

Feasibility Study of the Health Empowerment Intervention to Evaluate the Effect on Self-  
Management, Functional Health, and Well-Being in Older Adults with Heart Failure

by

Ramesh Devi Thakur

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Graduate Supervisory Committee:

Julie Fleury, Chair  
Nelma Shearer  
Michael Belyea

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## ABSTRACT

The population of older adults in the United States is growing disproportionately, with corresponding medical, social and economic implications. The number of Americans 65 years and older constitutes 13.7% of the U.S. population, and is expected to grow to 21% by 2040. As the adults age, they are at risk for developing chronic illness and disability. According to the Centers for Disease Control and Prevention, 5.7 million Americans have heart failure, and almost 80% of these are 65 years and older. The prevalence of heart failure will increase with the increase in aging population, thus increasing the costs associated with heart failure from 34.7 billion dollars in 2010 to 77.7 billion dollars by 2020. Of all cardiovascular hospitalizations, 28.9% are due to heart failure, and almost 60,000 deaths are accounted for heart failure. Marked disparities in heart failure persist within and between population subgroups. Living with heart failure is challenging for older adults, because being a chronic condition, the responsibility of day to day management of heart failure principally rests with patient. Approaches to improve self-management are targeted at adherence, compliance, and physiologic variables, little attention has been paid to personal and social contextual resources of older adults, crucial for decision making, and purposeful participation in goal attainment, representing a critical area for intervention. Several strategies based on empowerment perspective are focused on outcomes; paying less attention to the process. To address these gaps between research and practice, this feasibility study was guided by a tested theory, the Theory of Health Empowerment, to optimize self-management, functional health and well-being in older adults with heart failure. The study sample included older adults with heart failure attending senior centers. Specific aims of this feasibility study were to: (a) examine the

feasibility of the Health Empowerment Intervention in older adults with heart failure, (b) evaluate the effect of the Health Empowerment Intervention on self-management, functional health and well-being among older adults with heart failure. The Health Empowerment Intervention was delivered focusing on strategies to identify and building upon self-capacity, and supportive social network, informed decision making and goal setting, and purposefully participating in the attainment of personal health goals for well-being. Study was feasible and significantly increased personal growth and purposeful participation in the attainment of personal health goals.

This dissertation is dedicated to my beloved father, who left for his heavenly abode on May 9, 2013. He was the great source of inspiration, for my being in the PhD program.

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## OPERATIONAL DEFINITIONS

Heart Failure	Chronic heart failure is defined as a patho-physiological state, in which an abnormality in cardiac function is responsible for failure of the heart to pump an adequate amount of blood to meet the metabolic requirements of the tissues.
Self-Care	Self-care is defined as a naturalistic decision making process involving the choice of behaviors that maintain physiologic stability, and the response to symptoms when they occur (Riegel, et al., 2009).
Quality of Life	The World Health Organization (WHO) defines quality of life as “individuals’ perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (WHO, 1997).
Self-Capacity	Self-capacity reflects the notion of successful interpersonal functioning to the extent individual is able to maintain a sense of identity, self-awareness, tolerates and control strong emotions, and forms and maintains meaningful relationships with other people (Elliot, 1994).
Social Support	Social support is the perception or experience that one is cared for and loved, esteemed, part of a mutually supportive network (Taylor, 2011).
Social Network	Social networks are the social structures that provide connection, and potential support (Berkman, et al., 2000).
Social Services	Social services include home and community care services, with the aim to assist older persons to live independently in their homes and to maintain their quality of life as long as possible (Low, Yap & Brodaty, 2011).



Participation in Health Care	Participation is an interaction, or series of interactions between a patient, and the health care system, or health care professional, in which patient is active in providing information to aid diagnosis and problem solving, sharing preferences and priorities for treatment and management, asking questions, and contributing to identify the best approaches congruent with his/her needs (Small, et al. 2013).
Empowerment	Empowerment is a dynamic health process that emphasizes “purposefully participating in a process changing oneself and one’s environment, recognizing patterns and engaging inner resources for well-being.” Health empowerment emphasizes facilitating one’s awareness of the ability to participate knowingly in health and health care decisions (Shearer, 2007, 2009).
Self-Management	Self-management reflects the ability of an individual to manage symptoms, treatments, life style behavior changes and consequences of the chronic condition (Richard & Shea, 2011).
Functional Health	Functional health is an individual’s ability to perform normal daily activities for meeting basic needs, fulfilling usual roles, and maintaining health and well-being and can be influenced by physiological impairment, symptoms, mood and health perceptions of individual (Leidy, 1994).
Well-Being	Well-being is a positive outcome that is meaningful for people and for many sectors of society, because it tells us that people perceive that their lives are going well (CDC, May 31, 2016).

## **Chapter 1**

### **INTRODUCTION**

The population of older adults in the United States is growing disproportionately, with corresponding medical, social and economic implications. According to the Administration on Aging (2012), the number of Americans 65 years and older constitutes 13.7% of the U.S. population, and is expected to grow to 21% by 2040. As the adults age, they are at risk for developing chronic illness and disability (Healthy People, 2020).

Heart failure is a chronic illness that is highest among older adults, and is a major factor in mortality, morbidity, and poor quality of life (Healthy People, 2020). According to the Centers for Disease Control and Prevention (2014), and National Health and Nutrition Examination Survey (NHANES) data from 2007 to 2010 (Go, et al., 2013), 5.1 million Americans have heart failure, and 660,000 new cases are added yearly. Almost 80% of patients are 65 years of age and older. By 2030 almost 8 million Americans will be living with heart failure, and 2 million of them will be 80 years of age. Therefore, as the aging population grows, there is expected growth in the population with heart failure (Heidenreich, et al., 2011).

Heart failure occurs when the heart is unable to provide sufficient blood to meet the metabolic demands of body tissues (Yancy, et al., 2013). Heart failure is the outcome of injury to the myocardium from cardiovascular conditions including hypertension, cardiac valvular disorders, coronary heart disease, and cardiomyopathy as well as extravascular conditions including diabetes, cardio toxic drugs, infections, and renal

failure (Hunt, et al., 2005; Kemp, & Conte, 2012; Kusumoto, 2006). Neurohormonal and inflammatory responses to injured myocardium result in hemodynamic congestion, including pulmonary congestion, leading to dyspnea, and peripheral congestion, leading to peripheral edema and ascites. Symptoms such as nausea, lack of appetite and fatigue are also common (Kemp, & Conte, 2012; Katz, 2003).

This chapter provides an overview of the social and economic burden of heart failure among older adults, in the United States, antecedents of heart failure, and the consequences of heart failure as well as experiences of older adults living with heart failure. The importance of self-management to improve self-care behaviors, functional health, and quality of life of older adults with heart failure is highlighted. Empowerment interventions targeting self-management, self-care behaviors, and quality of life of older adults with heart failure are reviewed. The chapter concludes with specific aims relevant to testing a theory-based intervention of health empowerment to improve awareness of personal resources and social contextual resources in older adults with heart failure, to attain their personally relevant health goals for self-management resulting in improved quality of life and well-being.

### **The Social and Economic Burden of Heart Failure in Older Adults**

By 2030 almost 8 million American will be living with heart failure. The prevalence of heart failure is expected to increase by 23% and the number of older adults living with heart failure is projected to increase by 46% between 2012 and 2030 (Heidenreich, et al., 2013). The prevalence of heart failure will increase with the increase in aging population, thus increasing the costs associated with heart failure from 34.7 billion dollars in 2010 to 77.7 billion dollars by 2020 (AOA, 2012; Lopez-Sendon, 2011;

The Impact Goal 2020; American Heart Association, 2014). Heart failure expenditure to treat older adults aged 65 years and above will increase from 69% in 2012 to 80% in 2030. The medical costs are projected to increase from \$23.9 billion to \$53.1 billion, whereas indirect costs are projected to increase from \$9.8 billion to 16.6 billion between 2012 and 2030 (Heidenreich et al., 2013). In addition, by including the cost accounted for comorbid conditions, the costs may rise to 160 billion dollars.

### **Antecedents to Heart Failure**

Antecedents common to heart failure include hypertension, diabetes and coronary heart disease (CDC, 2014). Almost 73 million persons in United States are diagnosed with hypertension, 29.1 million with diabetes and 16.8 million are diagnosed with coronary heart disease (Lloyd-Jones, et al., 2013). With the increase in the prevalence of hypertension and decrease in mortality from coronary heart disease, the incidence of heart failure is expected to increase disproportionately (Ford, et al., 2007). Almost 7 out of 10 individuals with chronic heart failure suffer with hypertension (Heidenreich, et al., 2011). A large proportion of the population suffers with more than one antecedent of heart failure, which increases the intensity of long lasting challenges of heart failure on society.

### **Consequences of Heart Failure**

Pulmonary and peripheral hemodynamic congestion in heart failure results in dyspnea and fatigue in older adults and may limit exercise tolerance. The severity of heart failure ranges from slight physical limitation to inability to carry out physical activity as classified by New York Heart Association (1994). Being a progressive, and debilitating syndrome, heart failure may lead to many adverse physical, and psychosocial

consequences, including lack of physical strength, and inability to care for self as well as others (Friedman, 2003; Pihl, et al., 2005).

Heart failure contributes significantly to both patient burden, and national healthcare expenditure, with large number of older adults hospitalized, as compared with any other medical condition (Ambrosy, et al., 2014; Dunlay & Roger, 2014). Mortality related to heart failure is high among Medicare beneficiaries, with a high percentage not surviving three years following heart failure hospitalization (Heidenreich et al., 2013). In addition, the prevalence of comorbid conditions increases with age, and further complicates the clinical course of older adults with heart failure (Center for Medicare and Medicaid Services, 2015; Masoudi, et al., 2005).

Interaction between heart failure and comorbid conditions is complex, as comorbid conditions act as risk factors, causes of progression, and precipitating factors for decompensation. Older adults with heart failure and comorbid conditions, typically are prescribed multiple medications, are served by multiple physicians, and undergo multiple procedures, which make their self-management complex, and result in poor outcomes (Lien, Gillespie, Struthers, & McMurdo, 2002; Rich, 2003).

Heart failure accounts for more than one million U.S. hospitalizations annually, and is the contributory diagnosis in an additional 2 to 3 million hospitalizations. Of all cardiovascular hospitalizations, 28.9% are due to heart failure, and almost 60,000 deaths are accounted for heart failure. Heart failure was the primary diagnosis in 1.801 million physician visits in 2010 (Go, et al., 2013). According to Go and colleagues (2013), the annual number of hospitalizations can be attributed to lack of understanding of self-management in heart failure, lack of awareness of resources available and how to utilize

resources. Current approaches of therapy such as pharmacological, and self-management, focused on sign and symptoms, compliance and behavior change, mortality rates approach 20% per year. Heart failure related deaths had steady decline between 2000 and 2012, the rate has increased again from 81.4 per 100,000 in 2012 to 84.0 in 2014 (CDC, January 04, 2016). In addition, etiology of heart failure and disparities in heart failure are the predictor of mortality (Lopez-Pazos, et al., 2011)

Disparities in heart failure are related to age, race, income, education, genetic factors, geographical location, lack of insurance, access to care and communication barriers (American Heart Association Statistics Update, 2015). Age disparities are evident in majority of heart failure trials in the past, where older adults 65years and above were excluded from the trials (Dalane, Kitzman, Michael, & rich, 2010). Despite impressive declines in mortality, marked disparities persist within and between population subgroups (Leeper, & Centeno, 2012). The prevalence of heart failure will remain highest among blacks and will rise by 29% between 2012 and 2030 (Heidenreich et al., 2013; Will, Valderrama, & Yoon, 2012). Onset of heart failure is before age 50 among blacks, which may be attributed to hypertension, obesity and chronic kidney disease.

Heart failure related mortality is consistently higher in African American than whites. Black men are 3.4 times as likely to be hospitalized as white men whereas black women are 6.5 time as likely to be hospitalized as white women (Will, Valderrama, & Yoon, 2012). According to a retrospective review, African-Americans were prescribed lesser diagnostic procedures, thrombolytic therapy and revascularization procedures (Casale, et al., 2007). In addition, one in three individuals in the United States will be of

Hispanic origin by 2050. Hispanics are younger at onset of heart failure and are likely to have greater number of risk factors for heart failure such as diabetes mellitus, hypertension and obesity, as well as are likely to have less insurance and access of care (American Heart Association, 2015).

In women as compared to men, disparities in treatment of hypertension and myocardial infarction, contribute for poor outcomes (McSweeney, Pettey, Lefler & Heo, 2012). Prehospital delays are longer in women as compared to men, and in Black women who rely on spirituality rather than seeking treatment as compared to whites (Moser, Kimble, & Alberts, 2006; Lefler, & Bondy, 2004). In addition, eligibility for public insurance is a significant predictor for hospital delays. Self-management practices and clinical outcomes differ by race, especially in Blacks who show poor engagement in self-management strategies (Hughes, & Granger, 2014). Dietary habits, and exercise practices among different cultures also contribute to self-management disparities.

### **Older Adults Living with Heart failure**

**Experiences.** Living with heart failure is challenging for both patients and caregivers. The management of symptoms of heart failure including dyspnea, fatigue and activity intolerance, requires older adults to follow substantial life style modifications, which may conflict with their preferences, culture, and traditions, thus making the self-management more complex (McMahon, & Lip, 2002). To understand the experiences of older adults living with heart failure, Bosworth and colleagues (2004) explored the perceived quality of life, and found that feelings of frustration, social isolation, and inadequate knowledge about resources were common. Brannstrom and colleagues (2006) and Martensson and colleagues (1998), highlighted the feeling of uncertainty, and

powerlessness among patients with heart failure. Patients used the terms ‘roller coaster life’ and ‘knocking on death’s door’ to describe living with heart failure. Older adults expressed their feelings of restlessness, being a burden on others, imprisoned in distrust, and fear of death (Ekman, et al., 2000; Falk, et al., 2013; Yu, et al., 2008). Rather than accepting themselves with the disease, majority of patients attempted to dissociate the awareness of deleterious disease impact, from their own existence (Buetow, et al., 2001).

Patients used violent metaphors to convey the severity of effects of living with heart failure, including being ‘imprisoned’ in the body, feeling like they were ‘drowning’ (Brannstrom, et al., 2007; Mahoney, 2001; Zambroski, 2003). Patients were confused about, what is going on, in their body (Duhamel, et al., 2007; Horowitz, et al., 2004; Rodriguez, et al., 2008). Many older adults did not know what to do, or where to go for help; the decision was dependent on perceived options, and time (Eldh, et al., 2006; Schnell, et al., 2006; Horowitz, et al., 2004). Lack of self-confidence to perform at previous levels of activity was associated with a great deal of loss, and grief among heart failure patients.

Patients’ failure to realize their own capacity and fear may prevent them from engagement in activities of daily life (Pihl, et al., 2011). Rodriguez and colleagues (2008) reported that patients lose their self-confidence due to the fear of getting worse, and having no future and demand information about heart failure, its treatment and self-management. Pihl, Fridlund and Martensson, (2011) interviewed 15 patients suffering with chronic heart failure; participants perceived need of finding practical solutions in daily life, for having realistic expectations about the future, not believing in one’s own ability, and losing one’s social role in daily life. The inability to trust in their self-



capacity led some of the participants to become passive which influenced their social network and position in the society. The experiences of older adults living with heart failure are summarized in Table 1.

**Resources.** Family support was mentioned as a reliable resource to facilitate effective coping (Bennett, et al., 2000; Europe, & Tyni-Lenne, 2004). Ways to reconcile living with heart failure were described as finding purpose and meaning in the illness experience such as caring for their loved ones, believing in God, and accepting and letting go (Mahoney, 2001). Patients valued, and could rely on intensive support provided by the caregivers (Edmonds, et al., 2005, Patel, et al., 2007). Participants reported a variety of personal resources such as their own experience; input from significant others, opinions of neighbors and friends, and a belief in God that helped them to cope with heart failure (Zambroski, 2003). Patients viewed social support as powerful motivator and facilitator for desired change in health behavior (Fleury, 1991; Shearer, & Fleury, 2006). Resources in heart failure are summarized in Table 1.

Table 1  
*Experiences of Older Adults Living with Heart Failure*

Experiences	Resources
<ul style="list-style-type: none"> <li>• Inadequate knowledge what is going in the body</li> <li>• Feeling of frustration</li> <li>• Feeling of uncertainty</li> <li>• Powerlessness</li> <li>• Roller coaster life</li> <li>• Knocking the death’s door</li> <li>• Feeling of restlessness</li> <li>• Burden on others</li> <li>• Not believing in one’s own ability</li> <li>• Imprisoned in distrust</li> <li>• Lack of self-acceptance with disease</li> <li>• Lack of confidence</li> <li>• Social isolation</li> </ul>	<ul style="list-style-type: none"> <li>• Family support a reliable resource</li> <li>• Finding purpose in life</li> <li>• Caring for their loved ones</li> <li>• Believing in God</li> <li>• Accepting and letting go</li> <li>• Support provided by caregivers</li> <li>• Own experience, input from significant others</li> <li>• Opinion from neighbors and friends</li> <li>• Practical solution for problem of losing social role</li> <li>• Solutions to have realistic expectations about future</li> </ul>

## **Self-Management of Heart failure**

The science of self-management in heart failure is evolving (Gardetto, 2011) and has become the core component of heart failure disease management programs and chronic care models (Shively, et al., 2013). Consistency in mortality and hospitalizations in heart failure over the last decades has attracted considerable attention of stakeholders toward self-management, and highlighted the imperative need to improve health outcomes in heart failure, and generalize evidence based research in practice (Gardetto, 2011). However, many approaches to improve self-management, are focused on physiologic and clinical variables, preference of hospital and care provider's performance (Gardetto, 2011). Little attention has been given to patient-centered approaches, though crucial for improvement of self-management in heart failure (Bos-Touwen, et al., 2015).

Factors such as, symptoms, medications, lack of social and financial support, lack of awareness of personal and social contextual resources, and comorbid conditions, elevate the complexity of self-management in older adults living with heart failure. Thus, understanding of factors which promote self-management in heart failure, is critical to develop effective strategies for self-management (Gardetto, 2011). Currently, the focus of numerous existing self-management strategies is on signs and symptoms, social relations, self-care behaviors, patient engagement and compliance, less attention is given to personal and social contextual resources of older adults with heart failure. Self-management is regarded as a key component of National Prevention Strategy self-care process which may empower older adults for deliberate decision making in response to symptoms (Riegel, and Dickson, 2008; Vrijens et al., 2012; Hughes, & Granger, 2014; Richard, & Shea, 2011; National Prevention Council, 2011; Montross, et al., 2006).

From the perspective of heart failure, self-management includes, medication management, symptoms management, dietary modifications, and activity adjustments (Yancy, et al., 2013). Self-management reflects the ability of the individual to manage symptoms, treatments, life style behavior changes and consequences of the chronic condition (Richard, & Shea, 2011). According to Lorig and Holman (2003), self-management includes three self-management tasks: (a) medical management, (b) role management, and (c) emotional management and six self-management skills: (1) problem solving, (2) decision making, (3) resource utilization, (4) developing patient provider partnership, (5) action planning and (6) self-tailoring.

Currently, emphasis of self-management strategies is on facilitating patients' engagement for actively managing their day to day self-care activities (Coulter, 2012). Engagement in self-management is influenced by several factors including, comorbid conditions, polypharmacy, dietary compliance issues, psychosocial concerns, financial concerns, age-related issues, and awareness of personal and social contextual resources. Patient engagement has resulted in outcomes including decreased mortality, hospitalizations, and emergency room visits (Riegel, Jaarsma, & Stromberg, 2012). Thus, self-management strategies which focus on engagement of patients in self-management, have become the backbone of disease management programs at national and organizational levels.

