree

4. I think I am more educated about my health than most US citizens.
   Strongly disagree  Disagree  Undecided  Agree  Strongly agree

5. I use the information I have learned about my illness when talking with my nurse.
   Strongly disagree  Disagree  Undecided  Agree  Strongly agree

6. I use the information I’ve learned about my illness when making decisions about my health.
   Strongly disagree  Disagree  Undecided  Agree  Strongly agree

7. I am more assertive about my health care needs than most US citizens.
   Strongly disagree  Disagree  Undecided  Agree  Strongly agree

8. If my nurse asks me to do or take something I don’t understand I ask questions.
   Strongly disagree  Disagree  Undecided  Agree  Strongly agree

9. I don’t get what I need from my nurse because I am not assertive enough.
   Strongly disagree  Disagree  Undecided  Agree  Strongly agree

10. I frequently make suggestions to my nurse about my health care needs.
    Strongly disagree  Disagree  Undecided  Agree  Strongly agree

11. If my nurse asks me to do or take something I don’t agree with, I question it.
12. I consider my overall needs, preferences, and responsibilities when making health care decisions.*

13. I tell my nurse my needs, preferences, and responsibilities when discussing my plan of care.*

14. Sometimes I think I have a better grasp of what I need than my nurse does.

15. Sometimes there are good reasons not to follow the advice of a nurse.

16. If I am given a medicine by my nurse that I don’t agree with, I am likely not to take it.

17. I don’t always choose to do what my nurse has asked me to do.

18. I would ask to speak to a supervisor if not satisfied with my nursing care.*
Health Care Relational Trust Scale: Trust in Clinic Nurses
Trust in your nurses involves having shared goals and mutual respect between you and your nurses.

Directions:
Read each statement and decide which response best describes how you feel about your nurses. Circle your response.

1. How often do your nurses discuss options and choices about your care with you?

None of the time  A little of the time  A moderate amount of the time  Most of the time  All of the time

2. My nurses are committed to providing the best care possible.

None of the time  A little of the time  A moderate amount of the time  Most of the time  All of the time

3. My nurses are sincerely interested in me as a person.

None of the time  A little of the time  A moderate amount of the time  Most of the time  All of the time

4. My nurses are excellent listeners.

None of the time  A little of the time  A moderate amount of the time  Most of the time  All of the time

5. My nurses accept me for who I am.

None of the time  A little of the time  A moderate amount of the time  Most of the time  All of the time

6. My nurses tell me the complete truth about my health-related problems.

None of the time  A little of the time  A moderate amount of the time  Most of the time  All of the time

7. My nurses treat me as an individual.

None of the time  A little of the time  A moderate amount of the time  Most of the time  All of the time

8. My nurses make me feel that I am worthy of their time and effort.

None of the time  A little of the time  A moderate amount of the time  Most of the time  All of the time

9. My nurses take the time to listen to me during each interaction.

None of the time  A little of the time  A moderate amount of the time  Most of the time  All of the time
10. I feel comfortable talking to my nurses about my personal issues.

<table>
<thead>
<tr>
<th>None</th>
<th>A little</th>
<th>A moderate</th>
<th>Most</th>
<th>All</th>
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<tr>
<td>of the time</td>
<td>of the time</td>
<td>amount of the time</td>
<td>of the time</td>
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11. I feel better after interacting with my nurses.

<table>
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<tr>
<th>None</th>
<th>A little</th>
<th>A moderate</th>
<th>Most</th>
<th>All</th>
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</thead>
<tbody>
<tr>
<td>of the time</td>
<td>of the time</td>
<td>amount of the time</td>
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12. How often do you think about asking for a new nurse?

<table>
<thead>
<tr>
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<th>A moderate</th>
<th>Most</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>of the time</td>
<td>of the time</td>
<td>amount of the time</td>
<td>of the time</td>
<td>of the time</td>
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</table>

13. How often do your nurses consider your need for privacy?

<table>
<thead>
<tr>
<th>None</th>
<th>A little</th>
<th>A moderate</th>
<th>Most</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>of the time</td>
<td>of the time</td>
<td>amount of the time</td>
<td>of the time</td>
<td>of the time</td>
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</tbody>
</table>
Medical Outcome Study-Social Support

People sometimes look to others for companionship, assistance or other types of support. How often is each of the following kinds of support available to you if you need it?