The National Institute of Nursing Research (NINR, 2011) in its strategic plan, has emphasized the importance of self-management of symptoms, and treatment of chronic conditions. Self-management of heart failure is an integral constituent of scientific statement of the American Heart Association (AHA) and guidelines from the

interdisciplinary American College of Cardiology Foundation /American Heart Association Task Force (Riegel, et al., 2009; Yancy, et al., 2013). Institute on Medicine (IOM), and Centers for Disease Control & Prevention (CDC) describe self-management as the top priority of U. S. healthcare.

Self-management is associated with prevention, early detection of health problems, better quality of life, improved health outcomes, and reduced health care costs (Deakin, Mcshane, Cade, & Williams, 2005; Jovicic, Holroyd-Leduc, & Straus, 2006; Moser, et al., 2012). There is growing evidence about the effectiveness of self-management programs for improving self-care behaviors and quality of life of heart failure patients (Lorig, et al., 2001; Lorig, & Holman, 2003). However, goals and dimensions of chronic disease management programs vary substantially. Findings from several studies on self-management of heart failure show diversity in characteristics and risk factors, barriers and challenges, associated with poor self-management (Cameron, Worrall-Carter, Riegel, Lo, & Stewart, 2009; Riegel, et al., 2009).

Several self-management interventions are developed and evaluated, to assist the older adults to acquire self-management competences through patient education and training (Bos-Touwen, et al., 2015). Connely and colleagues (1993) developed a conceptual model, the Model of Self-Care in Chronic Illness (MSCCI), to describe, explain and relate the variables that impact self-care behaviors in chronic illness. As per the Model of Self-Care in Chronic Illness (MSCCI), determinants of self-care and self-care behaviors in chronic disease patients included gender, age, income, education, social support, symptoms and comorbid conditions. However, testing of the determinants of

MSCCI in heart failure populations has resulted in inconsistent findings which limited its application in future studies.

Similarly, Lorig and Colleagues (1999) developed the “Chronic Disease Self-Management Program (CDSMP)” to teach patients how to manage the consequences of the chronic condition. The CDSMP is based on Bandura’s self-efficacy theory in which self-efficacy refers to the confidence for self-management. The CDSMPs have been used at a larger scale in concert with recommendations from clinical guidelines and have resulted in reduced disease related hospital admissions, and costs, improved health related quality of life as well as functional capacity (Clark, Inglis, McAlister, Cleland, & Stewart, 2007; McAlister, Lawson, Teo, & Armstrong, 2001; Jovicic, Holroyd-Leduc & Straus, 2006; Jaarsma, et al., 2008).

In contrast, an independent randomized controlled trial, Medicare Health Support Pilot Program (MHSP) including nine disease management programs with 30,000 patients with heart failure and diabetes, concluded that programs did not decrease mortality, hospitalizations, and costs and did not improve self-care, self-care efficacy as well as mental and physical health (Kapp, McCall, Cromwell, Urato, & Rabiner 2008; Smith, et al., 2005). Poor outcome does not mean that program is not effective, it may be attributed to the design issues, lack of patient centered approaches, inadequate intervention dose, resulting in low power to measure the true effects (Dickson, Melkus, Dorsen, Katz, & Riegel, (2015).

Similarly, evaluation of CDSMP in multiple healthcare settings, has resulted in variability in program outcomes (Kennedy, et al., 2007; Baker, et al., 2005; Kendall, et al., 2007). Inconsistencies such as positive changes in self-reported health (Lorig, et al.,

2005) whereas Barlow and colleagues (2005) reported no positive changes. Further Kennedy et al. (2007) reported positive changes in fatigue and exercise whereas Goepfing, and colleagues (2007) reported no positive changes. Disease management programs vary in number, type and operationalization of variables, description of content, implementation process and usual care conditions. In heart failure management programs 50% of the symptoms monitoring is done by the clinicians thus discourages the participation of patient in self-management (Wakefield, Boren, Groves, & Conn, 2013). Majority of self-management frameworks have provided the understanding of chronic illness without explicating the mechanisms of self-management from the perspective of individual living with heart failure (Samson, & Siam, 2008).

The importance of emotional and existential resources in reconciling and deriving meaning from the illness experience as highlighted in the qualitative research on living with chronic heart failure, is not addressed in the self-management processes (Whittemore, Chase, Mandle, & Roy, 2002). In addition, chronic disease management programs are referred as bundled interventions as they combine number of interventions that are implemented simultaneously, which makes it difficult, to identify the active ingredients of bundle (Wakefield, Boren, Groves, & Conn, 2013). Therefore, ongoing efforts are needed to explicate the mechanisms of self-management, to address the existential and emotional processes and to know the positive effects of different elements of chronic disease self-management programs on quality of life and wellbeing of older adults with heart failure.

Inconsistency in the findings of these programs, may be attributed to heterogeneity of programs, patient characteristics, and low treatment fidelity

(Trappenberg, et al., 2013; Dickson, Nocella, Yoon, Hammer, Melkus, & Chyun, 2013). The variability in chronic disease program components, health outcomes, methods of evaluation and measurement has made the comparison of effectiveness and outcomes difficult in these programs (Ditewig, Blok, Havers, & van Veenendaal, 2010). No doubt, chronic disease management programs have become central theme of discussion related to self-management however, inclusion of patient as central part in the health care team is yet to be evaluated. Including patients' perceptions of their own needs and strengths, which are fundamental for their self-management, although ignored in the past research, would make considerable difference in the self-management outcomes (Clark & Thompson, 2008; Evangelista, & Shinnik, 2008).

Focus of self-management is on helping people with chronic conditions to become informed and active participant in their own care (Gardetto, 2011). Therefore, approaches to self-management need to be individualized, to develop educational and behavioral interventions for older adults with heart failure (Cameron, et al., 2010). Rather than predefining the goals and outcomes by health professionals, involving patient to discuss and negotiate, considering their priorities related to specific situation, maintaining function and access to social services available, is extremely important for the future self-management strategies (Aujoulat, dHoore, & Deccache, 2008; Riegel, et al., 2009; Lee, Tkacs, & Riegel, 2009). Participating in the self-care increases the self-confidence, and improves self-management and functional health (Riegel, & Dickson, 2008).

Lack of awareness of self-capacities, social support and social network and social services affects self-management and self-management affects health outcomes of older adults with heart failure. However, limited attention has been paid to the relevance of

personal and social contextual resources in self-management research, which are crucial for patients to be successful in achieving their health goals (Dumbar, Clark, Quin, Gary, & Kaslow, 2008; Stromberg, Jaarsma, & Riegel, 2012). Patients who lack confidence in their self-capacities, and lack social support and social network, would benefit from health empowerment interventions designed to build upon their capacities and social network (Shearer, Fleury, & Belyea, 2010; Shearer, 2007, 2009).

### **Empowerment Perspective on Self-Management**

Self-management as monologue among health professionals and stakeholders, and paradigmatic shift from medical model approach to empowerment approach emerged together. Feste and Anderson (1995) defined the patient empowerment as a concept related to health which assumes that to be healthy, people must be able to bring about changes, not only in their personal behavior, but also in their social situations and the organizations that influence their lives. Empowerment perspective recognizes patient as an active participant in managing his/her illness and calls for a collaborative approach, to share information, expertise and support by the nurse to facilitate the optimal self-management decisions based on patient's health priorities and goals (Anderson and Funnel, 2005; Shearer, Fleury, Ward, & O'Brien, 2012). Empowerment is a relational, dynamic human health process in which patient purposefully participates in change consistent with self-management of heart failure (Shearer, & Reed, 2004). Approaches that motivate, empower and encourage patients to make informed decisions, and assume responsibility for self-care may be most effective in building confidence in self-management (Evangelista & Shinnick, 2008). Helping older adults with heart failure, to realize and build upon their strengths such as personal resources and social contextual



resources provide fuel and energy for empowerment thus enhance self-confidence in self-management (Cowger, 1994).

From empowerment perspective, empowerment is power is inherent in the individual and ongoing, relational, innovative and expressive of human health pattern of well-being (Shearer, 2004, 2009). In the present research, empowerment approach focuses on older adults' strengths, and abilities which can contribute significantly to improve self-management, functional health and well-being of older adults with heart failure (Shearer, et al., 2007; Shearer, 2009). Key elements in strength based perspectives include, identifying strengths such as personal, and social contextual resources, exploring older adults' understanding of facts, believing and listening older adults, engaging them in the self-management to attain their health goals of perceived well-being (Shearer, 2009). Personal strengths lie within interpersonal motivation, emotions, and the ability to think clearly. Social contextual strengths include, family network, significant others, voluntary organizations, community groups, and public institutions (Small, et al., 2013).

Shearer, (2004) found that recognition of self-capacity among older women enhanced their ability to participate in problem solving. Shearer and Fleury (2006) found that social resources fostered health empowerment through consistent availability, and support in addressing life changes. Identifying the personal and social contextual resources of older adults with heart failure, and building these in collaboration can enhance the sustainability of self-management outcomes (Shearer, Fleury, Ward & O'Brien, 2012).

Shearer, Fleury, Ward, and O'Brien (2012) conducted a review of empowerment interventions with community dwelling older adults to examine how empowerment is

conceptualized across interventions, the guiding theoretical frameworks, the outcomes measured and the findings of these interventions. Their findings, support the efficacy of empowerment interventions to enhance self-management of chronic conditions among older adults and improve their perceived well-being.

### **Empowerment Approaches to Self-Management**

Empowerment is both a process and an outcome, where process is the movement from powerlessness to increased power, and outcome concerns with the consequences of a process (Zimmerman, 1995). Empowerment process is the mechanism through which individual gain mastery and control over the concerned situation, develop critical awareness of their environment and participate in decisions that affect his/her life (Zimmerman & Warschausky, 1998). Empowerment outcomes refer to dependent variables in research studies or consequences of empowerment such as control, awareness and participation in goal attainment.

According to Kieffer (1984), empowerment is not a commodity to be acquired rather a transforming process, constructed through learning and development. Empowerment is not the final state, but empowerment process strengthens the ongoing capacity for desired actions under changing situations (Staples, 1990). Self-management is the component of empowerment model of interventions, based on collaborative approach focusing on nurse and patient relationship, whereby patients are taught to deal with the medical, social and emotional consequences of chronic disease and about their responsibilities to manage the disease at three levels.

However, from the process perspective of empowerment, the emphasis is on identifying and building strengths of older adults with heart failure, mutual goal setting

and making informed decisions to attain their health goals (Shearer, Cisar, & Greenberg, 2007). The outcome perspective becomes evident when there is measurable increase in patient's ability to make informed decisions. Participation in self-management is the fundamental base for the empowerment approach and is necessary for effective management of chronic conditions (Shearer, et al., 2007; Funnell & Anderson, 2004). Participation in self-management enhances self-confidence, and quality of life and adds to patient's well-being, the outcomes of empowerment process (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008). Yang, Hsue, and Lou (2015) and Artinian, and colleagues (2002) reported that empowerment was statistically significant predictor of self-care behaviors in diabetes and heart failure patients. Therefore, interventions targeted on self-management, self-care behaviors and quality of life reflect empowerment perspective.

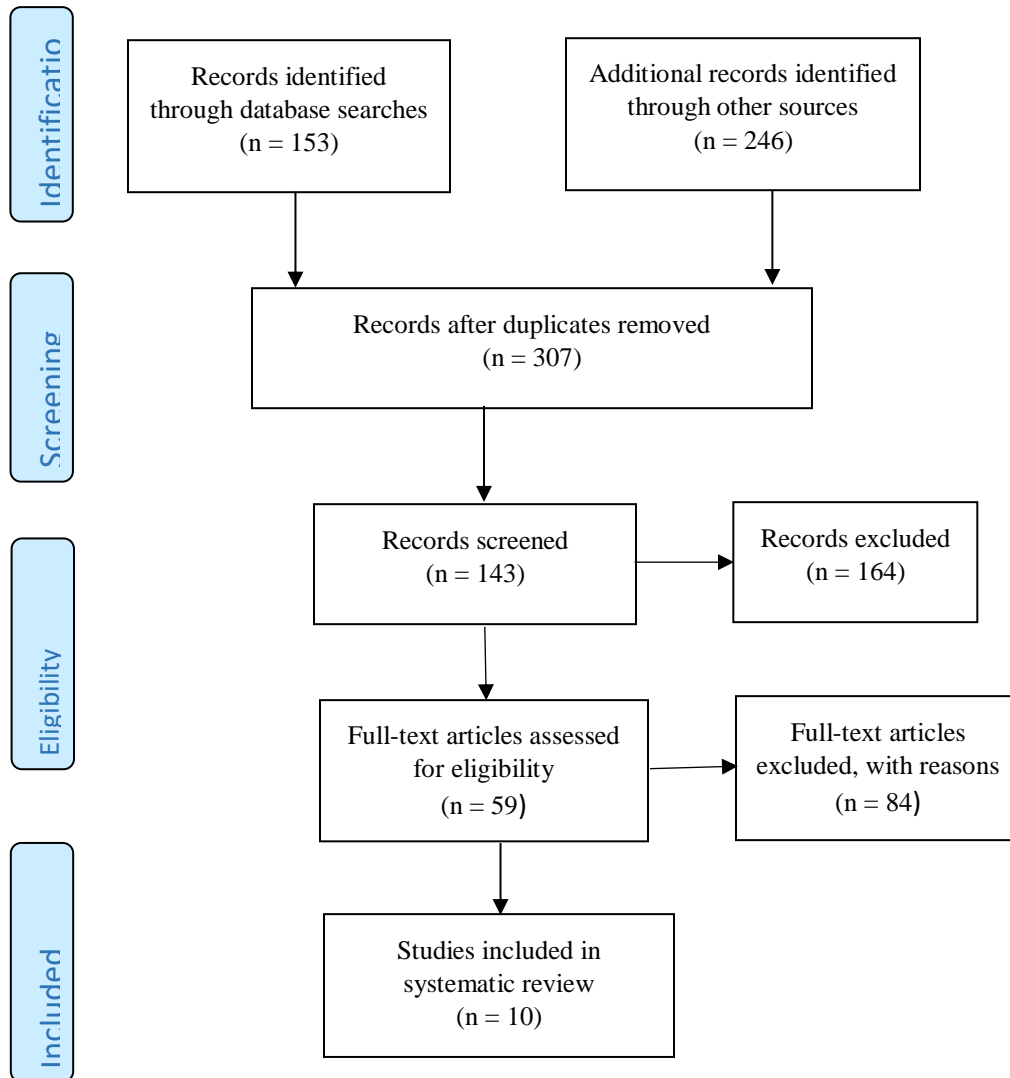
### **Literature Review Methods**

A systematic review was conducted to understand conceptualization, and methodological issues related to the design, and implementation of intervention studies, to promote health empowerment in older adults with a diagnosis of heart failure. Considering scarcity of the Health Empowerment Interventions, studies focusing on self-management, self-care behaviors and quality of life, reflecting outcome perspective of empowerment, were included in the review (McAllister, Dunn, Payne, Davies, & Todd, 2012). From the outcome perspective empowerment is operationalized through self-management, participation in goal attainment, and functional health, in older adults with heart failure (Shearer, et al., 2007). The literature search strategy was guided by clear

aims and objectives for randomized controlled trials, focused on self-management, self-care behaviors, functional health, and quality of life of older adults with heart failure.

The literature search was carried out for English language articles in electronic databases of PubMed, and CINAHL, by using key words (heart failure, self-management, empowerment, intervention and randomized controlled trials). The search was restricted to first level of evidence that includes randomized controlled trials, published during 2005-2015. This time frame was chosen to focus on the current evidence of heart failure interventions, to know the state of science of self-management in heart failure. First level of evidence was included which is designed to be unbiased and have less risk of systematic error. The initial search resulted in 153 articles. Hand searches of articles identified additional 246 citations. In total, 399 articles and abstracts were retrieved and 92 duplicates were removed. Three hundred seven articles were screened, 143 met the criteria for review and 164 were excluded from the review due to research design, outcome variables, NYHA class and sample characteristic such as age.

Inclusion criteria included: (a) English language; (b) older adults 60 years and older; (c) randomized controlled trials; and (d) empowerment model of interventions, based on collaborative approach focusing on nurse and patient relationship for educating the patients to deal with medical, social and emotional consequences of heart failure and about their responsibilities in self-management. Exclusion criteria included: (a) focus on acute heart failure; (b) did not focus on empowerment either as a process or an outcome; (c) class IV of NYHA; and (d) not a randomized controlled trial. A final sample of 10 articles was included in the review (Figure 1)



**Figure 1.** PRISMA Flow Diagram of Systematic Review

**Data collection tool.** A structured data collection tool designed by Blue and Black (2005) and modified by Shearer, Fleury, Ward and O'Brien, (2012), was utilized to extract data from each selected article. Critical elements of tool included: (a) author's name(s), year of publication and title of the intervention, (b) setting and sample characteristics, (c) definition of empowerment/self-management and theoretical perspective, (d) Study methods including design, intervention components and dose, (e) outcome measures, (f) outcomes. Sample characteristics included the target population,

sample size, participant's age, and gender, education and ethnicity as well as inclusion and exclusion criteria. Intervention characteristics included, critical input, delivery settings, interventionists, mode, dose and duration, fidelity, follow up and attrition.

## **Review Results**

### **Study Characteristics**

All the studies reviewed were randomized controlled trials with pre-post design. Sample sizes were estimated through power analysis in four (Shearer, Cisar & Greenberg, 2007; Tomita, et al., 2009; Brodie, Inoue & Shaw, 2008; Smeulders, et al., 2010) of the studies whereas intention to treat analysis was specified in two of the studies reviewed. Withdrawals and drop outs were documented in eight of the studies reviewed. The focus of interventions was to improve self-management, self-care behaviors and quality of life of older adults with heart failure.

**Sample.** The median sample size of studies reviewed was 52, ranging from 20 to 605. Of the ten studies reviewed, samples were estimated through power analysis in four studies, which enhances the power of studies, the probability that a study will successfully detect a statistically significant difference between study groups. Ethnicity was described in six of the studies reviewed. Whites were the majority population (Westlake, et al., 2007; Shearer, et al., 2007; Caldwell, et al., 2005) while Asians (2.5%) and Native Americans (1.14%) were the minority population (Shearer, et al., 2007; Tomita, et al., 2009) respectively. Caucasian were found in majority (85%) (Tomita, et al., 2009) and African American were found in majority (60%) (Brandon, et al., 2009). Sample mean age ranged between 49 to 81 years with an overall mean age of 62.64 years. Both genders were included in the studies, and number of females ranged from 27.4%

(Smeulders, et al., 2010) to 70% (Brandon et al., 2009). Education years of participants were less than 12 years (Bakan & Akyol, 2008; Brandon, et al., 2009; Tomita, et al., 2009), and high school (Baker, et al., 2011; Westlake, et al., 2007; Shearer, et al., 2007). Caldwell, and Colleagues (2005) reported the mean education years  $14\pm 3.3$  whereas Smeulders, et al. (2010) reported middle educational level of majority of participants.

Patients were included in the studies, based on age, diagnosis of heart failure, ejection fraction 40 or <40%, NYHA functional class, speaking English language, no impairment of cognitive status, able to comprehend telephone conversation, had phone at home, living with heart failure more than 6 months, remain in city during the study, trip to physician office within one year and willing to give informed consent. Patients were excluded from the study if they were scheduled for surgery, had cognitive impairment, neurological disorder with impaired cognition, untreated malignancy, were part of formalized heart failure program, living outside catchment area, expectancy less than intervention period, enrolled in other studies, and had stroke with cognitive impairment in the last 3 months.