**Directions:**

Read each statement and decide which response best describes how often you experience the following kinds of support. Circle your answer.

1. **Someone you can count on to listen to you when you need to talk.**
   - None of the time
   - A little of the time
   - A moderate amount of the time
   - Most of the time
   - All of the time

2. **Someone to give you information to help you understand a situation.**
   - None of the time
   - A little of the time
   - A moderate amount of the time
   - Most of the time
   - All of the time

3. **Someone to give you good advice in a crisis.**
   - None of the time
   - A little of the time
   - A moderate amount of the time
   - Most of the time
   - All of the time

4. **Someone to confide in or talk to about yourself or your problems.**
   - None of the time
   - A little of the time
   - A moderate amount of the time
   - Most of the time
   - All of the time

5. **Someone whose advice you really want.**
   - None of the time
   - A little of the time
   - A moderate amount of the time
   - Most of the time
   - All of the time

6. **Someone to share your most private worries and fears with.**
   - None of the time
   - A little of the time
   - A moderate amount of the time
   - Most of the time
   - All of the time

7. **Someone to turn to for suggestions about how to deal with a personal problem.**
   - None of the time
   - A little of the time
   - A moderate amount of the time
   - Most of the time
   - All of the time

8. **Someone who understands your problems.**
   - None of the time
   - A little of the time
   - A moderate amount of the time
   - Most of the time
   - All of the time

9. **Someone to help you if you were confined to bed.**
   - None of the time
   - A little of the time
   - A moderate amount of the time
   - Most of the time
   - All of the time
10. **Someone to take you to the doctor if you needed it.**
   - None
   - A little
   - A moderate
   - Most
   - All
   - of the time
   - of the time
   - amount of the time
   - of the time
   - of the time

11. **Someone to prepare your meals if you were unable to do it yourself.**
   - None
   - A little
   - A moderate
   - Most
   - All
   - of the time
   - of the time
   - amount of the time
   - of the time
   - of the time

12. **Someone to help with daily chores if you were sick.**
   - None
   - A little
   - A moderate
   - Most
   - All
   - of the time
   - of the time
   - amount of the time
   - of the time
   - of the time

13. **Someone who shows you love and affection.**
   - None
   - A little
   - A moderate
   - Most
   - All
   - of the time
   - of the time
   - amount of the time
   - of the time
   - of the time

14. **Someone to love and make you feel wanted.**
   - None
   - A little
   - A moderate
   - Most
   - All
   - of the time
   - of the time
   - amount of the time
   - of the time
   - of the time

15. **Someone who hugs you.**
   - None
   - A little
   - A moderate
   - Most
   - All
   - of the time
   - of the time
   - amount of the time
   - of the time
   - of the time

16. **Someone to have a good time with.**
   - None
   - A little
   - A moderate
   - Most
   - All
   - of the time
   - of the time
   - amount of the time
   - of the time
   - of the time

17. **Someone to get together with for relaxation.**
   - None
   - A little
   - A moderate
   - Most
   - All
   - of the time
   - of the time
   - amount of the time
   - of the time
   - of the time

18. **Someone to do something enjoyable with.**
   - None
   - A little
   - A moderate
   - Most
   - All
   - of the time
   - of the time
   - amount of the time
   - of the time
   - of the time

19. **Someone to do things with to help you get your mind off things.**
   - None
   - A little
   - A moderate
   - Most
   - All
   - of the time
   - of the time
   - amount of the time
   - of the time
   - of the time
Hospital Anxiety and Depression Scale (HADS)

Directions:
Circle the words that are the closest to how you have been feeling in the past week. Don’t take too long over your replies: your immediate is best.

1. I feel tense or ‘wound up’:
   - most of the time
   - a lot of the time
   - from time to time, occasionally
   - not at all

2. I still enjoy the things I used to enjoy:
   - definitely as much
   - not quite so much
   - only a little
   - hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:
   - very definitely and quite badly
   - yes, but not too badly
   - a little, but it doesn’t worry me
   - not at all

4. I can laugh and see the funny side of things:
   - as much as I always could
   - not quite so much now
   - definitely not so much now
   - not at all

5. Worrying thoughts go through my mind:
   - a great deal of the time
   - a lot of the time
   - from time to time, but not too often
   - only occasionally

6. I feel cheerful:
   - not at all
   - not often
   - sometimes
   - most of the time
7. I can sit at ease and feel relaxed:
   Definitely
   Usually
   not often
   not at all

8. I feel as if I am slowed down:
   nearly all the time
   very often
   sometimes
   not at all

9. I get a sort of frightened feeling like ‘butterflies’ in the stomach:
   not at all
   occasionally
   quite often
   very often

10. I have lost interest in my appearance:
    Definitely
    I don’t take as much care as I should
    I may not take quite as much care
    I take just as much care as ever

11. I feel restless as I have to be on the move:
    very much indeed
    quite a lot
    not very much
    not at all

12. I look forward with enjoyment to things:
    as much as I ever did
    rather less than I used to
    definitely less than I used to
    hardly at all

13. I get sudden feelings of panic:
    very often indeed
    quite often
    not very often
    not at all
14. I can enjoy a good book or radio or TV program:
   Often
   Sometimes
   not often
   very seldom
Symptom Status Questionnaire

Instructions: Please read each of the statements carefully, and then circle the number that best describes your condition or how much you were bothered by these symptoms during past 4 weeks.

1. Did you have shortness of breath during day time?
   - 0. No (If your answer is no—please go to question 2)
   - 1. Yes (If your answer is yes—please fill out 1a, 1b, 1c)
     - 1a. How often?
       - 1) Less than once per week
       - 2) 1-2 times per week
       - 3) 3-5 times per week
       - 4) Nearly daily per week
     - 1b. How severe?
       - 1) Slight
       - 2) Moderate
       - 3) Severe
       - 4) Very severe
     - 1c. How much did it distress or bother you?
       - 0) Not at all
       - 1) A little bit
       - 2) Somewhat
       - 3) Quite a bit
       - 4) Very much

2. Did you have shortness of breath when you lay down?
   - 0. No (If your answer is no—please go to question 3)
   - 1. Yes (If your answer is yes—please fill out 2a, 2b, 2c)
     - 2a. How often?
       - 1) Less than once per week
       - 2) 1-2 times per week
       - 3) 3-5 times per week
       - 4) Nearly daily per week
     - 2b. How severe?
       - 1) Slight
       - 2) Moderate
       - 3) Severe
       - 4) Very severe
     - 2c. How much did it distress or bother you?
       - 0) Not at all
       - 1) A little bit
       - 2) Somewhat
       - 3) Quite a bit
       - 4) Very much
3. Did you have fatigue or lack of energy?
   0. No (If your answer is no—please go to question 4)
   1. Yes (If your answer is yes—please fill out 3a, 3b, 3c)
      → 3a. How often?
         1) Less than once  2) 1-2 times per week  3) 3-5 times per week  4) Nearly daily
         → 3b. How severe?
         1) Slight  2) Moderate  3) Severe  4) Very severe
      → 3c. How much did it distress or bother you?
         0) Not at all  1) A little bit  2) Somewhat  3) Quite a bit  4) Very much

4. Did you have chest pain?
   0. No (If your answer is no—please go to question 5)
   1. Yes (If your answer is yes—please fill out 4a, 4b, 4c)
      → 4a. How often?
         1) Less than once  2) 1-2 times per week  3) 3-5 times per week  4) Nearly daily
         → 4b. How severe?
         1) Slight  2) Moderate  3) Severe  4) Very severe
      → 4c. How much did it distress or bother you?
         0) Not at all  1) A little bit  2) Somewhat  3) Quite a bit  4) Very much
5. Did you have leg or ankle swelling?