**Settings.** Settings were identified in all the studies reviewed. Out of ten studies reviewed, seven were conducted in U. S. and rest in Netherlands, Turkey, and United Kingdom. Two studies were conducted in the rural settings (Caldwell, et al., 2005; Brandon et al., 2009). The sites were cardiology clinics in four, home based in three and clinic plus home based setting, hospital wards, and home health agencies in three of the studies reviewed. Participants were recruited from the outpatient cardiology clinic (Smeulders, et al., 2010), university affiliated outpatient heart failure clinic (Westlake, et al., 2007), regular outpatient clinic appointment (Baker, et al., 2011) cardiology clinic in

rural setting (Caldwell, et al., 2005), cardiology and internal disease clinic (Bakan & Akyol, 2008) and utilizing names from the Heart Failure Diagnosis Related Group (DRG) provided by the cardiologist (Brandon, et al., 2009).

Brodie, and colleagues (2008) recruited the participants admitted to care of elderly and the general medical wards at two hospitals, Tomita and colleagues (2009) from three hospitals, and two insurance companies, Shearer and colleagues (2007) from patient unit of a metropolitan hospital and Duffy and colleagues (2009) recruited participants from home health agencies associated with three referring hospitals.

**Theoretical perspectives.** Theory is an internally consistent group of relational statements that presents a systematic view about a phenomenon and that is useful for description, explanation, prediction and prescription (Walker & Avant, 2011). Out of ten studies reviewed, theoretical perspectives guiding interventions' design, implementation, and evaluation were used in eight of the studies. Bakan, and Akyol (2008) used Roy's adaptation model based on assumptions of general system theory, and adaptation level theory, to guide their intervention. The focus of the theory is on environmental stimuli and the biopsychosocial responses which emphasizes interaction between person and environment. Gaining knowledge about heart failure, physical activity, diet, medications and compliance with the treatment plan and participation in decision making reflected social perspective of empowerment.

Theory of health empowerment guided by Rogers' Science of Unitary Human beings' principle of integrality, the person-environment process, guided the intervention by Shearer and colleagues, (2007). From Rogerian perspective empowerment fosters purposeful participation in change for goal attainment of improved self-management and



functional health. Empowerment recognizes that nurses do not create change in their patients, rather facilitate the change process by bringing their own knowledge to the situation. M-TOMITA (Model Toward Optimal Independence through Technological Adoption) based on transtheoretical model, social support theory and mass communication theory, was the guiding source for the web-based intervention by Tomita and colleagues (2009). According to transtheoretical model empowerment process progresses through stages from contemplation, preparation and action to maintenance. Model is useful only when people have knowledge about their condition.

Participatory Action Research Model, based on worldviews of critical theory and constructivism was used by Westlake and colleagues (2007). They did not describe the key elements of participatory action model and did not link it to the theory of problem, theory of intervention and health outcomes. Quality of life and perceived control reflected the outcome perspective of empowerment in their web-based intervention. Brandon and colleagues (2009) used Orem's Self-Care Deficit Theory to guide their intervention, based on assumptions that self-care deficits may occur due to lack of knowledge, and lack of social support. Patients gain knowledge specific to their situation, identify the course of action and determine the effectiveness of actions. Education and support which addresses deficit in self-care, empower the patients. Bandura's self-efficacy theory guided the intervention by Smeulders and colleagues (2010), in which, self-efficacy refers to confidence to achieve certain goals and reflects the perspective of empowerment.

In Quality Care Model, patient-provider and patient-healthcare team relationships are fundamental for self-management, and reflect the empowerment perspective (Duffy,

et al., 2010). Social Cognitive Theory and Adult Learning Theory guided the intervention by Baker, and colleagues (2011) to improve knowledge of heart failure, self-care behaviors and heart failure specific quality, which reflected the empowerment perspective. The focus of these theories is on social context, experience, and motivation of older adults with heart failure. Caldwell and Colleagues (2005) and Brodie, Inoue and Shaw (2008) did not use theoretical perspective to guide their interventions.

### **Intervention Characteristics**

**Critical inputs.** Critical inputs are the central concepts of theory that define the intervention. Critical inputs in the studies included, cognitive-behavioral approaches targeted on self-management related factors, education, counseling, and reinforcing positive health beliefs. Shearer, and colleagues (2007) designed telephone delivered Health Empowerment Intervention (HEI), to provide information, identify and build strengths for enhancing self-management, functional health and participation in self-management. The key elements of the intervention included standardized heart failure education plan, mutual patient-nurse process and standardized script for phone call. Telephone enhanced disease management was targeted to minimize readmissions, and to improve quality of life through heart failure education based on guidelines for self-care behavior by the American Heart Association (Brandon, et al 2009).

Caldwell and colleagues, (2005) designed their intervention to improve knowledge, and patient reported self-care behavior through education, counseling and reinforcement. Heart failure education was provided by using brochure on heart failure published by the American Heart Association, and educational and counseling sessions using flip charts. Tomita, and colleagues, (2009) focused on an intervention to change

one's behavior through a multidisciplinary approach, and developed a web-based intervention using guidelines published by the National Institute on Aging and National Library of Medicine, provided computer, internet access, and basic computer training to the participants, and support at suitable stages of behavior change. Intervention by Westlake and colleagues (2007) focused on self-management of heart failure and quality of life through informational, psychosocial and spiritual support. A web site was developed by PhD prepared cardiovascular nurses, based on teaching booklet used routinely in heart failure clinics. Patients were provided password to access the modules.

Smeulders, and colleagues (2010) designed their intervention to improve psychological attributes, self-care behaviors and quality of life by using structured chronic disease self-management program to enhance self-efficacy through skill mastery, reinterpretation of symptoms, modeling and social persuasion. Bakan and Akyol (2008) focused on counseling and education, exercise, and social support for adaptation in persons with heart failure by using a booklet "How I can learn to Live with Heart Failure" and a crossword puzzle. Intervention was designed to focus on symptom monitoring and providing emotional support to older adults with heart failure by using intervention protocol, telephone schedule and providing weighing scale to the participants. (Duffy, et al., 2010).

Brodie, and colleagues (2008) provided information about daily activities and motivated the older adults with heart failure to set goals and take decisions by using standard care package on information and recommendations to increase physical activity and motivational interview programme. Baker, and colleagues (2011) provided information support, education support and reinforcement to improve knowledge of heart

failure, self-care behaviors and heart failure related quality of life by providing educational manual “Caring for your heart: living well with heart failure” and weighing scale to the participants

**Mode of delivery & dose.** Intervention dose is characterized in different ways such as telephone calls, session attendance, contacts, and completion of online modules, depending on the mechanism for intervention delivery. Mode of delivery of interventions was through face-to-face contact, and telephone calls in six of the studies reviewed (Shearer, Cisar, & Greenberg, 2007; Duffy, et al., 2010; Baker et al., 2011; Brandon, et al., 2009; Bakan & Akyol, 2008; Caldwell, et al., 2005). Westlake et al. (2007) and Tomita et al. (2009) delivered their intervention through internet. Brodie and colleagues (2008) delivered their intervention through home-based sessions, whereas Smeulders and colleagues (2010) delivered the intervention through group sessions. Shearer, and colleagues, (2007) utilized six telephone calls to deliver the intervention, making first call after 1 -3 days after the discharge of patient, and then 2,4,6,8 and 12 weeks following a standardized script to guide the calls.

Duffy, and colleagues (2010) delivered the intervention through home visits and telephone calls for six weeks whereas Baker, and colleagues (2011) used one face-to-face session and 5 to 8 telephone calls for delivering the intervention. Brandon, and colleagues, (2009) delivered their intervention through seven telephone appointments whereas intervention by Caldwell, and colleagues, (2005) was delivered through two contacts including, one-on-one education and counseling session by using colored flip charts, and one telephone call after one month in intervention group for reinforcement.

Bakan and Akyol, (2008) delivered intervention through two one to one counseling sessions each of one hour duration, two phone calls and one group meeting at one month over a 3-month period. Tomita and colleagues (2009) developed a web-based intervention using guidelines published by the National Institute on Aging and National Library of Medicine to deliver informational, instrumental, appraisal and emotional support for one year. Smeulders and colleagues (2010) delivered the intervention through 6 weekly sessions of two and a half hour each, whereas Brodie and colleagues (2008) conducted eight home based counseling sessions of one hour each, to deliver the intervention. Westlake and colleagues (2005) delivered the three modules on heart failure education through web for 12 weeks.

**Duration of contact.** Program duration including period of time during which the intervention is delivered, varied among the interventions. Duration of telephone calls ranged between 5 and 40 minutes. Duration of weekly sessions ranged from one hour (Brodie, et al., 2008) to two and a half hour (Smeulders, et al., 2010). Duration of contact in the web based interventions was continuous through web and emails, whenever needed by patients.

**Intervention fidelity.** Intervention fidelity is adherence and conformity to intervention's protocol which include training of interventionists, intervention delivery, and intervention receipt. Shearer, and colleagues (2007) described the fidelity in detail including training of the interventionists, regular meetings, telephone script and audio-taping the telephone call to monitor the integrity of the intervention. In telephone based interventions the telephone log was maintained by the interventionists (Brandon, et al., 2009; Duffy, et al., 2010; Shearer et al., 2007; Bakan & Akyol, 2008). Duffy and

colleagues (2010) addressed the intervention fidelity by documenting the patient's participation, and response to intervention and nurse's opinion of the conduct, and effectiveness of the intervention.

In several studies, researchers described the content of intervention, qualifications of interventionists and their training, without specifying the training methods, and expected competencies. In a number of studies reviewed, researchers paid little attention to procedural consistency, satisfaction of the participants, and interventionists with the program.

**Follow-up and attrition.** Follow up means to maintain contact with the research participants to monitor the effects of intervention /treatment, whereas attrition represents the loss of participants from a study either in the intervention or control group. In 50% of studies reviewed, follow up was done for 3 months. Follow up for 12 months was only done in two studies by Smeulders and colleagues (2010) and Tomita and colleagues (2009). In a study by Baker and colleagues (2011) follow up was for one month. Positive intervention effects were reported among participants followed for shorter time as well as for long term follow up, so it was difficult to say, what was the minimal effective dose? The attendance rate was documented in seven of the studies, for rest of the three it was evident from the data analysis. Attrition was specified in six of the studies reviewed and ranged from 2.2% to 35.5%.

Shearer and colleagues (2007) reported 2.2% attrition rate, Tomita and colleagues (2009) 20%, Baker and colleagues (2011) 14%, Brodie and colleagues (2008) 35.5%, and Smeulders and colleagues (2010) 16.4% with reasons as death, nursing home placement, noncompliance, refusal, admitted to respite nursing, health problems, loss of interest, too

challenging and surgical procedure due to complications. Attrition of 5% is less likely to introduce bias whereas 20% or more is likely to introduce bias and impact the validity (Dumville, Togerson, & Hewit, 2006). Brodie and colleagues (2008) recommended to recruit more participants in the future studies to account for attrition to follow up. Tomita and colleagues (2009) and Smeulders and colleagues (2010) addressed the attrition through intention to treat analysis.

### **Outcome Measures**

Outcome measures to measure self-management, self-care behavior, and quality of life, varied across studies reviewed, SF-36 and SF-12 were widely used generic measures for the measurement of health-related quality of life. SF-36 was used by Shearer and colleagues (2007) and Brodie and colleagues (2008) to assess physical and mental component of health status. Although, self-completion version of the scale, has been shown not to work well in older adults. Westlake and colleagues (2007) used SF-12 to assess the physical, and mental health, a short version of SF-36.

Minnesota Living with Heart Failure Questionnaire (MLHFQ) was used by Brandon, et al. (2009), Brodie, et al. (2008), and Bakan and Akyol, (2008) to measure heart failure specific quality of life. It measures the effect of heart failure, and its treatments on an individual's quality of life and the impact of heart failure on physical, emotional, social and mental dimensions of health. Similarly, multiple outcome measures were used to measure self-care behaviors. European Heart Failure Self-Care Behavior Scale was used by Caldwell, et al. (2005) and Smeulders, et al. (2010). For measuring self-management, Shearer et al. (2007) used Self-Management of Heart Failure Scale (SMHF). SMHF scale is designed to reflect patient's abilities to maintain illness stability,

and manage symptoms. To measure self-care behavior Brandon and colleagues used Self-Care Behavior Scale (SCB).

Patient satisfaction was measured with Home Care Client Instrument revised by Duffy and colleagues (2009). Control Attitude Scale was used to measure the degree of control the patient feels about his/her health status by Westlake and colleagues (2007). Motivation to participate in change was measured through Readiness to Change Tool by Brodie and colleagues (2008). Ability to participate in goal attainment was measured by Shearer et al. (2007) by using Power as Knowing Participation in Change Tool (PKPCT). However, patients encountered difficulty in understanding the directions to complete PKPCT.

## **Outcomes**

**Quality of life.** Quality of life improved significantly in eight of studies reviewed. Shearer and colleagues (2007), who designed telephone delivered empowerment intervention, reported significant effect on mental component score, 45.9 in the pre-test to 50.0 in the post test ( $F = 4.48$ ,  $df = [1, 145.5]$ ,  $p = 0.36$ ) in the intervention group as compared to the attention control group. Significant short term effect on cardiac specific quality was reported by Smeulders et al. (2010). Brodie and colleagues (2008), Tomita and colleagues (2009), and Bakan and Akyol (2008) reported significant improvement in general quality of life, whereas in studies by Duffy et al. (2009), and Baker et al. (2011), quality of life improved but no significant difference was observed. Westlake and colleagues (2007) reported significant improvement in quality of life (repeated measure variance +3.9) for physical component score, whereas Brandon, and colleagues (2009)



reported significant improvement in emotional component of quality of life in intervention group ( $F=7.63$ ,  $p=.013$ ) but not in NYHA class III participants.

**Self-care behavior, knowledge & self-management.** Self-care behavior improved significantly ( $p = 0.001$ ), ( $p = 0.03$ ), ( $p = 0.001$ ), ( $p = 0.001$ ) in studies by Brandon et al. (2009), Caldwell et al. (2005), Baker et al. (2011), and Smeulders et al. (2010) respectively. Shearer and colleagues (2007) reported significant improvement in self-management in intervention group ( $t(28) = 4.03$ ,  $p < 0.001$ ), whereas significant improvement in cognitive symptoms' management ( $p < 0.001$ ,  $d = 0.45$ ) was reported by Smeulders and colleagues (2010).

Significant improvement in knowledge of heart failure self-management was reported by Baker and colleagues (2011), and Caldwell and colleagues (2005) in intervention group ( $p = 0.01$ ). Other health outcomes reported in studies reviewed, include significant improvement in perceived control (Westlake et al., 2007), satisfaction with home care, receptivity of intervention, sustained participation (Duffy et al., 2010), a significant decrease in hospital readmissions (Brandon et al. 2009), significant improvement in physical and social functioning (Brodie et al. 2008), adherence to program 85%, significant increase in exercise, satisfaction with the web based intervention 84.6%, heart failure better than one year before 92.3%, improvement in self-efficacy and motivation scores (Tomita et al. 2009), significant difference in 6 minutes-walk distance, social support, cholesterol and LDL levels at post-test in the intervention group (Bakan & Akyol 2008), and significant increase in self-efficacy,  $4.8 \pm 2.0$  to  $7.6 \pm 1.8$ , ( $p < 0.001$ ) in intervention group from baseline to one month (Baker et al., 2011).

There was no difference in perceived autonomy, symptoms of anxiety and depression, self-efficacy expectancies, and health care utilization between intervention and control group (Smeulders et al., 2010). Shearer and colleagues (2007) found no significant difference in scores of “Power as Knowing Participation in Change Tool (PKPCT), and functional health score of SF-36. These findings were attributed to difficulty to complete the semantic differential scale (PKPCT) by participants and inability of SF-36 to capture small changes in the function consistent with the patient participation.

### **Summary of Strengths, and Limitations**

Disproportionate increase in both incidence and prevalence of heart failure among older adults 65 years and above, results in enormous burden on patient, family, society and healthcare system. Innovative and patient centered approaches to enhance self-management of heart failure among older adults with heart failure are extremely important to minimize the current burden of heart failure on patient as well as on healthcare system. Approaches based on empowerment model, whereby focus is on strengths rather than weaknesses of the older adults with heart failure, can bring significant improvement in self-management, functional health and well-being of older adults with heart failure. Several chronic disease self-management programs, and interventions tested among older adults with heart failure, have been found inconsistent in their outcomes.

The findings from this review have shown that self-management interventions reflecting social and outcome perspective of empowerment, significantly improved self-management, self-care behaviors and quality of life by enhancing participation in

decision making and goal setting, self- efficacy, perceived control, exercise, 6-minute walk and social functioning of older adults with heart failure. Strengths of this review include: (a) emphasis on nurse-patient relationship and social relationships; (b) engagement of patient in decision making and goal setting to attain his/her health goals; (c) emphasis on theoretical perspective to guide the research; (d) focus on importance of telephone calls to enhance health outcomes; (e) randomization of participants to experimental and control group, which expand understanding of collaborative approach, engagement of patient in self-management, theoretical perspective, and use of technology for improving self-management, self-care behaviors and quality of life of older adults with heart failure.

Limitations of this body of research include: (a) small sample sizes; (b) limited attention to mechanisms of change process underlying intervention; (c) limited attention to personal resources of the older adults with heart failure; (d) inadequate description of key concepts of interventions; (e) lack of details of linkage between theory of problem, theory of intervention and health outcomes; (d) use of multiple and self-report outcome measures to measure quality of life and self-management in studies reviewed, resulting in inconsistent results, questioning validity of interventions, and reducing power of studies, making it difficult to draw the conclusion about effectiveness and generalizability of the interventions. For the success of health empowerment interventions to promote self-management among older adults with heart failure, it is crucial to address these limitations in the current research.

All the studies reviewed, were randomized controlled trials, pre-post designs, which minimize bias and threat to internal validity by equalizing all conditions between

intervention and control group, except the intervention. It enhances external validity by defining the population of interest, the intervention is intended to help thus increases confidence with which causal relationships can be inferred.

The diversity of older adults with heart failure is evidential in the literature. Their characteristics such as cultural practices, dietary habits, and socioeconomic status and health practices have considerable effect on self-management in heart failure. The target population in number of studies reviewed was not diverse, whereas it is evidential that heart failure is the leading cause of morbidity and mortality and African Americans as well as other minority populations bear the large proportion of heart failure burden. Therefore, translatability of studies where majority of participants were either White or Caucasian, is limited for the diverse populations (Shearer et al., 2007; Tomita et al., 2009).

Use of theoretical perspectives in eight out of ten studies reviewed, to guide intervention implementation and evaluation was the key finding. Number of theoretical perspectives such as the Theory of Health Empowerment, Roy's Adaptation Model, Orem's Self-care Deficit Theory and Quality Care Model represented middle range and grand theories developed by nurse scientists. It supports the primary need of nursing profession to expand knowledge base of nursing science by testing existing theories. Theoretical perspective integrates the presenting problem, the mechanisms underlying change process and the outcomes in a unified whole. It helps to understand the intervention's active ingredients, mode, dose and delivery and manifestations of the problem it addresses (Sidani & Braden, 2011, p.64). Shearer and colleagues (2007), Tomita et al. (2009), Smeulders et al. (2010), and Bakan & Akyol (2008) integrated

theory of problem, underlying change mechanisms and outcomes as a unified whole in studies reviewed.