0. No (If your answer is no—please go to question 6)

1. Yes (If your answer is yes—please fill out 5a, 5b, 5c)

   5a. How often?
   1) Less than once  2) 1-2 times per week  3) 3-5 times per week  4) Nearly daily

   5b. How severe?
   1) Slight  2) Moderate  3) Severe  4) Very severe

   5c. How much did it distress or bother you?
   0) Not at all  1) A little bit  2) Somewhat  3) Quite a bit  4) Very much

6. Did you have difficulty sleeping at night?

0. No (If your answer is no—please go to question 7)

1. Yes (If your answer is yes—please fill out 6a, 6b, 6c)

   6a. How often?
   1) Less than once  2) 1-2 times per week  3) 3-5 times per week  4) Nearly daily

   6b. How severe?
   1) Slight  2) Moderate  3) Severe  4) Very severe

   6c. How much did it distress or bother you?
   0) Not at all  1) A little bit  2) Somewhat  3) Quite a bit  4) Very much

7. Did you have dizziness or loss of balance?

0. No (If your answer is no—please go to question 8)

1. Yes (If your answer is yes—please fill out 7a, 7b, 7c)

   7a. How often?
   1) Less than once  2) 1-2 times per week  3) 3-5 times per week  4) Nearly daily

   7b. How severe?
   1) Slight  2) Moderate  3) Severe  4) Very severe

   7c. How much did it distress or bother you?
   0) Not at all  1) A little bit  2) Somewhat  3) Quite a bit  4) Very much

Thank you.
APPENDIX C

HEALTH CARE RELATIONAL TRUST SCALE ORIGINAL
AND ADAPTED ITEMS
### Appendix C

#### Health Care Relational Trust Scale Original and Adapted Items

<table>
<thead>
<tr>
<th>Original Items</th>
<th>Adapted Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often does your health care provider discuss options and choices with you before health care decisions are made?</td>
<td>How often do your nurses discuss options and choices about our care with you?</td>
</tr>
<tr>
<td>My health care provider is committed to providing the best care possible.</td>
<td>My nurses are committed to providing the best care possible.</td>
</tr>
<tr>
<td>My health care provider is sincerely interested in me as a person.</td>
<td>My nurses are sincerely interested in me as a person.</td>
</tr>
<tr>
<td>My health care provider is an excellent listener.</td>
<td>My nurses are excellent listeners.</td>
</tr>
<tr>
<td>My health care provider accepts me for who I am.</td>
<td>My nurses accept me for who I am.</td>
</tr>
<tr>
<td>My health care provider tells me the complete truth about my health-related problems.</td>
<td>My nurses tell me the complete truth about my health-related problems.</td>
</tr>
<tr>
<td>My health care provider treats me as an individual.</td>
<td>My nurses treat me as an individual.</td>
</tr>
<tr>
<td>My health care provider makes me feel that I am worthy of his/her time and effort.</td>
<td>My nurses make me feel that I am worthy of their time and effort.</td>
</tr>
<tr>
<td>My health care provider takes the time to listen to me during each appointment.</td>
<td>My nurses take the time to listen to me during each interaction.</td>
</tr>
<tr>
<td>I feel comfortable talking to my health care provider about my personal issues.</td>
<td>I feel comfortable talking to my nurses about my personal issues.</td>
</tr>
<tr>
<td>I feel better after seeing my health care provider.</td>
<td>I feel better after seeing my nurses.</td>
</tr>
<tr>
<td>How often do you think about changing to a new health care provider?</td>
<td>How often do you think about asking for a new nurse?</td>
</tr>
<tr>
<td>How often does your health care provider consider your need for privacy?</td>
<td>How often does your nurses consider your need for privacy?</td>
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APPENDIX D

DIAGNOSIS RELATED INFORMATION DATA SHEET
## Diagnosis Related Information Data Sheet

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<tr>
<th>Code</th>
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<td>Obesity</td>
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<tr>
<td>2</td>
<td>PTCA/stent</td>
<td>Dyslipidemia</td>
</tr>
<tr>
<td>3</td>
<td>CABG</td>
<td>Family History</td>
</tr>
<tr>
<td>4</td>
<td>Valve Disease</td>
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</tr>
<tr>
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<td>Arrhythmia</td>
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<tr>
<td>6</td>
<td>HTN</td>
<td>LVEF</td>
</tr>
<tr>
<td>7</td>
<td>Rheumatic Heart Disease</td>
<td>ACC/AHA Stage</td>
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<td>Cancer</td>
<td>NYHA Class</td>
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<td>Alcohol</td>
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</table>
APPENDIX E

AGMC IRB APPROVAL
Appendix E

AGMC IRB Approval

Carolyn Kleman, PhDc, MHA, BSN, RN
1303 Autumn Lane
Akron, Ohio 44333

Dear Ms. Kleman:

RE: 16028 Social support, healthcare relational trust, and self-advocating behaviors as predictors of psychological distress and physical symptoms among patients with chronic heart failure: A mixed methods study

The Institutional Research Review Board at Akron General Medical Center has determined that the above study meets the requirements for expedited review. The IRB has followed the requirements of the Common Rule for the expedited review procedures. A member of the committee reviewed the above research protocol. The protocol, Recruitment Letter, Demographic Questionnaire, Adapted Patient Self-Advocacy Scale, Health Care Relational Trust Scale: Trust in Clinic Nurses, Medical Outcome Study-Social Support, Hospital Anxiety and Depression Scale, Symptom Status Questionnaire, Qualitative Strand (Interview) revised informed consent form, Version 3 dated August 16, 2016, and the Quantitative Strand (Survey) revised informed consent form, Version 3 dated August 16, 2016, have been granted expedited approval on August 22, 2016.

You are now approved to begin this study at Akron General Medical Center. This approval is for one year and expires on August 21, 2017.

HHS regulations and Institutional Research Review Board guidelines require that any changes in research methodology, protocol design or principal investigator have the approval of the IRB before implementation and continuation of the protocol. You must promptly report any protocol violations and any serious adverse events that occur in your study subjects during the study or within 30 days of completion of the study, even if the event was not considered to be related to study participation. The IRB further requests an annual progress report and a final report at the conclusion of the study.

If this study uses a consent form, the IRB approved consent form with the approval stamp and date on it is THE ONLY consent form that is to be used to consent patients. This form must
have the required signatures and times on it, a copy given to each subject, a copy scanned into the
subjects' medical record, and a copy in the research study file. You must also document in the
progress notes that the subject was enrolled in a research study.

If you have any questions concerning this approval, please call the IRRB office at 330-344-6947.

Sincerely,

Kalisha Washington
Kalisha Roper-Washington, MA, CCRP
IRRB Coordinator
Assurance #FWA00001299 (Expires 11/12/2018)

/dp

cc: Kimberly Kerr, MSN
APPENDIX F

KENT STATE UNIVERSITY IRB APPROVAL
Appendix F

Kent State University IRB Approval

Kent State University Mail - RE: IRB application #16-527

RE: IRB application #16-527
1 message

Tue, Sep 6, 2016 at 2:28 PM

RAGS Research Compliance <researchcompliance@kent.edu> To: "cklemann@kent.edu" <cklemann@kent.edu> Cc: "Kalisha.washington@akrongeneral.org" <Kalisha.washington@akrongeneral.org>

RE: IRB application #16-527 – “Social Support, Healthcare Relational Trust, and Self-Advocating Behaviors as Predictors of Psychological Distress and Physical Symptoms Among Patients with Chronic Heart Failure: A Mixed Methods Study”

Kent State University accepts the review and continuing oversight of the human subject research listed above in conjunction with the Akron General Medical Center.

In accordance with the Institutional Review Board Authorization Agreement approved by Kent State University IRB (FWA0001853) and Akron General Medical Center (FWA0001299), the review performed by Akron General Medical Center’s institutional review board meets the requirements of Kent State University’s Office for Human Research Protections (OHRP)-approved Federalwide Assurance.

Kent State University remains responsible for ensuring compliance with the IRB’s determinations and with the Terms of its OHRP-approved FWA. Relevant minutes of the Akron General Medical Center IRB meetings will be made available to Kent State University’s IRB upon request.

United States Department of Health and Human Services (HHS) regulations require that any changes in research methodology, protocol design, or principal investigator have the prior approval of the designated IRB before implementation and continuation of the protocol.

Please keep the following procedures in mind both the Akron General Medical Center IRB and Kent State University IRB must be informed of any adverse events associated with the study.