Rest of the studies reviewed, did not provide details of linkage between problems of interest, mechanisms underlying change process and outcomes based on theoretical perspective used, which limit the understanding of intervention effects and replication of studies in future (Whittemore & Grey, 2002). In number of studies reviewed the operationalization of major concepts in the intervention, provided insufficient detail as well as inadequate description of concepts. Problem was not specified and was not consistent with the theory of intervention such as lack of confidence, lack of self-acceptance, lack of perceived power and lack of self-efficacy. Without identifying the problems or factors which are associated with the decreased empowerment in older adults with heart failure and assuming, that chronic illness is associated with decreased empowerment might lead to delivery of empowerment interventions to those, who will not be benefited. Future research need to be focused on defining the key concepts and operationalizing them in detail, and identifying the factors leading to decreased empowerment, while testing the theoretical frameworks and evaluating the effectiveness of interventions.

The conceptualization of empowerment perspective was not congruent in the studies reviewed. Confidence to achieve goals under specific conditions reflected the empowerment perspective in Bandura's Self-Efficacy Theory (Smeulders, et al., 2010). In Orem's Self-Care Deficit Theory (Brandon et al., 2009), education, and support to address self-care deficit empower the patient. In Quality Care Model patient-provider and patient-health care team relationships are fundamental for self-management and reflect

empowerment perspective (Duffy, et al., 2010). Social context, experiences and motivation of older adults are the requisites for empowerment in Social Cognitive and Adult Learning Theory (Baker et al., 2011), whereas empowerment is promoted through informational, instrumental, appraisal and emotional support (Tomita, et al., 2009). However, from the Rogerian perspective, empowerment fosters purposeful participation in change for goal attainment of well-being. In the Theory of Health Empowerment, the focus is on inherent potential of the older adults (Shearer, et al., 2007).

Of the eight studies that used theoretical perspective, six reflected the social perspective of empowerment by focusing on social context, interaction between person and environment, and social relationships. Empowerment was conceptualized from a social perspective that includes relationships, and social forces acting on older adults to promote a sense of control and power through transfer of power from one group to the other (Shearer & Reed, 2004). Although, focusing on older adults' strengths, awareness and access of needed resources can be a more sustainable approach. From the life span development perspective of empowerment, human beings are embedded in a dynamic context, are innovative and possess inherent potential (Shearer & Reed, 2004). To design intervention from life span perspective, identifying personal resources and social contextual resources of older adults and building upon these, is extremely important to foster purposeful participation in goal attainment (Shearer, Fleury, Ward & O'Brien, 2012). From the life span perspective, the focus of interventions is on maximizing strengths and minimizing weaknesses, thus optimizing inherent potential (Shearer & Reed, 2004). Future research is needed to facilitate the participation of older adults with heart failure in identifying personal and social contextual resources and accessing social

services available to identify personally relevant health goals and the ways to attain these goals (Shearer, 2009).

Ongoing efforts are required to identify the strengths of older adults with heart failure and barriers to self-management, for designing the interventions targeting specific strengths and barriers thus enhancing their effectiveness. Theory based interventions can enhance understanding of relevant problems, conceptual frameworks, and mechanisms underlying process of change as compared to interventions that lack theoretical perspective (Sidani & Braden, 2010, Shearer, Fleury, & Belyea, 2010).

Bakan and Akyol (2008) and Tomita and colleagues (2009) provided visual representations of theoretical frameworks in their studies, which better enhance the understanding of concepts and their relationships and change mechanisms underlying the intervention. Even in studies which resulted in positive intervention effects, the mechanisms leading to change were not described clearly which limit the translation of research in practice.

In a number of studies reviewed, critical inputs included cognitive behavioral approaches focusing on self-management such as education and counseling, providing information, reinforcing positive beliefs, psychological support, and skill mastery, reinterpretation of symptoms, modeling, social support and motivation. However, participating purposefully after realizing and building the strengths, to enhance self-management, and functional health of older adults with heart failure is crucial for sustaining the effects of interventions, was not considered in most of the studies reviewed.

Modes of delivery, dose and duration of interventions, which improved outcomes, varied in the studies reviewed, thus making it difficult to decide which mode, dose or duration was appropriate to improve the health outcomes. In six of the studies, researchers used telephone calls to reinforce the heart failure education and counseling, which improved the outcomes in most of the studies, but the dose and duration of calls varied across studies, which limited the comparison and applicability of research in future. These findings are consistent with previous reviews that has reported the significant effects of the intervention on self-management and quality of life of older adults with heart failure (Shearer, Fleury, Ward & O'Brien, 2012; Laramée et al., 2003).

Of ten studies reviewed, nine described fidelity, which was lacking details especially about procedural consistency, which lower the confidence to say that effects are due to intervention, thus limiting their applicability in clinical settings. The element of fidelity which was commonly reported in all the studies, was training and qualifications of interventionists. Details of intervention fidelity was provided by Shearer and colleagues (2007), Tomita and colleagues (2009) and Duffy, and colleagues (2010), which can enhance the validity of studies and the confidence to infer that outcomes are due to intervention no other factors.

Multiple outcome measures were used to measure the same outcome variable in different studies such as quality of life, self-care behaviors and self-management. Lack of consistency in the outcome measures makes it difficult to compare results across studies, to generate the best evidence. Most of the outcome measures were based on self-report, which can introduce bias related to personal characteristics and impact validity of studies. Of the ten studies reviewed, objective measures for 6-minute walk test and Low density



lipoproteins were used only in one study by (Bakyan & Akyol, 2008). Although there was significant improvement in self-management, self-care behaviors and quality of life in majority of the studies reviewed but variability in outcome measures can limit the generalizability (Shearer, Fleury, Ward and O'Brien, 2012).

Outcomes related to quality of life improved significantly but varied in relation to general and disease related quality of life as well as which domain of health improved. Brandon and colleagues (2009) reported improvement in quality of life in their study but not among the participants in NYHA class III, therefore the dose, duration and follow up of interventions need to be evaluated, in future for the patients with NYHA class III. The studies in which SF-36 was used to measure the quality of life, reported poor outcomes in physical dimension of health, so in future research the outcome measure such as MLHFQ could help to capture small changes in the physical dimension (Shearer, et al., 2007). Satisfaction of patients and interveners with the program, was not assessed in number of studies, which is crucial for modifying the interventions for the future research.

Considering cost effectiveness, and focusing on economically attractive interventions in the future reviews may provide needed direction for the translation of interventions in the clinical practice (Shearer, Fleury, Ward & O'Brien, 2012). Need to have consensus among researchers on outcome measures, selecting adequate sample, and cost effective analyses to promote translation of effective interventions in the clinical practice is extremely important. Long term follow up to see the sustainability of the outcomes was lacking, may be due to fear of small sample sizes and attrition.

Significant positive outcomes were reported in the telephone delivered, home based, and web based interventions, which may facilitate acceptability of interventions

among participants, while staying at home. Review supports the effectiveness of self-management interventions, to improve self-management, self-care behaviors and quality of life of older adults with heart failure. Chen and Li (2009) in their systematic review “effectiveness of interventions using empowerment concept for patients with chronic disease” also reported that interventions could improve health status, psychological condition and quality of life among patients with chronic diseases.

Based on the findings of this review best practices to improve self-management in older adults with heart failure would include (a) identifying and building personal and social contextual resources of older adults to enhance the sustainability of effects of interventions. (b) need to include patient’s perceptions of their needs and priorities which only they know best, while designing the interventions (c) more focus should be on minority populations as they are affected adversely due to health disparities, (d) designing the interventions based on technology so that patients can avail the benefits by staying at their own place, (e) conducting studies on large samples to enhance the generalizability, (f) need to standardize the outcome measures, intervention dose and delivery and to measure the long term effects to select the best evidence,

## **Conclusion**

The objectives of this review were: (a) to evaluate the evidence on effectiveness of empowerment interventions designed to improve self-management, self-care behaviors and quality of life of older adults with heart failure; (b) to understand the conceptual and methodological issues of empowerment interventions targeted on self-management of heart failure in older adults, and (c) to provide recommendations for future research in heart failure self-management. Findings of this review highlighted the strengths and

limitations of existing self-management strategies for older adults with heart failure, which would help to address the gaps in the research and would guide the future research. Significant improvement in self-management, self-care behaviors and quality of life in older adults with heart failure would contribute remarkably to minimize social and economic burden of heart failure. In addition, it would expand knowledge base of nursing and might act source for theorizing in the future.

### **Specific Research Aims.**

The planned study is a feasibility study to evaluate the acceptability, demand, implementation and efficacy of a theory based Health Empowerment Intervention (HEI) to promote purposeful participation in attainment of personally relevant health outcomes; self-management of heart failure, functional health and well-being of older adults with heart failure. The Theory of Health Empowerment is based on Rogers' Science of Unitary Human Beings' principle of integrality which posits that human beings are in mutual process with their environment in their daily living, and health experience (Shearer, 2007, 2009). In the Theory of Health Empowerment, health empowerment is relational process that emerges from the recognition of personal resources and social contextual resources.

**Specific Aim 1.** Examine the feasibility of the HEI in older adults with heart failure:

1a. what is the acceptability of the HEI in older adults with heart failure as measured by participant evaluation of the intervention procedure.

2a. what is the demand of the HEI in older adults with heart failure as measured through participant attrition rates and attendance of intervention sessions.

3a. what is the implementation fidelity of the HEI as measured through Index of Procedural Consistency.

**Specific Aim 2.** Evaluate the effect of the HEI on theoretical mechanisms; health empowerment and purposeful participation and outcomes; self-management, functional health and well-being among older adults with heart failure.

**Hypothesis.** Older adults with heart failure who receive the HEI will have significant improvement in theoretical mechanisms; health empowerment and outcomes; self-management, functional health and well-being, compared to the attention control group at 6 weeks (post-intervention).

### **Significance of Research**

Research is the link between theory and practice for the development of both theoretical, and practical knowledge for a practice based discipline (Kenney, 2002). As the present research is theory based, thus will act as linkage between theory and practice, and would expand the knowledge base of nursing science. Theory is important for the design, and evaluation of interventions, and for increasing the likelihood for greater prediction, and explanation. Middle range theories which are less abstract and narrow in scope can be tested, and measured in the clinical settings (Good & Moore, 1996). The focus of the present research is also on testing the feasibility of the HEI, based on the Theory of Health Empowerment, a middle range theory, to improve self-management of older adults with heart failure, which would contribute to achieve disciplinary goals of nursing science.

This research is consistent with the objective of Healthy People 2020 initiative to improve the functional health, and quality of life among older adults with heart failure. In

addition, it would also contribute in the direction of American Heart Association's 2020 Impact Goal of improving the cardiovascular health of all Americans by 20% and reducing deaths from cardiovascular diseases by 20% by 2020. The focus of the current research is, to make older adults with heart failure aware about their personal resources, and social contextual resources thus, facilitating their participation in self-management to improve their self-management, functional health, and well-being. Therefore, it will significantly contribute to achieve the missionary, and visionary goals of the American Academy of Nursing (Strategic Goals 2014-2017), American Nurses Association as well as of the National Institute of Nursing Research (2011).

According to the American Academy of Nursing, self-management is the fundamental concern and priority of nursing, focus of nursing theorists, and a nursing sensitive outcome. It is a major part of the national nursing research agenda for making new discoveries to enhance the evidence base, and improve treatment outcomes (National Institute of Health, Oct. 2010). The main goal of self-management interventions is to improve functional health, and quality of life outcomes in patients with chronic conditions. The National Institute of Nursing Research (2011) also advocates, empowering patients with chronic conditions to understand their disease condition, and to identify their resources for taking responsibility for their own health. The contribution of the present research cannot be ignored to add in the direction of national agencies such as American Heart Association (AHA) / American College of Cardiology (2013) to improve quality of life, and healthy behaviors across life span.

For the advancement of nursing science, relationships among theory, research and practice have been emphasized (Im & Chang, 2012; Meleis, 2004). Testing of the theory

based HEI among older adults with heart failure, fosters linkages between theory, practice and research thus, advancing the nursing science. Findings from this research will be linked to the existing literature adding to the knowledge base, and may become a source of theorizing in the future. From the practical perspective, results of this study may inform approaches to promote well-being of older adults thus, reducing the burden of chronic heart failure, on patients and health care system; improving nursing practice (Munhall, 2001). The findings, not only add value to health care delivery but would keep nursing science at the forefront that benefits the clinical practice.

The patient as a key person in decision making regarding care is current emphasis which is likely to continue in the future. While taking evidence to practice, patient's preferences are going to be the priority (Barrett, 2002). From the experiences of older adults living with heart failure, it is evident that they have lack of awareness of personal and social contextual resources. Despite abundance of research among older adults with heart failure, the mechanisms by which personal resources, and social contextual resources influence health, have not been given much importance although, extremely important to produce lasting changes in health outcomes. Future research which explores deeper understanding of patients' strengths, and their role in helping patients to self-manage their disease is mandatory. The importance of significant role played by social network, which is a critical component of the HEI, has been recognized by Cohen, Doyle, Skoner, Rabin and Gwaltney, (1997) and Cohen and Janicki-Deverts, (2009). According to American Heart Association (2015), 80% of patients consulted people from their social networks such as spouse, life partner or adult children about their symptoms prior to hospitalization.

In the present research, patient's self-capacities and social relationships are the core components, which were ignored in majority of interventions in the past (Shearer, Fleury, Ward & O'Brien 2012; Clark & Thompson, 2008). The goals and outcomes will not be predefined by the health professionals rather patient would be involved to discuss and negotiate, while giving priorities to specific situations. Patient engagement in self-management may reduce the health care utilization, therefore contributing significantly to minimize the social and economic burden of heart failure on patient, family, community, and healthcare system (Riegel, et al. 2009). Patients who engage in their self-management are likely to have better quality of life and reduced hospitalizations (Chin & Goldman, 1997; Granger, et al. 2009).

The theory, practice gap, which has been evident over the years, is yet existing (Reed, 2008). Empowerment approach expands one's awareness of resources, as well as understanding of clinical patterns, and their meanings (Johnson, & Reed, 2011; Shearer, 2009). Implementation of theory based intervention is a step toward minimizing the theory practice gap. On the other hand, explication of processes is a new requirement for nursing science, so theory guided intervention would contribute in this direction by explication of the mechanisms underlying change process (Benner, et al., 2009).

### **Relevance to Nursing Science**

A large number of self-management interventions in the past have produced inconsistent results, and failed to identify which components of the intervention has greatest influence on the health outcomes (Clark, Savard & Thompson, 2009). Most of the self-management interventions are based on traditional theoretical perspectives such as social cognitive theory, adult learning theory, self-efficacy theory, mass

communication theory, critical theory and transtheoretical model, which are borrowed from other disciplines therefore, advance the knowledge of respective disciplines. In contrast, the HEI in the present research, is guided by the Theory of Health Empowerment, a middle range theory, guided by Rogers' Science of Unitary Human Beings' principle of integrality thus, theoretical base of this theory belongs to the conceptual systems of nursing (Shearer, 2009). Therefore, testing of the HEI would expand the base of nursing science, not of other disciplines. The focus of numerous self-management interventions is on disease, and weaknesses, whereas focus of the HEI is on strengths, which can sustain the effect on self-management for longer time.

Relevance of the present research to nursing science represents its congruence between world views of researcher, the theorist and the nursing scientists. Worldviews are a systematic set of beliefs that are held true by scientific discipline such as researcher's philosophical orientation, beliefs about the nature of human beings, nursing science, and knowledge (DeGroot, 1988; Monti & Tingen, 1999; Parse, 2000).

Researcher's worldviews about nursing metaparadigm, underwent revolutionary change as she progressed in her PhD program. Catalysts that restructured her belief system include, designing "Mandala" depicting nursing metaparadigm, concept analysis, and theory synthesis as well as theory presentations.

Researcher's beliefs about human beings, environment and nursing used to be that human beings and environment are open systems, represent wheels in motion and interact with their internal and external environment. Interaction between nurse and patient is beneficiary for both as they share information and grow in the respective directions. As per restructured worldviews of researcher, human being is an open system, an energy



field sharing energy with the environment, which is also an open system and energy field. Human beings are irreducible, irreversible wholes, not only the sum of parts. Human beings are in continuous interaction with the environment and changing, change in the system can be identified by recognition of patterns (Rogers, 1992; Shearer, 2009). The new concepts, energy field, and pan dimensionality changed the belief of researcher about environment. Now the environment is an open system, and energy field, irreducible, irreversible and pan-dimensional. Human beings affect the environment and get affected by the environment. In research focused on human beings, the role played by environment cannot be ignored. Readings about empowerment, and empowerment theory restructured the researcher's view about health, now the focus is on life process and strengths of individuals rather than on illness. From the perspective of Theory of Health Empowerment, patient is viewed as an active participant in care rather than a passive recipient (Shearer, 2004, 2009). In the empowerment process nurse facilitates the purposeful participation of patient in the goal attainment of well-being (Shearer, Fleury & Belyea, 2010; Shearer, 2004, 2009).

According to assumptions of the Theory of Health Empowerment, empowerment is inherent power within the individual, and ongoing, a relational process expressive of mutuality between person and environment, an ongoing process of continuous innovative change, expressive of human health pattern of well-being (Shearer, 2009). The assumptions of the Theory of Health Empowerment are influenced by contextual-developmental, unitary-transformative, and simultaneous worldviews. The focus of these worldviews is on interaction of human beings with their environments. The philosophical claims of this theory are influenced by idealism, progressivism and humanism. The

influential worldviews and philosophical claims of the Theory of Health Empowerment are in congruence with the researchers' worldviews and philosophical claims.

Unitary transformative worldview is looked upon as epicenter for holistic thinking and problem solving in nursing science. From the perspective of unitary transformative worldview, human being is viewed as a whole, not only the sum of parts. Human beings are self-organizing fields, interacting with their environments, changing unpredictably, unidirectionally and expressive of human health pattern (Shearer, 2009). In the contextual developmental worldview, the emphasis is on experience accumulated over a life span, which is embedded in the context of the person, and in social interactions (Boyd & Bee, 2009; Shearer, 2007, 2009).

From the perspective of simultaneity worldview, humans are seen as more than the sum of parts, open fields, mutually interacting with the universe, create their own perception of health through personal knowledge and choice (Butts & Rich, 2013). It reflects the perspectives of nursing theorists Rogers (1992) and Parse (1987), in which human and environment are energy fields, integral with each other. Change is continuous, innovative, evolving and progressive toward the human being's potential. In the simultaneity worldview, the approach to empowerment is facilitative not authoritative (Parse, 1987). Nurse and client both share the information and both are empowered during the interaction and empowerment is viewed as relational and inherent process. (Connelly, Keele, Kleinbeck, Schneider & Cobb, 1993; Shearer, 2004, 2009).

In the Theory of Health Empowerment, the notion of modern idealism is that older adults have experienced the physical world in the past, and have representations of those experiences in the mind, which are valued, and used for developing their strengths

and for designing intervention strategies (Shearer, 2004, 2009). In idealism, past experiences are valued because they are constructed by the mind and are not universal (Kant, 1977). Humanism, is another influential philosophy of the Theory of Health Empowerment, which values potential of other human beings, and provide them opportunities to participate in decisions related to their life, believe their knowledge, and experiences accumulated over their life span (The American Humanist Association, 2003). In progressivism, history cannot be ignored, change is continuous and innovative which is based on needs, experiences and abilities of human beings. Philosophical claims of researcher are also based on idealism, humanism and progressivism which are influential philosophies in the Theory of Health Empowerment.