If you have any questions or concerns regarding this agreement, please contact me at 330-672-2704 or Pwashko@kent.edu

Kent State University Office of Research Compliance
224 Cartwright Hall | Fax 330.672.2658

Doug Delahanty | IRB Chair | 330.672.2395 | ddelahanty@kent.edu
Tricia Sloan | Coordinator | 330.672.2181 | psloan1@kent.edu
Kevin McCreary | Assistant Director | 330.672.8058 | kmccrea1@kent.edu
Paulette Washko | Director | 330.672.2704 | pwashko@kent.edu

https://mail.google.com/mail/u/1?ui=2&ik=80a4b51008&view=pt&gmm=%20application%3D%20true&search=0q09hI=15700c1d0ed2e3e3&imh=15700c1d0ed2e3e3
APPENDIX G

CONSENT FORM
Appendix G

Consent Form

Quantitative Strand (Survey) Consent Form

AKRON GENERAL MEDICAL CENTER

Consent to Participate in Research, 03.28.19

Social support, healthcare relational trust, and self-advocating behaviors as predictors of psychological distress and physical symptoms among patients with chronic heart failure: A mixed methods study

Principal Investigator: Carolyn Kleman, Ph.D.

Introduction to Research at Akron General Medical Center

Doctors, nurses, and medical researchers at Akron General Medical Center want to know more about the nature of disease and how to improve the lives of patients and their families. One way to learn more about diseases and their treatment is by asking patients to take part in research studies like this one. You are being invited to participate in this research study. Before you agree to take part though, you need to know what to expect. Please take your time and read the information in this document carefully to understand what risks might be involved, what benefits you might gain, and your rights as a research participant. Ask questions about anything that is unclear to you. If you decide to participate, you will be given a copy of this consent form to keep for your records.

Information about this Study

Why am I being asked to participate?

You are being asked to participate in this study because you have had the diagnosis of heart failure for at least 3 months and have visited the AGMC Heart Failure Clinic at least twice in the last year.
How many people are going to participate in this study?

About 75 other people are going to take part in this study at Akron General Heart Failure Clinic.

Who is doing this study?

The study is being led by Carolyn Kleman from Kent State College of Nursing, and will be carried out with the assistance from AGMC staff members Kimberly Kerr and Teresa Hodgkiss. This research team will work with you at The AGMC Heart Failure Clinic, and other locations if more convenient to you.

Who can be in this study?

Participants in this study are individuals who have been diagnosed with heart failure for at least 3 months and who have had at least visits to the AGMC Heart Failure Clinic in the last year. Individuals must be able to speak and read English to participate in this study.

What is the purpose of this study? What are the investigators trying to find out?

We are trying to find out if relationships with other people, including your nurses, affect your ability to speak-up (advocate) for yourself in healthcare interactions. And how speaking-up for yourself affects your health.

Information about your Role as a Study Participant

What will I have to do?

You will fill out a survey that asks questions about the support you get from others, your trust in the clinic nurses, your experience speaking-up for yourself, and your current health symptoms. The survey contains 79 questions. You will circle one answer per question. The researcher will stay with you to physically assist in filling out the form if needed.

How long will I be part of this study?

The survey will take approximately 30–45 minutes to complete.
Information about the Possible Risks of Participating in the Study

There are no anticipated risks related to this study. You will be answering survey questions.

Information about the Possible Benefits of Participating in this Study

There may not be any direct benefit to you for participating in this study. The study may benefit future patients because nurses will have greater knowledge about positive ways to support the advocacy efforts of patients.

What if I Decide not to Participate?

Participation in this study is voluntary. If you do not wish to participate in the study, you will still receive the standard therapy used by your nurses and physicians in the treatment of your disease or condition. There will be no changes in your care based on your decision.

Can I Stop Taking Part in the Study Once I have Enrolled?

You may withdraw from the study at any time, without any penalty to you.

Confidentiality of Personal Information

*How will my personal information be kept confidential?*

Your personal information will be password protected and will be kept locked in the Investigators office during the study.

If the Principal Investigator decides to report study results in research articles or scientific presentations, no individual information about you will be revealed. The information collected about all of the study participants is grouped together without any way of identifying individuals from within that group.