By testing the feasibility of the Theory of Health Empowerment, researcher will definitely add in the substance of nursing theories. The focus of the Theory of Health Empowerment is on person-environment process, for enhancing the well-being of older adults. Strength based perspective embedded in this theory can revolutionize the health care in the 21<sup>st</sup> century by reducing burden of care and cost (Wright, 2006). For continued development of nursing knowledge, there is need to synthesize knowledge from diverse perspectives, such as post empiricism, post modernism, critical theory, post constructivism, feminist, and hermeneutics as well as testing and developing new theoretical thoughts (Kagan, Cowling, & Chinn, 2010). In the present research, combining inductive, and deductive approaches, considering empiricist, historicist, and pragmatic perspectives, using multiple measures to data collection, and using multiple analytical techniques are the diverse approaches to be followed to synthesize nursing knowledge, which shows its relevance to nursing science.

Currently, integration of multiple perspectives in research is the contemporary issue in nursing academia, especially focusing on middle range theories and linking theories to research. Theory of health Empowerment is a middle range theory so its application in research follows the current trend to use middle range theories for advancing nursing science. From the pragmatist's perspective, concept or theory should be evaluated by how effectively it explains, and predicts phenomena rather than describing a mind-independent reality (Clapietro, 1989). Carper (1978) followed neo-American pragmatist ideas, and proposed four ways of knowing described as empirics, aesthetics, ethical, and personal knowledge that influence generation of knowledge. While testing the feasibility of the theory author would be using multiple ways of knowing such as reminiscence, questionnaires, and interviews. In addition, theory testing will be advancing the influential philosophies and perspectives of the theorist by testing this theory.

For the advancement of nursing science, close relationships among theory, research and practice have been emphasized since the early years of nursing discipline (Im & Chang, 2012; Meleis, 2004). Testing of the Theory of Health Empowerment in the real settings among older adults with heart failure, will help in linking theory; practice and research thus, advancing the nursing science. From the practical perspective, it might improve well-being of older adults, thus reducing the burden on patients, and health care system, and can become best evidence to improve nursing practice (Munhall, 2001).

The function of each theory is to solve scientific problems in the discipline by viewing the person as a whole rather than the sum of parts (Jaccard & Jacoby, 2010). In the Theory of Health Empowerment also, the aim is to view the person as unitary, and

build strengths to address the problem by engaging patient as a key person in decision making; focusing on patient's preferences as priority (Barrett, 2002). In future, there is need of strong research designs to take the innovations to clinical practice. Replication of studies in different populations, and settings is essential to confirm that the findings are strong (Polit & Beck, 2012). The Theory of Health Empowerment encompasses the decision-making component, and considers patient preferences as critical elements to improve well-being. Its replication in the future can take it to the highest level of evidence.

### **Summary**

The United States population has almost doubled from 150 million to 310 million people between 1950 and 2010. The proportion of older adults 65 years and above has increased by 15.1% as compared to 9.7% increase in total population between 2000 and 2010. With the increase in aging population, there will be proportional increase in the prevalence of heart failure. Increase in aging population with heart failure has substantial burden of care and cost, on patient, family and healthcare system. Heart failure being a chronic condition, responsibility for day to day management primarily rests with the patient. Thus, designing interventions which focus on patient's strengths rather than weaknesses would be the sustainable step in this direction.

Identifying the strengths of older adults with heart failure and building those strengths can remarkably contribute to minimize the burden of care and cost. Ongoing efforts in this direction would definitely contribute in realizing the goals of national agencies such as National Institute of Nursing Research, American Heart Association,

Centers for Disease Control and Prevention as well as Institute of Medicine to improve self-management in heart failure.

Above all, testing the Theory of Health Empowerment, a middle range theory, would coincide with the contemporary trend of nursing academia and would significantly expand the knowledge base of nursing as well as contribute innovatively in the efforts of nursing scientists' movement from the pre-scientific to scientific era.

## **Chapter 2**

### **THEORETICAL FRAMEWORK**

Intervention theory integrates the theory of presenting problem, intervention critical inputs, theoretical mechanisms, and expected outcomes into a unified whole. In addition, it explicates the mechanisms, the conditions under which mechanisms are operated, and resulting outcomes (Sidani & Braden, 2011, p. 64). In the proposed research, the Theory of Health Empowerment designed by Shearer (2004, 2007, & 2009) will be used to explain and predict the relationships between theory of problem, critical inputs, theoretical mechanisms and expected outcomes (Shearer, Fleury & Belyea, 2010).

This chapter provides an overview of the Theory of Health Empowerment guiding the HEI for older adults with heart failure including origin, focus and empirical base of theory, its underlying assumptions and worldviews, theoretical constructs, critical inputs, theoretical mediators and expected outcomes. Empirical evidence supporting the relevance of key constructs of the theory, for improving self-management, functional health, quality of life and well-being among older adults with heart failure is summarized.

## **Theory of Health Empowerment**

Middle range theories foster development of substantive knowledge, through explicating and expanding phenomena of interest to nursing (Fawcett, 1984). Being narrower in scope, concerned with less abstract and specific phenomena, composed of fewer concepts and propositions, appropriate for empirical testing and applicable directly to practice for explanation and implementation, the use of middle range theories has garnered much attention in research (Fawcett, 2005; Smith & Liehr, 2014; Walker & Avant, 2011; Meleis, 1997). Increased use of middle range theories is evident in the review of empowerment interventions for older adults by Shearer, Fleury, Ward and O'Brien (2012) and in the review of interventions to improve self-management, self-care behaviors and quality of life among older adults with heart failure, conducted by the researcher in the present research.

According to Shearer, (2009), the Theory of Health Empowerment is a middle range theory, guided by Rogers' Science of Unitary Human Beings' principle of integrality; human beings are in continuous interaction with their environment in their daily living, and health experience, which results in change, reflected through pattern, self-organization, diversity and innovation, by focusing on individual values and beliefs about health (Rogers, 1992, 1994). Health empowerment from the perspective of the Theory of Health Empowerment, is a dynamic health process, which emphasizes purposeful participation in a process of changing oneself, and one's environment, recognizing patterns and engaging inner resources for well-being (Shearer & Reed, 2004; Shearer, 2007, 2009). The theory identifies health empowerment as a relational process,

which emerges from a synthesis of personal resources and social contextual resources (Shearer, 2009).

**Origin of theory.** The origin of the Theory of Health Empowerment is rooted in the practice, and research experience of the theorist. Shearer (2011) described her iterative process of developing the Theory of Health Empowerment. Her past practical experiences which were lying dormant, reawakened during her doctoral education and provided the base for theory building. She blended her undergraduate experiences, clarified her worldviews based on the readings and discussion about contextual-dialectic (Pepper, 1948), life span development literature (Lerner, 1997), simultaneity worldview (Parse, 1987) and Unitary transformative worldview (Newman, 1992). In addition, concept analysis and clarification of the concept empowerment, and qualitative as well as her quantitative research, provided a foundation for her theory (Shearer, 2004, 2007, 2009; Shearer & Fleury, 2006). Initial development and testing her model of health empowerment, proposed positive relationships between person-environment, and conceptualized it in two concepts: contextual factors, and relational factors, but later she named contextual factors as personal resources, and relational factors as social contextual resources (Shearer, 2004).

**Focus of theory.** The main focus of the Theory of Health Empowerment is on the outcome well-being. As the focus of the present research is on well-being of older adults with heart failure, so theoretical framework of the Theory of Health empowerment was used as a guiding framework. In the health empowerment approach the patient is viewed as being able to purposefully participate in the process of change (Shearer, 2009). The Theory of Health Empowerment emphasizes a focus on strengths including personal



resources such as self-capacities (internal strengths) and on social contextual resources such as social support, social network and social services available (external strengths) (Shearer, 2004). The theory emphasizes recognition of and engagement in personal and social contextual resources to purposefully participate in the attainment of health goals, thereby promoting well-being (Shearer, 2009). Empowerment emerges from the realization and building upon, of personal resources and social contextual resources (Shearer, 2004, 2009).

**Assumptions and worldviews.** The foundation of the Theory of Health Empowerment includes, assumptions, worldviews, and philosophies. Assumptions include:

1. Empowerment is the power that is inherent in the individual and ongoing. It exists as an essential characteristic or belongs to the individual by its nature.  
Empowerment is not fostered by others, individuals empower themselves therefore, helping the individuals to realize this power may facilitate their participation in decision making and goal setting to attain their goal of well-being.
2. Empowerment is a relational process expressive of mutuality between person and environment. Person and environment are in mutual and continuous exchange of matter and energy and affect each other in the process.
3. Empowerment is an ongoing process of change that is continuously innovative.  
When individuals face specific situations or challenges, they either find or facilitated to find solutions, according to their choices and priorities, a pathway to innovation. The process of change is continuously innovative and evolving throughout the life span of an individual.

4. Empowerment is expressive of a human health pattern of well-being (Shearer, 2009). Health patterning enhances the power for realizing human's potential for change which optimizes one's well-being (Shearer, 2004). The change is reflected through patterns or organization which can be assessed through nursing knowledge pertaining to nursing practice and research.

Worldviews influencing the Theory of Health Empowerment about metaparadigm include, simultaneous worldview, contextual-developmental, and unitary-transformative (Shearer, 2000, 2004, 2009), however inclination of theorist is more toward simultaneity. In the simultaneity paradigm, human beings are seen as more than the sum of the parts; they are open, and mutually interacting with the universe, and create their own perception of health through personal knowledge and choice (Butts & Rich, 2013; Rogers, 1992). This reflects the perspective of nursing theorists Rogers (1992) and Parse (1987) in which human and environment are energy fields, integral with each other and are identified by pattern manifestation which reflects innovative wholeness.

Change is continuous, innovative, evolving and progressive toward the human being's potential. From the perspective of simultaneity worldview, the approach to empowerment is facilitative, not authoritative (Parse, 1987) and empowerment is viewed as relational and inherent process (Connelly, Keele, Kleinbeck, Schneider & Cobb, 1993; Shearer, 2004, 2009). In health empowerment, the emphasis is on inherent potential, choices and participation in health. (Shearer, 2000). Human beings optimize health through personal knowledge and choices based on personal situation and values (Shearer, 2000). The interaction between human beings and the environment is reciprocal where

human beings affect their environment, and are affected by the environment (Shearer, & Fleury, 2006).

In the contextual developmental worldview, the emphasis is on experience accumulated over a life span, which is embedded in the context of the person, and in the social interactions (Boyd & Bee, 2009; Shearer, 2007). From this perspective individuals differ by their context and experiences thus, individualization of strategies is essential, one strategy cannot fit all. According to unitary-transformative worldview, human beings are viewed as a whole, not only the sum of the parts, self-organizing fields, interacting with their environments, and change is unpredictable, unidirectional and expressive of human health pattern (Newman, 1992).

**Philosophical claims.** Philosophical claims of the Theory of Health Empowerment are based on idealism, progressivism, and humanism. According to idealism, the epistemic basis of claims about the phenomena of interest are perceptual experiences (Searle, 1995). In the Theory of Health Empowerment, the notion of modern idealism is reflected through the strengths and experiences of older adults which are valued, and used for designing the intervention strategies, and develop the strengths of older adults. Progressive scientific view holds that historical achievements and experiences are a must for the knowledge building in science (Harold, 2003). Similarly, the focus of the Health Empowerment Intervention to build on past experiences of older adults and resources available to enhance purposeful participation in change process, depicts progressivism. Humanists see potential in people at all levels of society, and encourage an extension of participatory democracy to provide equal opportunities for everyone (The American Humanist Association, 2003). In the Theory of Health

Empowerment, personal resources which include past experiences and knowledge, awareness, choices and freedom to act intentionally, reflect humanism.

**Empirical base of theory.** Initially, Shearer (2004) conducted a study to determine the relationships of contextual factors operationalized as demographics (age, ethnicity, marital status, number of children, education and household income) and relational factors operationalized as social and professional support to health empowerment in women with children, and found that these factors explained significant variance in health empowerment measured as knowing participation in change and life style behavior. Shearer and Fleury (2006) conducted a qualitative study which clarified the social support needs, and resources including contextual factors used by older women to facilitate health empowerment. To refine her Theory of Health Empowerment further, Shearer (2007) conducted a qualitative study with home bound older women. Health empowerment was identified as a participatory process, women clarified the role of personal resources, including self-capacities that promoted personal growth and change, and awareness of social contextual resources that fostered purposeful participation in the attainment of personally valued goals leading to well-being (Shearer, 2007).

Based on the Theory of Health Empowerment, Shearer and colleagues (2007) conducted a study to examine the effects of a telephone delivered empowerment intervention on clinically and theoretically relevant outcomes in patients with heart failure, including purposeful participation in goal attainment, self-management of heart failure and perception of functional health. The telephone delivered empowerment intervention facilitated self-management among the intervention group. The results

provide a beginning understanding of the strategies to improve self-management among patients with heart failure and future research.

Shearer (2009) described a theory driven approach to develop an intervention designed to foster awareness of and engagement in personal resources and social contextual resources. Shearer, Fleury and Belyea (2010) conducted a randomized controlled trial to evaluate the feasibility of the HEI and to explore its effect on the theoretical mediating variables of health empowerment and purposeful participation in goal attainment and outcome variables of well-being with homebound older adults. The intervention group had significant attainment of their goals and increase in the personal growth from baseline to 6 weeks as compared to attention control group. Overall the intervention was acceptable and had significant impact on health empowerment and purposeful participation in goal attainment.

Shearer, Fleury, Ward and O'Brien, (2012) conducted a critical review of empowerment intervention studies with community-dwelling older adults. The findings support the efficacy of empowerment interventions to enhance management of chronic conditions among older adults and to improve their well-being. The Theory of Health Empowerment has been used as guiding framework for research by doctoral students (Curtis, 2011).

### **Link Between Theory of Intervention and Theory of Problem**

The Theory of Health Empowerment addresses a lack of awareness and engagement in personal resources, and social contextual resources in older adults with heart failure. Facilitating awareness of personal resources and social contextual resources, may enhance their ability to knowingly participate in decision making, and goal setting,

thus facilitating the attainment of their health goals, thereby promoting well-being (Administration on Aging, 2012; Cowger, 1994; Shearer, Greenberg & Cisar, 2007). Engaging older adults in their self-management by providing opportunities to make informed decisions, is the current emphasis rather than making them dependent (Lachman & Firth, 2004; Rowe & Kahn, 1997).

Patient empowerment refers to well informed patients, taking responsibility for their own health (Anderson & Funnell, 2009; Bodenheimer, Lorig, Holman, & Gurbach, 2002). For patient empowerment, there is need of a person-centered approach, where patients are treated as experts and the health care providers as facilitators (Shearer, 2004, 2000, 2009; Shearer & Fleury, 2006; Shearer & Reed, 2004). The fear of becoming dependent, disability, lack of social support, and lack of awareness of social services available, immensely impact self-management and functional health of older adults with heart failure (Waterworth & Gott, 2010). The patient-professional partnership, which includes collaborative care and self-management education, is a new paradigm to facilitate purposeful participation in self-management. The core of collaborative care is to recognize patients as experts of their own lives, in collaboration with health care professionals as facilitators of participatory decision making process, which is the essence of the HEI (Shearer, 2009).

Heart failure is chronic, debilitating and depressive syndrome, which has substantial impact on the well-being and quality of life of older adults, therefore making self-management more complex. In addition, challenges related to age, comorbid conditions, medications and life style modification may lead to distress and the feeling of powerlessness among older adults with heart failure (Brannstrom, et al., 2006;

Martensson, et al., 1998). According to Freire, (1973) powerlessness occurs when an individual assumes the role of an object acted upon by environment, rather than a subject acting with the environment. The HEI is designed to foster well-being among older adults by focusing on their strengths and engaging them in their own care, by acting with the environment rather than acted upon by the environment.

According to Aujoulat, et al. (2007) patient empowerment has two dimensions, intrapersonal and interpersonal. From the intrapersonal perspective, empowerment is considered as a process of personal transformation (Paterson, 2001; Golant, Altman, & Martin, 2003). From the interpersonal perspective, the empowerment is the process of sharing knowledge, values and power. Empowering potential reflects continuous process of growth and development of individuals guided by numerous strategies which result in emergence of new health patterns (Fleury, 1991). The emergence of the person's potential because of empowerment process is an accomplishment within a true relationship (McWilliam, et al., 1997; Paterson, 2001; Shearer, 2007). Health Empowerment Intervention encompasses the relational, and dynamic process which can help older adults to participate purposefully in continued growth (Rodin & Langer, 1977; Shearer, 2009).

Building of strengths which is a key element of the Theory of Health Empowerment, may facilitate older adults with heart failure to realize their potential through reminiscence and how they have been successful in their roles, and have faced and managed the life situations in the past. The lifelong treasure of knowledge and experience of older adults with heart failure is a valued resource that will be utilized to

optimize their self-management, functional health and well-being (Shearer, et al., 2007; Shearer, et al., 2010).

Social contextual resources such as social support and social service utilization play an important role to improve self-management in heart failure. Shearer (2000) documented that social support was the key strength of women and facilitated women's sense of power over personal health, in the similar way for older adults with heart failure, social relations can facilitate a sense of power, and well-being. From the perspective of empowerment, the theory of problem, and the theory of intervention are congruent.

### **Health Empowerment Theoretical Framework**

The Theory of Health Empowerment is designed by Shearer (2004, 2009) to promote the use of personal and social contextual resources with the goal of fostering well-being in older adults. According to Shearer (2009), the theoretical foundations of the Theory of Health Empowerment are based on four assumptions: empowerment is inherent, relational, continuous and expressive of human health pattern. In the conceptual framework, health empowerment is identified as emanating from a synthesis of personal resources and social contextual resources.



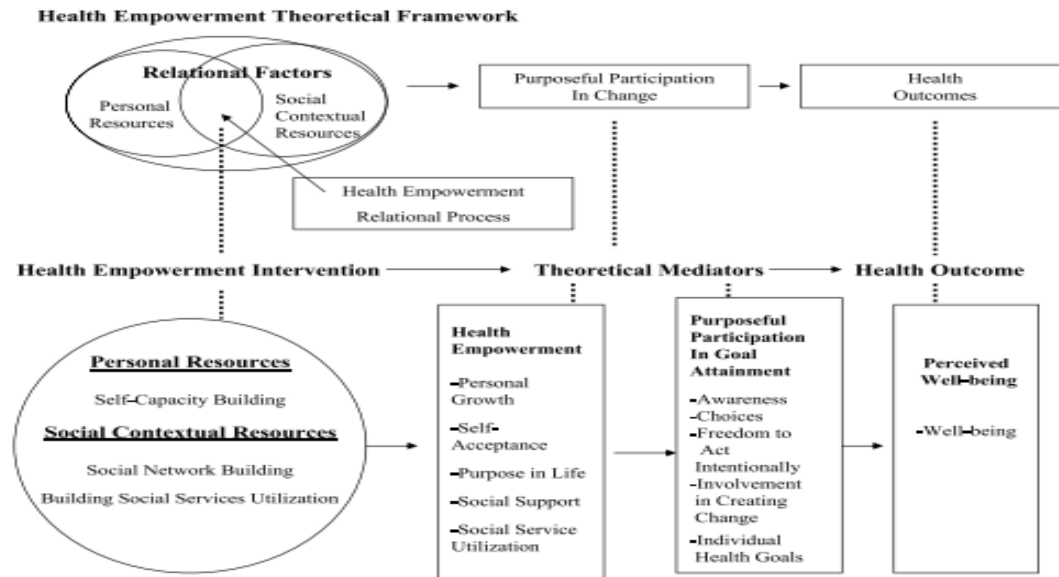


Figure 2. Health Empowerment Theoretical Framework (Shearer, 2009)

Personal resources identify unique characteristics of older adults, including self-capacities, and social contextual resources including social support, social networks, and social services support available. From this perspective, empowerment is a dynamic and relational process which emphasizes purposeful participation in a process of changing oneself and one’s environment, recognizing human health patterns, and engaging with personal resources and social contextual resources for well-being (Shearer & Reed, 2004).

### Key concepts

Primary concepts within the Theory of Health Empowerment include personal resources, social contextual resources, and theoretical mechanisms of health empowerment and purposeful participation in goal attainment and the health outcome of perceived well-being (Figure 1).

**Personal resources.** Personal resources in the Theory of Health Empowerment include unique characteristics of older adults, such as self-capacity (Shearer, 2009). Personal resources include unique characteristics which are outside the scope of the demographics (Shearer, 2007). Self-capacity is viewed as inherent strength and mental, emotional or physical ability to do something. Shearer (2007), found that personal resources were reflected through the unique characteristics, such as promoting change, and growth through recognizing personal strengths, and taking care of self, among older women. Recognizing personal resources led to the perception that they were strong individuals, had purpose in life and were taking care of their families. Self-capacity includes the perception of strengths among older adults that they were strong individuals, who took care of others, and had managed situations in their life. Facilitating the recognition of their strengths, may help older adults to make decisions to change oneself, or one's environment, and to face the challenges of life (Appelbaum & Grisso, 1988; Lai & Karlawish, 2007; Naik, Lai, Kunik & Dyer, 2008).

Older adults suffering with heart failure are exposed to numerous challenges related to disease condition and age, such as physical, physiological and psychosocial changes. Comorbid conditions, polypharmacy, multiple healthcare providers due to fragmentation of the health care system, as well as multiple health facilities in the absence of effective transition care models, have increased the complexity in the management of care in heart failure. In addition, issues like poverty, isolation, lack of insurance and poor socioeconomic conditions may fuel the situation further. Despite these challenges of chronicity, multiplicity and complexity, older adults with heart failure have strengths perceived as a personal resource. In the health empowerment process

emphasis is on facilitating the awareness of older adults of their strengths and building upon them, to engage them in purposeful participation in goal attainment (Forman, et al., 2011; Shearer, 2007, 2009).

In a study conducted by Zambroski (2003), older adults reported a variety of personal resources such as their own experience; input from significant others, opinions of neighbors and friends, and a belief in God that helped them to cope with heart failure. Internal strengths lie within interpersonal motivation, emotions, and the ability to think clearly while external strengths come from the family network, significant others, voluntary organizations, community groups and public institutions.

Intervention studies designed to improve the individual's awareness of personal resources have proved effective in initiating activity level, and sociability (Rodin & Langer, 1977). A collaborative approach encompassing unconditional respect for values and beliefs, and accurate empathy, might help older adults with heart failure to actualize their full potential to manage their chronic condition (Riegel, et al. 2006). Peoples' belief in their own abilities and unique personal characteristics may help to foster confidence in their ability to take initiative in changing their lives (Lord & Hutchison 1993; Yu, Lee, Woo & Thompson, 2004).

**Social contextual resources.** From the perspective of the Theory of Health Empowerment, social contextual resources include social support, social network and social services utilization which are related to physical and psychological well-being of older adults (Shearer, 2009). Social support refers to the reciprocal exchange of assistance, and protection, both tangible and intangible that shepherd a person through life (Langford, et al., 1997). Social support influences symptoms, functional status, health

perceptions and overall quality of life. Social support is positively related to subjective well-being (Langford, et al., 1997; Pinguart, 2001). Interpersonal relationships provide emotional, and appraisal support as well as instrumental, and informational support (Gallagher, Luttik & Jaarsma 2011). The quality of relationships of older adults with their family members is associated with their personal feelings of well-being (Berkman, et al., 2000; Ryan & Willits, 2007).

In a study of participants in a congregate meal program, Shearer and Fleury (2006) reported that social resources fostered health empowerment by being continuously available, and providing support to face life situations. Women reported support in the form of information, feedback and reinforcement as well as acknowledgement, and encouragement for sharing their feelings. Social services such as community and organizational agencies provided opportunities for the participants to remain active in the community thus building individual and collective capacities. Active participation through neighborhood resources, government funded programs such as senior centers, and social service programs, helped the women to be connected, and stay mentally and physically active.

Social support and environmental factors have potential to improve heart failure outcomes (Bennett, et al., 2001; Rockwell & Riegel 2001). Simpson and colleagues (2002) found that patients having a network of friends and family members to support them, reported less barriers to take medications for heart failure. Lyyra and Heikkinen (2006) and Murberg (2004) reported a significant relationship between mortality and social network among stable congestive heart failure patients, which supported that patients with strong social network of family and friends lived longer. According to

Litwin and Shiovitz-Ezra (2006), older adults who were embedded in networks, depicting diverse relationship types, such as ties with friends and community networks, showed lower risk of mortality than the participants who had restricted networks.

In their studies, Friedmann and colleagues (2006), Luttik and colleagues (2005), and Coyne (2001) reported the positive relationship between social support and health related quality of life. High levels of perceived social support helped patients to cope with stress associated with debilitating disease to better adherence to self-management, to improve the quality of life, and to lower hospital admission rates (Dimatto, 2004; Happ, Naylor & Roe-Prior, 1997). Functional support had stronger association with adherence than structural support, which suggests that mere number and presence of other people does not matter, it is the quality of relationships that matters (Dimatto, 2004).

Kieffer (1984) identified relationships as part of developmental processes of empowerment, which provided social and emotional support as well as raised critical awareness of the participants. In addition, Christens (2010) identified that intentional one to one relationship development broaden participants' networks of relationships, and helped them to develop new understanding of the social world. Social relations expand one's own identity, develop a public self and help in transformation of self through collective decision making (Keddy, 2001). Social support provided by caregivers was a valuable and reliable resource for the older adults with heart failure to manage their chronic condition (Edmonds, et al., 2005, Patel, et al., 2007).

From the perspective of the Theory of Health Empowerment, social services include community and organizational structures such as home nursing, house cleaning, shopping, transportation, day care, social outings, home visits, senior centers, dial a ride

or cab connection, public health and private for profit and non-profit organizations and allied health services (Shearer, 2009; Low, Yap & Brodaty, 2011). Gott and colleagues (2007) explored the provision and barriers, related to social services for older adults with heart failure, and found that accessing the services, was the key barrier along with inadequate and inappropriate services. Information on how to access social services, is crucial for their utilization by older adults with heart failure.

**Health empowerment.** In the Theory of Health Empowerment, health empowerment is a theoretical mediator. Empowerment emerges from awareness of personal resources and social contextual resources for purposeful participation in goal attainment (Shearer, 2007, 2009). Health empowerment from the perspective of the Theory of Health Empowerment is a dynamic health process, which emphasizes purposeful participation in a process of changing oneself, and one's environment, recognizing patterns, and engaging inner resources for attaining the goal of well-being (Shearer & Reed, 2004).

Empowerment is reflected through personal growth, purpose in life, self-acceptance, social network and social service utilization and leads to purposeful participation in goal attainment, thereby promoting well-being (Shearer, 2004, 2007). The essence of empowerment as an active process is the human activity in the direction of change from the passive to an active state. The empowerment process integrates self-acceptance and self-confidence, social and political understanding as well as individual ability to participate in decision making (Parsons, 1988).

**Purposeful participation in change.** Purposeful participation in goal attainment is reflected through awareness, choices, freedom to act intentionally, and involvement in

creating change (Barrett, 1990). Participation in determining health goals and making choices depends upon awareness, and freedom to act intentionally (Caroselli & Barrett, 1998). Shearer (2004, 2007) has supported purposeful participation in goal attainment as a core component of health empowerment process. Home bound older women associated their purposeful participation in change with identification of health goals and awareness of personal, and social contextual resources (Shearer, 2007).

Participation is a process with the patient and health care professional, in which patient is active in providing information, sharing preferences, and priorities for treatment and management, asking questions, and contributing to the identification of the best approaches congruent with his/her needs (Small, et al., 2013; Shearer, 2009).

Participation of patients in their own care may be enhanced by facilitating their awareness that they have potential to participate, providing information, and opportunities to grow, facilitating collaboration with family, friends and providers and providing autonomy in decision making (Laschinger, et al., 2010).

In a study of telephone delivered intervention, Shearer and colleagues (2007) reported that patients with heart failure purposefully participated in identifying and attaining their health goals. For example, a man who knew the importance of weight monitoring, used a portable scale while he took his motorcycle trip, rather than cancelling the trip. Similarly, another man worked with his daughter to locate a mail order pharmacy selling the prescription medications at cheaper rate than the local pharmacy. The examples reflect that how HEI facilitated purposeful participation in solving their own problems to attain their health goals.

Shearer, Fleury, and Belyea (2010) reported that there were significant differences between men in intervention and attention control group for the scores of awareness, choices and involvement in creating change. The findings supported that intervention facilitated men's awareness about the choice to participate in determining and attaining their health goals. Thompson (2007) in his review article, "the meaning of patient involvement and participation in health care consultations: a taxonomy", reported that participation is co-determined by patients, and health professionals and results from reciprocal dialogue and shared decision making. However, not everyone wants to participate, participation in self-management depends on functional limitation, seriousness of illness, personal characteristics of patient and rapport between patient and health professional (Riegel & Carlson, 2002; Granger, et al., 2009).

**Goal attainment.** Goal attainment is possible when older adults with heart failure are aware of and engage with their resources, have purpose in life, and purposefully participate in heart failure management (Shearer, 2009). In a review of qualitative studies on living with heart failure, patients reported a variety of personal resources such as own experience, support from family and friends, opinion of neighbors and friends and belief in God that helped them to attain their health goals (Zambroski, 2003). Older adults with heart failure described ways to reconcile living with heart failure, such as finding purpose in life, and meaning in the illness experience through caring for loved ones and believing in God (Mahoney, 2001).

**Well-being.** Well-being is viewed as a primary health outcome from the perspective of the Theory of Health Empowerment. Well-being is defined as life satisfaction and harmony (Gueldner, 2005). Emotional well-being is reflected through



perceived life satisfaction, happiness, cheerfulness and peacefulness, psychological well-being includes self-acceptance, personal growth, hopefulness, purpose in life, control of one's environment, self-direction and positive relationships whereas social well-being is reflected through social acceptance, belief in potential of people, usefulness to society and sense of community (Ryff & Keyes, 1995). Age, income, and education are positively related to subjective well-being whereas loneliness is negatively associated with emotional well-being (Yang, et al., 2008). Psychosocial resources such as optimism and social support have been found as predictors of well-being among older adults (Ferguson & Goodwin, 2010; Seeman, Lusignolo, Albert & Berkman, 2001).

Subjective well-being represents a positive attitude toward life which includes feeling of happiness, morale, positive affect and life satisfaction (Diener, 1984; Litwin & Shiovitz-Ezra, 2011). The frequency and intensity of these emotions have independent influences on well-being. Well-being of patients with heart failure is influenced by the progressive and the depressive course of disease, as well as lack of awareness of personal and social contextual resources (Brodie, Inoue, & Shaw, 2008; Shearer, 2009). Ferguson and Goodwin (2010) evaluated the role of psychosocial resources to improve well-being among older adults and found that positive affect was a predictor of subjective and psychosocial well-being and perceived social support mediated the relationship (Seeman, et al., 2001). Inner strengths such as self-capacities are an important resource that promote well-being, as well as purpose in life, an intentional characteristic of well-being (George, 2010). Empowerment interventions promote awareness of personal and social contextual resources among heart failure patients and enhance well-being (Shearer, 2007).

## **Theoretical Basis of the Health Empowerment Intervention**

The HEI for older adults with heart failure is guided by conceptual framework of the Theory of Health Empowerment. The HEI is aimed at facilitating the participation of older adults in the process of recognizing personal resources, and social contextual resources and identifying desired health goals, and engaging in ways to attain these goals. Theoretical elements of the HEI include: (a) problem; (b) critical inputs; (c) mediating processes; and (d) expected outcomes. The theoretical elements of the HEI for older adults with heart failure are summarized in Table 3.

**Problem.** In the case of older adults with heart failure, lack of awareness of personal resources and social contextual resources because of the burden of disease, and its consequences, can influence older adults' self-management, functional health and well-being substantially (Brannstrom, et al., 2006). In the same way, their social relationships are also affected immensely due to fatigue, medications, and age related issues. They may have lack of knowledge related to social services available; to be availed whenever required (Pihl, et al., 2011). Despite all these deficits, older adults have strengths such as self-capacities, and social networks, which have been largely ignored in the past research, paying more attention to the disease and symptoms (Shearer, 2009).

Table 3.  
*Theoretical Elements of HEI for Older Adults with Heart Failure*

<b>Problem</b>	<b>Critical Inputs</b>	<b>Mediating Processes</b>	<b>Expected Outcomes</b>	<b>Structural elements</b>
<ul style="list-style-type: none"> <li>• Lack of awareness of personal resources</li> <li>• Lack of awareness of social contextual resources</li> </ul>	<ul style="list-style-type: none"> <li>• Personal resources (self-capacity)</li> <li>• Social contextual resources (social network and social service utilization)</li> </ul>	Health empowerment <ul style="list-style-type: none"> <li>• Personal growth</li> <li>• Purpose in life</li> <li>• Self-acceptance</li> <li>• Social support</li> <li>• Social service utilization</li> </ul> Purposeful participation in goal attainment <ul style="list-style-type: none"> <li>• Awareness</li> <li>• Choices</li> <li>• Freedom to act intentionally</li> <li>• Involvement in creating change</li> <li>• Individual health outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• Self-management</li> <li>• Functional health</li> <li>• Well-being</li> </ul>	<ul style="list-style-type: none"> <li>• Participant characteristics</li> <li>• Interventionist characteristics</li> <li>• Contextual characteristics</li> </ul>

From the perspective of an empowerment approach, empowerment oriented language can help to redefine our roles as professional helpers which replaces the term client with participant, and expert with the facilitator (Rappaport, et al., 1985). Identifying strengths and building upon them, for purposeful participation in attaining personally relevant health goals are vital elements of empowerment approach, to optimize self-management, functional health and well-being among older adults (Shearer, 2004; Shearer & Fleury, 2006; Andersson, Eriksson, & Nordgren, 2012). In an empowerment approach the focus is on older adults as unique persons, having their own experiences and resources, which may be utilized to develop strategies for enhancing perceived quality of life and well-being.

**Critical inputs.** Critical inputs of an intervention consist of components and activities included in the intervention (Sidani & Braden, 2011). Critical inputs for the HEI in older adults with heart failure include personal resources and social contextual resources. Personal resources include self-capacities (rediscovering self, reinforcing strengths, building knowledge about heart failure and promoting problem solving) and social contextual resources include social network building and building social service utilization. Critical aspects of the treatment to enhance the health empowerment of older adults include, facilitating recognition and engagement, and building of self-capacity, supportive social networks, and social service utilization (Shearer, 2009).

For realization of personal resources, the HEI incorporates reminiscence, where each participant is encouraged to recall a time that they faced a situation, participated in decision making and goal setting, and attained their health goals. Reminiscence is the process of recalling past experiences, which provide an opportunity to remember the richness of the past, to realize their potential and take control of their life (Shearer, 2009). Reminiscence may promote the unfolding of life changing experiences that could facilitate recognition, and building of self-capacity. Through reminiscence activities, older adults with heart failure will have an opportunity to remember their past experiences, and identify the inherent strengths that will enhance their participation in self-management and optimize their functional health, quality of life, and well-being. The HEI fosters recognition of strengths, purpose in life, and fosters personal growth and self-acceptance (Shearer, 2009), thus would help the older adults with heart failure, who experience lack of purpose in life, personal growth and self-acceptance.

The HEI promotes the use of self-talk for positive thinking, using thought restructuring, a strategy used to promote positive, and realistic optimism. In thought restructuring the negative thought is interrupted by using verbal command STOP. If a negative message is difficult to change, the participant is taught breathing technique to relax, which help them to focus on their strengths, and to restructure the negative thought into positive (Shearer, 2009). The HEI facilitates the identification of life goals, and experiences that reflect purpose in life, and help the individual to grow and diversify.

Social network building is accomplished through a guided plan, designed to increase awareness of social contextual resources and reinforce identified social resources (Shearer, 2009). Older adults with heart failure will be encouraged to identify social network resources as well as supportive people, and to identify the benefits, and limitations of support provided by them. Problem solving techniques would help the older adults to identify other supportive persons.

Building social service utilization includes the recall of social services used in the past, as well as increasing awareness of new resources specific to the needs of older adults with heart failure. Information about the available resources, and how to access these, including needed materials, would be provided to older adults with heart failure (Shearer, 2009).

Problem solving and role playing are used as strategies to facilitate reconnecting with others, seeking help, contacting, and communicating with social service agencies. Utilization of social services as needed, can improve quality of life of older adults with heart failure. The key elements of the HEI are building trust and rapport with the participants and maintaining patient-centered approach (Shearer, 2004, 2007, & 2009).

Older adults typically use wisdom, experience, and positive attitude to address life challenges, thus health care professionals should pay attention to older adult's strengths while assisting them to participate in decision making. Engagement through purposeful participation in decision making, goal setting and goal attainment is crucial for the empowerment of older adults with heart failure.

**Theoretical mechanisms.** Mediating variables specifies cause and effect sequence between problem, intervention and outcome as well as clarifies the essential process of change. Mediators link the independent variable with the dependent variable (Sidani & Braden, 2011). The HEI leads to a transformation in which individual identifies his/her ability to participate purposefully in goal attainment, and facilitates the awareness of resources, and how to access them for enhancing self-management and functional health, and well-being. Health empowerment and purposeful participation are mediators which link the critical inputs with the outcome of well-being.

**Health empowerment.** Health empowerment is reflected through personal growth, purpose in life, self-acceptance, social support and social service utilization. Personal growth means that the individual has a feeling of continued development, sees self as growing and expanding, and is open to new experiences, has a sense of realizing his or her potential, sees improvement in self and behavior over time and is changing in ways that reflect increased self-knowledge, and effectiveness (Shearer, 2007, 2009; Shearer, Fleury & Belyea, 2010).

Among older adults with heart failure this process of personal growth will be facilitated by the health professionals through problem solving, and self-advocacy, so that they can realize their worth, and don't feel a lack of confidence (Bosworth, et al., 2004).

Identifying and strengthening patient's self-capacities can increase patients' self-confidence, and satisfaction with care, and optimize health outcomes (Bagheri, Yaghmaei, Ashktorab, & Zayeri, 2012; Shearer, 2007).

Purpose in life means the individual has goals in life, and a sense of directness, realizes the meaningfulness of present and past life, and has aims, and objectives for living. It is evident in the literature that older adults with heart failure reported powerlessness, and lack of purpose in life therefore, the HEI may foster purpose in life such as helping others, connecting with others, and engaging in hobbies (Brannstrom, et al., 2006; Martensson, et al., 1998; Ryff & Keyes, 1995). Self-acceptance means that an individual possesses a positive attitude toward the self, acknowledges and accepts multiple aspects of self, including chronic disease such as heart failure, including good and bad qualities, as well as feels positive about past life.

Social support and social service utilization reflect that an individual has a warm, satisfying, trusting relationships with others, is concerned about the welfare of others, understands the give and take of human relationships and has awareness of social services available and utilizes them whenever needed (Ryff & Keyes, 1995). Building social support and social network and information about the available social services, can contribute significantly toward attainment of health goals. Patients with heart failure require support, especially from family members to assist them in symptom management, and taking medications, offering cues for action, helping with transportation for attending health care appointments, assisting with household activities, and emotional support (Wingham, Harding, Britten & Dalal, 2014).