*Who will know that I am participating in this study?*

Every effort will be made to protect your privacy and maintain the confidentiality of your medical records and survey responses during this study. From time to time, though, it might be necessary for certain people to check parts of your medical
record to make sure that the study data are complete. Whenever such checks are made, only study data is recorded, not any personal or unrelated medical information about you. The only people who may have access to your study data are the lead investigator, study staff, and Akron General Institution Research Review Board staff (the committee that oversees research involving human subjects).

Will I be Paid to take part in this Study?

You will be offered a $25.00 Target™ gift card for your participation.

Your Rights as a Participant in this Research Study

Anyone who volunteers to participate in a research study is entitled to certain protections under federal law. The law requires that you be given enough information to decide if you want to participate in the study, that risks and benefits are explained to you and that any risks that may exist be minimized. This law, requires that your participation be voluntary, without force or pressure to take part, and that you have the right to leave the study at any time without penalty.

For questions regarding participation in this research study, including the risks and benefits involved, you may contact the Principal Investigator, Carolyn Kleman at 330-338-7894. If any questions, concerns, or complaints arise about the study in the future, you may also contact the above.

If you have questions or concerns about your rights as a research participant, you may call the Akron General Medical Center Institutional Research Review Board at 330-344-6947. The Institutional Research Review Board is responsible for making sure that all human subjects’ research at Akron General Medical Center is conducted in compliance with federal regulations.

Please understand that by signing this consent form you do not give up any of your legal rights. Your signature indicates that you have been informed about the research study and that you are agreeing to participate. A copy of this signed consent form will be provided to you for your records.
Informed Consent Statement

I have read this informed consent or had it read to me and my questions have been answered. I agree to take part in this research study.

________________________________________
Subject or Authorized Representative Signature

________________________________________
Printed name of Subject or Authorized Representative

________________________________________
Signature of Person Obtaining Consent Date and Time

________________________________________
Printed name of Person Obtaining Consent

________________________________________
Signature of Witness (if applicable) Date and Time

________________________________________
Printed name of Witness (if applicable)

If you would like a summary of study results mailed to you, please check yes.

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APPENDIX H

RECRUITMENT LETTER
Appendix H

Recruitment Letter

Date:

Dear ____________________________,

My name is Carolyn Kleman and I am a student at Kent State University working on a Doctor of Philosophy degree in Nursing. As a nursing professional I am interested in how relationships with others affect the person with heart failure’s ability to speak-up or self-advocate and how speaking-up affects emotional and physical health. You are eligible for this study because you have had the diagnosis of heart failure for at least three months and have visited the AGMC Heart Failure Clinic at least twice in the last year. The study will assess if the relationships you have with family, friends, and nurses affect your ability to speak-up for yourself and assertively communicate your needs to your nurses. It will also look to see if there is a relationship between speaking-up for yourself and your emotional and physical health.

There are two phases of this study. The first involves a 79 question survey which will take approximately 30-45 minutes to complete. After completing the survey, a few participants will be asked if they would like to participate in the second phase of the study, which involves a face to face interview and will take approximately 45 minutes to one hour and 15 minutes. The second phase of the study can be completed at another time agreed upon time if necessary.

You will be offered a $25 dollar Target™ gift card for participating in phase one of the study. If you are asked and choose to participate in phase two of the study you will be offered another $25 dollar Target™ gift card.

Your participation is confidential and voluntary and you can decline to answer any questions. You can withdraw your consent and/or discontinue participation at any time without penalty.

If you have any questions or concerns about the research, please feel free to contact me Carolyn Kleman (phone) 330-338-7894 (e-mail) ckleman@kent.edu, College of Nursing, Kent State University, 800 East Summit Street, P.O. Box 5190, Kent, Ohio 44242.

This study #16028 has been approved by the Akron General Research Board on August 23, 2016.

Sincerely,
Carolyn Kleman

Please fill in the following information and circle your preferred method of contact:

Name______________________________

Phone____________________________

E-mail____________________________

By filling in the above information you are agreeing to be contacted for potential participation in this study. Thank you.
REFERENCES
REFERENCES


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