***Purposeful participation.*** Participation in change is characterized by the continuous mutual process of people with their environments. Purposeful participation has four measurable dimensions such as awareness, choices, freedom to act intentionally and involvement in creating change. Awareness of the context in which people live has significant impact on the well-being of individuals. The way in which people make their own choices, depends upon the opportunities, and services available, and freedom to act intentionally as well as involvement in creating change results from the awareness of resources (Barrett, 2010). According to Elder (1998), life choices are contingent on the opportunities and constraints of social structure and culture. The life course of individuals is embedded in and shaped by historical times, and places, they experience throughout their lives.

In a study of participants in a senior congregate meal site, Shearer and Fleury (2006) concluded that social resources supported the participants through consistent availability and presence in addressing life changes within the aging process. Support came in the form of information, feedback, and reinforcement as well as encouragement for sharing the feelings. The contextual resources consisted of opportunities to participate in the community activities, creating, and sustaining friendship, and remaining active. Social services utilized by the participants were senior centers, social service programs and dial-a-ride cab.

***Intervention outcomes.*** The goal of the HEI is to optimize self-management, functional health, and well-being of older adults with heart failure. Health empowerment outcomes include, awareness of personal and social contextual resources, self-growth,



purpose in life, self-acceptance, social service utilization, participating knowingly in decision making and goal setting to attain goal of well-being.

### **Summary**

Despite several interventions focusing on self-management of older adults with heart failure, the mortality and hospitalization rates have not changed over the last two decades. The findings of the interventional research to optimize self-management in older adults with heart failure are inconsistent, which demands ongoing efforts to identify the factors related to the poor outcomes. Currently the focus of self-management interventions is on disease and signs and symptoms, with limited attention paid to strengths of older adults with heart failure. Identifying and building the personal resources and social contextual resources may result in sustainable effects of the intervention.

The HEI, which encompasses a strength based perspective and a patient centered approach, may contribute significantly to optimize self-management, functional health, and well-being among older adults with heart failure. The Theory of Health Empowerment guides understanding of the linkages between presenting problem, critical inputs, underlying mechanisms of change and outcomes for older adults with heart failure. Testing the feasibility of intervention will link the theory with practice and generate nursing knowledge, to expand base of nursing science.

### **Chapter 3**

#### **METHODS**

##### **Health Empowerment Intervention for Self-Management**

The HEI was based on the critical inputs of the Theory of Health Empowerment (Shearer, Cisar & Greenberg, 2007; Shearer, Fleury & Belyea, 2010), a systematic review of health empowerment interventions to enhance self-management, functional health and well-being of older adults (Shearer, Fleury, Ward & O'Brien, 2012), as well as systematic review of interventions focusing on self-management, self-care behaviors, and quality of life, conducted in the current research. The HEI was guided by standardized protocol and focus was on strengths, experiences and priorities of older adults to individualize the care.

### **Research Design**

Research design is the comprehensive plan to address a research question and enhance the internal validity of research. In this study, a randomized controlled trial (RCT) design was used to address the problem of lack of awareness of personal and social contextual resources in older adults with heart failure to purposefully participate in self-management for impacting their functional health and well-being. Eligible participants were assigned randomly to either the HEI or the Attention Control (general health topics) groups. Participants in the HEI group participated in 60-minute weekly group sessions for 6 weeks, whereas participants in the Attention Control group received sessions on general health topics, following the same schedule.

Pretest-posttest design with one between-subjects factor (HEI versus Attention Control) and one within-subjects factor (T1 & T2) was used. All the participants were tested at baseline, prior to the study protocol (T1), and immediately after completion of the study protocol (T2) on the dependent variables. Repeated measures design is a research design in which participants are measured two or more times on the dependent

variables. RCT design yields strong evidence about intervention effects, as well as offers greater corroboration and confidence with which causal relationships can be inferred. Randomization enhances the comparability of the groups by equalizing the characteristics that might impact the relationship between intervention and outcome measures, minimizing allocation bias (Stang, 2011). This feasibility study provided an opportunity to estimate effect size, power and sample size needed for a larger efficacy study in the future (Bowen et al 2009). The validity and credibility of the findings is enhanced by using an Attention Control group which helps discriminate treatment outcomes from outcomes, controls for potential confounding variables, and reduces bias, such as disease process and participant or researcher expectations (Kinser, & Robins 2013).

## **Research Methods**

**Sample.** Participants included older adults with heart failure, who could provide informed consent and attend weekly intervention sessions. As this was a feasibility study, a small sample size was appropriate for estimating an effect size for a larger randomized controlled trial, and for evaluation of intervention acceptability, demand, implementation and efficacy (Hertzog, 2008). The sample consisted of 20 participants. A dropout rate of 30% was expected as characterized in related studies among older adults (Schulz & Grimes, 2002). Convenience sampling technique was used to recruit the study participants (Polit & Beck, 2012). Inclusion criteria for the participants included: (1) diagnosed with heart failure for greater than 6 months, and NYHA class I, II and III based on patient self-report; (2) ability to read and understand English; (3) willing to give informed consent to participate in the study; (4) age 60 and above; (5) no cognitive impairment as measured by Mini Mental State Examination (MMSE). Exclusion criteria

included a diagnosis of dementia, participating in any other research project, and in NYHA class IV. As receipt and enactment of the HEI demands cognitive capacity for goal setting and evaluation, older adults diagnosed with dementia based on a score of 24 on MMSE were excluded from the study.

**Setting.** The feasibility study was conducted in the senior centers associated with Tempe Community Action Agency in Arizona. A senior center is designated as a community focal point through the Older Americans Act (National Council on Aging, 2015). According to the National Institute of Senior Centers, a senior center is a place where older adults come together for services and activities that reflect their experience and skills, respond to their diverse needs and interests, enhance their dignity, support their independence, and encourage their involvement in and with the center and the community (National Council on Aging, 2015). The location of senior centers provided easy access for participants sharing public transportation and increased the likelihood of participation in the ongoing center activities (Dickson, Melkus, Dorsen, Katz & Riegel, 2015).

The setting was the key component of treatment delivery system relevant to providing specified treatment. The HEI and the Attention Control Group sessions were conducted in the Granite Reef Senior Center, Scottsdale, Arizona. For implementation of the HEI and delivering of general health topics to the Attention Control Group, rooms were designated in the senior center, with adequate lighting and ventilation as well as comfortable seating arrangement which fostered interaction, discussion, and delivery of intervention sessions as planned. Rooms used for conducting sessions were reserved, in advance, to be dedicated to the study meetings as scheduled. The HEI and general health

topics to the Attention Control Group were delivered in dedicated spaces controlled for noise interruptions, random irrelevant activities, and inconsistencies that may interrupt delivery or impact implementation fidelity. Senior center is equipped with additional facilities such as parking and bathrooms. No participant reported any discomfort, fatigue or shortness of breath, during the implementation of the HEI and the Attention Control Group sessions.

**Recruitment and retention.** The study protocol was discussed with the administrators and staff of the Granite Reef Senior Center and North Tempe Multigenerational Center. Participants were recruited by the investigator in the senior centers, over two-month period from May, 2016 to July, 2016. Recruitment methods included: distributing recruitment flyers, introductory cards, face-to-face contact, and telephone reminders (Shearer, Fleury, & Belyea, 2010b). Face-to-face interaction enhanced the recruitment of older adults in this feasibility study and is supported as an effective approach by Ford, Havstad, and Davis (2004), who reported that face to face interaction approach to recruitment was more effective as compared to other approaches. In this feasibility study the participants were recruited from diverse populations, representative of older adults in Maricopa County.

The population in Arizona is expected to grow by 80%, from 6,401,568 to 11,562,584 whereas the number of Arizonans 65 years and older is projected to increase 174%, from 883,014 to 2,422,186 between 2010 to 2050. The proportion of older adults aged 65 and above, which was 14% in 2010, is expected to be 21% of the total population in 2050. The projections by race and ethnicity from 2010 to 2050 include White non-Hispanic, 83% to 60%, Hispanic, 11% to 28%, African American, 2% to 3%, American

Indian and Alaska Native will remain the same, and Asian and Pacific Islander 2% to 6% respectively (Arizona Department of Health Services, 2014).

The estimates for Maricopa County in 2014 include total population 4,087,191, number of older adults 65 years and above 13.8%, Whites 84.4%, Blacks 5.7%, American Indian and Alaska Natives 2.8%, Asian 4.1%, Native Hawaiian and other Pacific Islander 0.3% and Hispanics 30.3% (United States Census Bureau, 2014). Heart failure is the leading cause of death in Arizona, and accounts for 1 in 4 deaths. In 2008 number of hospitalizations due to heart disease was 67,307 that accounted for 184 hospitalizations each day (Arizona Department of Health Services, 2014). According, to the Center for Population Dynamics at Arizona State University (2012) and Population Demographics for Scottsdale Arizona in 2016 and 2015, white (89%), Hispanic or Latino (8%), Asian (3%), African American (1%), Native American (below 1%) and Native Hawaiian and Pacific Islander (below 1%) constituted the demographics of population. The percentage of participants in this feasibility study for different ethnic groups was representative of the demographics of the Scottsdale (Arizona) population, attending senior centers.

Laditka, Laditka and Drake (2006) examined senior center service use among African American, Hispanic, and non-Hispanic White older adults in a national sample; where white men used the senior center service, the least. Giunta and colleagues (2012) reported that African Americans and Latinos were more likely to participate in diverse senior centers as compared to Asian and Pacific Islanders or Caucasians. Therefore, participants were recruited from the diverse senior centers in Arizona who represented the diverse population of older adults with heart failure, Caucasian being the majority.

To enhance retention of participants, face-to-face interaction between the researcher and participants using introductory cards, and invitation/reminder phone calls were used to convey a welcoming attitude, and a compensation of twenty-dollar gift card per measurement time was given to each participant. In addition, to enhance participation, potential benefits of research findings to others were emphasized. Harris and colleagues (2008) reported that older adults who received a follow-up call following an invitation letter were 1.5 times more likely to participate in intervention as compared to those who did not receive follow up call. The schedule of their participation including frequency, and duration was explained clearly and reinforced through reminders and face-to-face meetings to enhance retention. Information about data collection procedures such as frequency, duration, dose and length of participation was shared, and was reinforced through verbal reminders and meetings. Participants were informed about what to anticipate before each measurement time point and testing protocol.

Attendance was monitored throughout the intervention sessions to enhance study retention. After checking the attendance rosters weekly, reminder calls were made to the participants who missed session. The interventionist met weekly with the mentors and research team to discuss study progress about recruitment, retention, implementation, adverse events, data collection and management, and new research information.

### **Data Collection Procedures**

Testing procedures in the HEI and the Attention Control groups were congruent. Testing procedures were conducted by the researcher who completed interventionist training conducted by the mentors in four sessions through live interaction.

The study was approved by the Institutional Review Board of Arizona State University. A letter of support from the Tempe Community Action Agency's Director of senior centers was included in the IRB application package. The study was explained at senior centers' gatherings. If an older adult expressed an interest in participating, and met the inclusion criteria, a written informed consent was provided. The researcher met with each participant individually to inform them about the risks, benefits, and options for participation in the study. A written copy of the consent was provided to each participant for review, and participants and their significant others were encouraged to ask questions, and clarify any concerns.

Participants were randomized to the HEI or the Attention Control group. A table of blocked random numbers generated from SPSS was used for randomization. Two blocks of random numbers for 20 individuals, assigned to two conditions (10 in each group) were generated. In random assignment, every participant had equal chance to be in either of the conditions, maximizing the chances of having participants with similar characteristics in both the HEI and the Attention Control groups, minimizing systematic error, and enhancing internal validity.

**Intervention protocol.** Participant identity was coded on the questionnaire, to maintain confidentiality. Weekly sessions of one hour of the HEI were conducted for six weeks, and were reinforced through positive feedback in each consecutive session. Group sessions have resulted in significant improvement in the outcomes of heart failure hospitalization and mortality (Kozak, et al., 2007; Stewart, 2013; Shearer, Fleury, & Belyea, 2010 & Shearer, Cisar & Greenberg, 2007).



The Attention Control group received one-hour weekly sessions for six weeks on general health topics adapted from the healthy aging publications of National Institute on Aging (2009). Shearer, Fleury, and Belyea, (2010) used the same source for general health topics for the Attention Control group in their study. The Attention Control group content did not contain theoretically relevant concepts of the HEI. Content of Health Empowerment and Attention Control conditions is summarized in Table 4.

**Table 4**  
***Critical Content of Six Weeks’ Health Empowerment Intervention, and General Health Topics for the Attention Control Group***

<b>Session</b>	<b>Critical Content of the Health Empowerment Intervention</b>	<b>General Health Topics of the Attention Control Group</b>
<b>Week 1</b>	<p><b>“Rediscovering Self “Building Self-capacity</b></p> <ul style="list-style-type: none"> <li>• Introduction to the HEI group session and expectation of participants.</li> <li>• Orient the participants to purpose and goals of HEI session and the intervention manual to achieve their personally relevant health goals related to their chronic illness</li> <li>• Use constructive reminiscence to explore and identify personal strengths and skills of participants that lead to personal growth</li> <li>• Emphasize physical and emotional strengths present in the participant that can assist him/her in achieving personal health goals</li> <li>• Provide feedback and encouragement to the participants regarding their progress</li> </ul>	<p>Introduction to group sessions and expectation of participant</p> <p>General topic Falls and Fractures</p>
<b>Week 2</b>	<p><b>“Creating Possibilities Making Progress”</b></p> <ul style="list-style-type: none"> <li>• Review with the participants’ knowledge gained from session 1, discover how participants view self-talk</li> <li>• Introduce the session and highlight what will be covered this week</li> <li>• Facilitate recognition of personal resources using personal resource activity</li> <li>• Review handout of self-talk and use of positive self-talk activity</li> <li>• Facilitate thought restructuring and discuss how strength like self-advocacy will be used to attain health goals. Linking strengths, skills and</li> </ul>	<p>Aging and Skin care</p>

achievements and ability for self-advocacy that will facilitate achieving personally relevant health goals related to heart failure

- Provide feedback and encouragement to the participants regarding their progress

**Week 3**

**“Building Social Support”**

Aging and Eye care

- Review with the participants the knowledge of self-talk and self-advocacy from session 2.
- Introduce session and highlight what was covered last week and what will be covered this week
- Examine a time when social networks or social support was important and useful. Identify people who turned to in the past for social support
- Identify and discuss the benefit of social support.
- Demonstrate problem solving techniques that can be used to identify, connect and build a social network of supportive people
- Review personal health goals and facilitate discussion on how to build social network of the participant to support the participant as they work toward the attainment of personally relevant health goals related to heart failure
- Provide feedback and encouragement to the participants regarding their progress

**Week 4**

**“Accessing Services” Social Service Utilization**

Teeth and Mouth care

- Review with the participants the strength and knowledge gained from session 3
- Highlight what was covered last week and introduce what will be covered this week
- Use constructive reminiscence to facilitate the participants thinking about a time in their life that they used community resources of social services
- Apply problem solving approach to access social service agencies needed to attain personally relevant health goals
- Share resources related to heart failure. Facilitate discussion on how resources can be used to manage their disease and facilitate the attainment of health goals.
- Review personal health goals and facilitate discussion on how to utilize community agencies/social services and other resources in the community to attain personally relevant health goals related to heart failure
- Provide feedback and encouragement to the participants regarding their progress

**Week 5**

**“Building Bridges” through Communication**

Osteoporosis

- Review with the participants the strength and knowledge gained in session 4
- Highlight what was covered last week and introduce what will be covered this week
- Discuss effective communication
- Review and discuss tips for effective and assertive communication.
- Guided effective communication activity
- Review personal health goals and facilitate discussion on how to apply what was learned regarding communication, especially patient provider communication and how this session can be used to attain personally relevant health goals specific to heart failure.
- Provide feedback and encouragement to the participants regarding their progress

**Week 6**

**Attainment of Goals**

Aging and exercise

- Review with the group the strength and knowledge gained from session 5
- Highlight what was covered last week and introduce what will be covered this week
- Facilitate the participant recognition of decisions and changes they have made during the last six weeks
- Discuss how these changes have helped them to manage their HF and attain their health goals.
- “You as a Change Agent”
- Awareness of your capacity and enhanced abilities related to personal growth, self-advocacy, social support and recognition of service resources
- Access to and utilization of social services/community resources to purposefully participate in self-management and active communication with others and especially your healthcare provider to attain your personally relevant health goals
- Review attainment of personally relevant health goals and facilitate discussion on how to apply what was learned during the 6 session to identify and attain future health goals.
- Closure

**Measurement**

- Time 1 baseline
  - Time 2 post intervention
- 

**Intervention.** A standardized format was followed in each session. Theory based content and goals for each session were written in a manual. The objective of the

intervention was to facilitate involvement of participants in the process of recognizing personal resources, social contextual resources and the identification of relevant health goals and the ways to attain these goals (Shearer, 2009; Shearer, Fleury, & Belyea, 2010).

The components of six weekly sessions of the HEI guided by the Theory of Health Empowerment included: (1) identifying personal resources and building self-capacity was the focus of first session, using constructive reminiscence to explore, and identify personal strengths, and skills which lead to personal growth.; (2) building self-capacity continued in the second session, using thought restructuring to enhance the personal strengths, self-talk, purpose in life, personal growth and self-acceptance and skills that will help in the attainment of goals related to heart failure; (3) recognizing and building social networks to enhance awareness of social support and techniques to connect with the social networks thus, identifying people who can support older adults with heart failure, and will be helpful in attaining their personal health goals. (4) identifying social and community services available and planning their utilization as required; (5) Communicating assertively and building social networks, using effective communication skills to connect with others, and expressing personal needs; and (6) reviewing progress in the attainment of identified health goals through purposeful participation including positive changes and opportunities for building self-capacity and social networks, accessing social services and reviewing health goals for future.

In each session, the progress made toward goal attainment was reviewed and discussed to progress with the intervention content. Feedback about the progress made to attain the personal health goals was provided to the participants in each session to

encourage them purposefully participate in attainment of their personal health goals (Shearer, Cisar, & Greenberg, 2007).

Informational content for the Attention Control group included: (a) falls and fractures, (b) aging and skin care, (c) aging and eye care, (d) teeth and mouth care, (e) osteoporosis and aging and (f) exercise. The first session focused on introductions, purpose of the program and health topic falls and fractures. In second session, the focus was on aging and skin care including age related, and other factors resulting in skin changes and the ways to take care of skin. Biological changes in the eyes and eye sight and strategies to take care of eyes was discussed in the third session. Dental care and bone health was discussed in fourth session. The fifth session focused on teeth and mouth care, whereas the importance of exercise was discussed in the sixth session.

### **Variables and Measurement**

In this feasibility study, the specific aims were to examine the feasibility of the HEI in older adults with heart failure including: (a) acceptability of the intervention; (b) demand of intervention; (c) implementation fidelity and (d) evaluate the effect of the HEI on health empowerment, purposeful participation in change, self-management, functional health, goal attainment, and well-being among older adults with heart failure. It was hypothesized that older adults with heart failure who receive the HEI would have significant improvement in health empowerment, purposeful participation in change, self-management, functional health, goal attainment and well-being, compared to the Attention Control group at 6 weeks (post-intervention).

Demographic characteristics, intervention acceptability, demand, and implementation fidelity were measured using standardized questionnaires and attendance

rosters. Cognitive function screening, heart failure functional status classification, health empowerment, purposeful participation in attainment of personal health goals, self-management, functional health, and well-being were measured using valid and reliable measures.

**Screening for cognitive function.** The Mini Mental State Examination (MMSE) tool was used to assess the cognitive status of the participants prior to enrollment. The MMSE is a widely-used screening measure for assessing dementia, and has been used to measure cognitive deficits in heart failure patients (Pressler, et al., 2010; Cameron, Worrall-Carter, Page, Baker & Ski, 2012; Ismail, Rajji, & Shulman, 2010). The MMSE consists of 11 questions testing five areas of cognitive function: orientation, registration, attention and calculation, recall, and language. Possible scores range from 1 to 30. Scores above 24 indicate no cognitive impairment, a requisite for participation in this study. A score below 24 out of 30 shows cognitive impairment: a score of 21-24 points mild, 10-20 points moderate and < 9 points as severe. The MMSE has established inter rater reliability ( $r=0.99$ ), sensitivity (0.91) and specificity (0.95), positive and negative predictive values (0.90 & 0.95) and Kappa score (0.86) for the diagnosis of mild dementia in older adults (Gungen, Ertan, Eker, Yasar, & Engin. 2002). Schwarz and Elman (2003) reported Cronbach alpha (0.84) for orientation, (0.63) for language and (0.67) for the total score of MMSE in patients with heart failure.

**Functional status classification.** Patients were selected based on the New York Heart Association Functional Classification; class I, II and III patients were recruited for the study. The NYHA classifies the patient in one of the four categories, based on how much they are limited in their physical activities (The Criteria Committee of the New

York Heart Association, 1994). NYHA functional classification of patients with heart failure is depicted in Table 5. Patients with heart failure with no physical limitation, having no fatigue with ordinary physical activity, or breathlessness, belong to class I, and with mild symptoms, having palpitation and breathlessness or angina pectoris with ordinary activity belong to class II.

Table 5.  
*New York Heart Association Function Classification*

<b>Class</b>	<b>Patient Symptoms</b>
<b>Class I</b>	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or dyspnea.
<b>Class II</b>	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitation, or dyspnea.
<b>Class III</b>	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnea.
<b>Class IV</b>	Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.

In class III patients have marked limitation in physical activity due to symptoms, and are comfortable only at rest. In class IV patients are unable to carry out any physical activity without discomfort, and experience severe symptoms even while at rest. There is general agreement about the validity of the NYHA functional classification instrument (Bennett, Riegel, Bittner & Nichols, 2002).

**Demographic variables.** Demographic variables measured include: (1) age in years; (2) race; (3) years of education; (4) number of individuals living in the house hold; (5) monthly household income; and (6) primary spoken language

**Intervention fidelity.** Intervention fidelity refers to the extent of consistency in the implementation of intervention as planned, or the degree of integrity of the intervention (Bellg, et al., 2004). Intervention fidelity encompasses theoretical fidelity referring to design of intervention and operational fidelity referring to implementation of intervention (Sidani & Braden, 2011; National Institute of Health). Congruence among critical inputs, components and activities identified in the intervention theory, and the activities undertaken indicate theoretical fidelity. Operational fidelity refers to the extent to which intervention is implemented as planned (Hart, 2009). Maintaining fidelity at both level is of critical importance for enhancing validity of the intervention.

Structural elements of the intervention including interventionists, participants and settings may impact the implementation of intervention as planned (Sidani & Braden, 2011). It is extremely important to identify and understand the impact of these factors on the intervention delivery to guide and modify the decisions and activities including: (1) training of interventionist to improve knowledge and skills as per demand of the situation; (2) receipt and enactment of the intervention by participants; (3) arranging the elements in the intervention setting to improve delivery; and (4) collecting data pertaining to factors influencing intervention delivery. Identification of barriers and facilitators to intervention implementation is part of fidelity assessment (Spillane et al., 2007; Borrelli, et al., 2002). The National Institute of Health' Treatment Fidelity Workgroup have identified five areas to ensure fidelity, including study design, training of interventionists, treatment delivery, treatment receipt, and treatment enactment (Bellg, et al., 2004; Borrelli, et al., 2005).



Fidelity related to study design was addressed through review of theory, intervention content, delivery methods and measurement by experts in the theory of intervention, to ensure that the critical inputs, underlying mechanisms and expected outcomes of the intervention are consistent with the underlying theory. An intervention manual specifying objectives, treatment dose including length of contact, number of contacts, as well as content of the intervention and duration of contact was utilized. The content of each session, providing step by step details of activities for delivering the intervention was included in the manual. A standardized manual specifying the objectives of the sessions and activities related to each session was provided to the participants in the first session. Content on general health topics for the Attention Control group was specified in a separate manual (Borrelli, 2011).

Training of interventionists with the skills and abilities required to implement the intervention, and monitoring procedural consistency was used to enhance the intervention fidelity (Wyatt, et al., 2010). Training was designed to enhance knowledge about heart failure, care of older adults, intervention delivery, recruitment, data collection, and communication. Delivery of the intervention was monitored through assessing the use of treatment manual, time spent in each session, attendance, and consistency of the delivery of intervention as specified in the manual. Field notes and an Index of Procedural Consistency was maintained to evaluate the implementation fidelity. Field notes were maintained for each intervention session, including outline of delivery methods, use of resources, activities, and time spent on each activity. Degree of implementation and frequency and duration of activities was evaluated through Index of Procedural Consistency as a basis to quantify intervention fidelity. Sessions were audiotaped

randomly to evaluate the adherence of the intervention delivery to the manualized protocol.

Receipt of intervention was assessed through an acceptability questionnaire reflecting understanding of intervention content. Weekly meetings were organized with the mentors to monitor progress and reinforce the positive aspects of intervention delivery, and modify the negative in future studies ((Witham, & Macmurdo, 2007; Shearer, Fleury & Belyea, 2010). No deviation from the protocol, such as adverse events, or challenges to the protocol occurred during implementation of the intervention. The Attention Control group had sessions on general health topics, focusing on falls and fractures, aging and skin care, aging and eye care, teeth and mouth care, osteoporosis and exercise, and did not contain the theoretically active components of the intervention.

**Intervention acceptability.** Intervention acceptability is the reaction of participants to the intervention, reflected through their views, preferences and expectations (Bowen, et al., 2009). Intervention acceptability was assessed using a brief questionnaire, to evaluate the understanding and usefulness of intervention content, satisfaction, as well as delivery including dose and format. The intervention acceptability questionnaire focused on content, length, format and timing, as well as general acceptability. The responses to questions ranged from 0 (not at all) to 3 (very well). A high score means general acceptability of the intervention.

**Intervention demand.** Intervention demand is reflected through data on estimated use of intervention activities among participants, including enactment of intervention content, expressed interest, attendance at intervention sessions and attrition from intervention. Understanding of these factors is critical to refine the intervention for

future research. The attendance at each session was maintained through an attendance roster. The attendance roster was checked weekly, and reminder call was given to any missing participants. There was no attrition of the participants who provided consent.

**Health empowerment.** Health empowerment was operationalized through Ryff's Psychological Scale (Ryff, 1989), measuring the dimensions of personal growth, purpose in life, social relationships, and self-acceptance. Each dimension has 14 items, which are measured on a 6 point Likert-scale from 1 (strongly disagree) to 6 (strongly agree). Subscale scores range from 14-84. However, for this study a short version of the scale with 28 items, each dimension with 7 items was used. Total scale scores range from 28 to 168, and for subscales score range from 7-42. High score for personal growth indicates a high level of continuous development, growth and expansion of self, openness to experiences, realizing personal strengths and change reflected through more knowledge.

A high score for purpose in life elicits a person's goals in life and sense of directedness, value of present and past life, and aims for living. Similarly, high score for self-acceptance depicts positive attitude toward accepting the self with heart failure. Validity for personal growth has been reported (0.85), for purpose in life (0.88) and for self-acceptance (0.91) respectively (Ryff, 1995). While tested with older adults, internal consistency of Ryff's Psychological Scale was: (0.87) for personal growth, (0.90) for purpose in life and (0.93) for self-acceptance (Ryff, 1989).

Social network building as an aspect of health empowerment was operationalized through Ryff's Psychological Scale (Ryff, 1989, 1991) measuring social support reflecting positive relations with others. This dimension of the scale consists of 14 items, measured on 6-point likert scale, 1 (strongly disagree) and 6 (strongly agree). Total score

ranges from 14 to 84, with a high score indicating positive relations with others, concern for the well-being of others and understanding the give and take of human relationships. However, for this study 7 items score ranging from 7 to 42 were included. The dimension has validity and internal consistency estimates ranging from (0.88) and (0.91) respectively for older adults (Ryff, 1989).

Social service utilization of community services, was operationalized through the Social Services Utilization Data Sheet. Participants were asked to list the community resources utilized recently and used in the past 6 weeks.

**Purposeful participation.** Purposeful participation in goal attainment consists of four subscales of experiencing change: awareness, choices, freedom to act intentionally, and involvement in change, operationalized through Power as Knowing Participation in Change Tool (PKPCT) (Barrett, 1990, Shearer, Fleury & Belyea, 2010). The PKPCT measures contextual awareness of people, the way people make choices, freedom to act intentionally and involvement in creating change (Barret & Caroselli, 1998).

The PKPCT is a 48-item semantic differential scale, with total scores ranging from 48-336; a higher score indicates a great degree of purposefully participating in change (Barrett & Caroselli, 1998). For each subscale, there are 12 items. Content validity for the PKPCT was established by a panel of experts familiar with Rogerian framework (Barret, 1990). The scale has demonstrated internal consistency with estimates ranging from (0.71) to (0.91) for awareness, (0.75) to (0.92) for choices, (0.71) to (0.91) for freedom to act intentionally, and (0.57) to (0.93) for involvement in creating change and (0.80) to (0.97) for total scale whereas construct validity ranged from (0.56) to (0.70) (Caroselli & Barrett, 1998).

**Self-management.** The Self-care of Heart Failure Index (SCHFI) was used to operationalize self-management decisions made in response to signs and symptoms. SCHFI was developed by Riegel, Carlson and Glaser (2000), published in 2004 (Riegel, Carlson, Moser, Sebern, Hicks & Roland, 2004) and was revised in 2009 by Riegel, Lee, Dickson and Carlson. The SCHFI consists of three subscales, including self-maintenance, self-management and self-confidence, including 22 items designed to reflect ability to maintain illness stability and manage symptoms when they occur. Self-maintenance subscale (section A) consists of 10 items that reflect self-maintenance behaviors that promote the management of symptoms through treatment adherence and management of symptoms when they occur. On the 4 point Likert Scale, each item score ranges from 1 (never or rarely) to 4 (always), resulting in total score of 40.

Subscale self-management (section B) consist of 6 items. The items are scored on a 4 point Likert Scale, with scores ranging from 1 (not likely) to 4 (very likely) except the first (“how quickly did you recognize it as a symptom of heart failure?”) and last (“How sure were you that remedy helped or did not help?”) items in the section. These items have a true 0 possible and are coded from 0 to 4. The highest possible raw score is 24, and the lowest possible raw scale score is 4. Subscale self-care confidence (section C) also consists of 6 items, scored on 4 point Likert Scale, with scores ranging from 1 (not confident) to 4 (extremely confident), resulting in total score of 24. The content validity of SMHFI has been established through review of existing literature. Face validity has been assessed through interviewing patients.

Concurrent validity of the scale was tested by comparing summary scores on SCHFI with the scores on European Heart Failure Self-Care Behavior Scale. Construct

validity was tested through confirmatory factor analysis to determine that individual items loaded on the self-care maintenance, self-management and confidence scales are in the same way as expected (Riegel, Lee, Dickson & Carlson, 2009). Internal consistency of the SMHFI subscales ranged from (0.79) to (0.92) (Riegel, Carlson & Glaser, 2000). Cronbach's alphas for the SMHFI in a study by Shearer, and colleagues (2007) was (0.62), (0.86) and (0.88) for the maintenance, decision making and self-confidence subscales respectively. In the updated version of scale, the Cronbach's alphas for subscales self-maintenance, self-management and self-confidence were (0.55), (0.59) and (0.82) respectively (Riegel, Lee, Dickson & Carlson, 2009).

**Functional health.** The Minnesota Living with Heart Failure Questionnaire (MLHFQ) was used to operationalize functional health, which includes physical, emotional and social components of functional status. The MLHFQ is a disease specific instrument used generally in research to measure the effects of heart failure on an individual's functional health (Rector, Kubo & Cohn 1987; Rector, et al., 1995). The MLHFQ constitutes 21 items. Degree of impairments in physical, emotional and social domains are rated on response scale range from 0 to 5, where 0 (no effect on life), and 5 (very much effect on life). Total score range from 0 to 105, with higher scores indicating more impairment, such as very limited physical activity, depressed, tired with a strong feeling of a burden on others. The MLHFQ test-retest reliability ( $r=0.87$ ) and Cronbach's alpha for the total scale (0.92) have been tested (American Thoracic Society 2007). Middel, et al. (2001) and Heo, Moser, Riegel, Hall, and Christman, (2005) reported Cronbach's alpha ( $> 0.80$ ) for MLHFQ. MLHFQ is highly correlated ( $r=0.81$ ) with the Chronic Heart Failure Questionnaire (Bennett, et al., 2002).

**Goal attainment.** Goal attainment was operationalized through the Goal Attainment Scale (GAS) (Kiresuk & Sherman, 1968). The attainment of personally relevant goals is an aspect of purposeful participation. The GAS is an individualized measurement approach that has been tested among older adults (Rockwood, Stolee, & Fox, 1993). The GAS is a five-point scale with ratings based on the achievement of one or more desired goals which are realistic to achieve in a given time frame. Each goal comprises a set of likely treatment outcomes assigned numerical values, with -2 representing the least favorable outcome, +2 the most favorable outcome and 0 the most likely considered outcome. Rockwood and colleagues (1993) report inter-rater reliability of the scale as (0.80) for older adults. As older adults might have multiple health concerns, a minimum of 1 to 3 goals is recommended.

**Well-being.** The health outcome of well-being was operationalized using the Well-being Picture Scale (WPS) (Gueldner, et al., 2005). The WPS contains 10 pairs of opposite drawings, which represent general well-being, integral to the person-environment process. The drawings are arranged on a white paper, at opposite ends of a seven-choice unnumbered semantic differential scale. The total score ranges from 10 to 70; a high score means a higher level of well-being. The WPS is designed for populations who have limited education, speak English as second language, have inadequate vision, and are too frail to respond to lengthy measures. The psychometric properties of WPS were tested in a sample of 2000 participants, with Cronbach's alpha ranging from (0.88) to (0.94) for internal consistency estimates (Gueldner, et al., 2005). Internal validity of WPS, assessed through item analysis, range from (0.41) to (0.78).

## Data Management and Analysis

Measurement tools and the data collection packet for T1 are provided in Appendix. Coded data collection forms completed by participants at each measurement time (T1-T2) were reviewed for missing data, and were stored in a locked file cabinet. Personal identifiers of participants were kept separate from data collection forms, and participants were assigned an identification number. Identifiers were not included in the reports or publications related to the study. Data was double entered in the computer using SPSS version 23 files. After entry, data was assessed for outliers, irregularities, and was compared with the raw data. Negatively worded items in the Ryff's Psychological Well-being Scale were reverse coded so that a high value indicates the same type of response in every item. One item in subscale of self-maintenance of heart failure in Self-care of Heart Failure Index was also recoded as it was negatively worded. Recoded items were computed to get the total scores on each scale and sub scales.

The SCHFI scores on self-maintenance, self-management and self-confidence were standardized to a score of 100 to make them comparable across scales (Riegel, et al., 2009). To compute a standardized self-maintenance scale score: (sum of section A items – 10) \* 3.333, self-management: (sum of section B items – 4) \* 5, and self-confidence (sum of section C-6) \* 5.56 formulas were used (Riegel, et al., 2009). Scores on Goal Attainment Scale were also standardized by using formula  $\sqrt{(0.7(1+1+1+1) + 0.3(16))} = \sqrt{(2.8+0.48)} = 2.75$ . T score  $50 + 10/2.75$  (raw score) for the total scale raw scores (Turner-Stokes, 2009). Cleaned data was set up for analysis of covariance using general linear model, after assessing for biases, and assumptions for inferential statistics, needed transformations were done.



**Specific Aim 1.** Descriptive analysis was used to examine and describe Specific Aim 1. Means and standard deviations were used to examine and describe continuous variables. Attendance rates, and reasons for absence in the sessions were analyzed for the HEI and the Attention Control Group through logs maintained by researcher.

**Specific Aim 2.** Analysis included:

1. Descriptive statistics to summarize demographic characteristics of the participants and outcome variables of interest.
2. Data was examined for normality of distribution as well as for outliers. Missing data was explored using SPSS 23 missing value analysis procedures. Missing data ranged from 0 to 9%. Values for missing data were imputed by using mean substitution.
3. Participants in the HEI and Attention Control groups were compared on demographic variables, using t-tests.
4. Correlation tables were constructed for theoretical change mechanisms and outcome variables at T1 using Pearson's product moment.
5. Descriptive statistics frequencies, and bar diagrams were used to characterize the feasibility of the HEI in older adults with heart failure including acceptability, demand, and implementation fidelity.
6. A general linear model approach to analysis of covariance in SPSS was conducted to evaluate changes in theoretical mechanisms and outcome variables as a function of time and treatment groups. The covariate in ANCOVA reduces the probability of Type II error when tests are made of main or interaction effects thus increases the precision with which treatment effects are estimated (Morrissette, & McDermott, 2013). Analysis was conducted including all the cases, as mean values were

substituted for the missing values. Preliminary analysis included Levene's test of variance equality which resulted in equal variance for all the variables. Further homogeneity of regression (slopes) assumption was evaluated which indicated that the relationship between covariate and the dependent variable did not differ significantly as a function of the independent variable. After conducting ANCOVA, follow-up analyses with demographic variables as covariates were conducted to see the difference between the HEI and the Attention Control groups.

7. Cohen *d* effect sizes for theoretical mechanisms and outcome variables were calculated by subtracting the mean of the Attention Control group from the mean of the HEI group and divided by the pooled standard deviation.

## **Chapter 4**

### **RESULTS**

The purpose of this study was to test the feasibility of the Health Empowerment Intervention (HEI) (acceptability, demand, implementation, limited efficacy) in older adults with heart failure, attending senior centers associated with Tempe Community Action Agency. The HEI is focused on optimizing self-management, functional health, and well-being in heart failure patients through enhancing awareness of personal and social contextual resources. The HEI is designed to facilitate realization of personal resources and social contextual resources, and building upon them, fostering participation in decision making and goal setting to achieve personal health goals and well-being.

This chapter provides an overview of: (a) data analysis; (b) participant characteristics; (c) internal consistency of instruments; (d) results including functional status classification as per New York Heart Association Functional Classification; (e)

cognitive health screening; (f) feasibility of the HEI which includes evaluation of acceptability, demand and implementation of the HEI; (i) the intended effects of the HEI on theoretical mechanisms and outcomes within and between treatment and control groups over time. Study results are presented as per specific aims.

Data were analyzed using SPSS version 23. Frequency distributions, plots and histograms were used to assess for violations of normal distribution. Descriptive statistics such as mean and standard deviation were used to describe and summarize the numerical data. Skewness and Kurtosis were used to describe the normality of distributions. The instruments were examined for internal consistency. Correlations were used to examine relationships between variables.

ANCOVA was conducted to evaluate the intended effects of the HEI on theoretical mechanisms and outcomes within and between the HEI and the Attention Control groups over time. To assess the robustness of our primary analysis, additional adjusted analyses were conducted to consider several potential confounding factors which can influence the estimate of the HEI effect.

Figure 2 outlines the recruitment flowchart (Schulz, et al 2010). In summary, 23 older adults with heart failure expressed their interest in participating the study and were screened for the eligibility. Twenty met the inclusion criteria, provided consent to participate in the study, and were randomized to either the HEI or the Attention Control Group. All the participants completed the study.

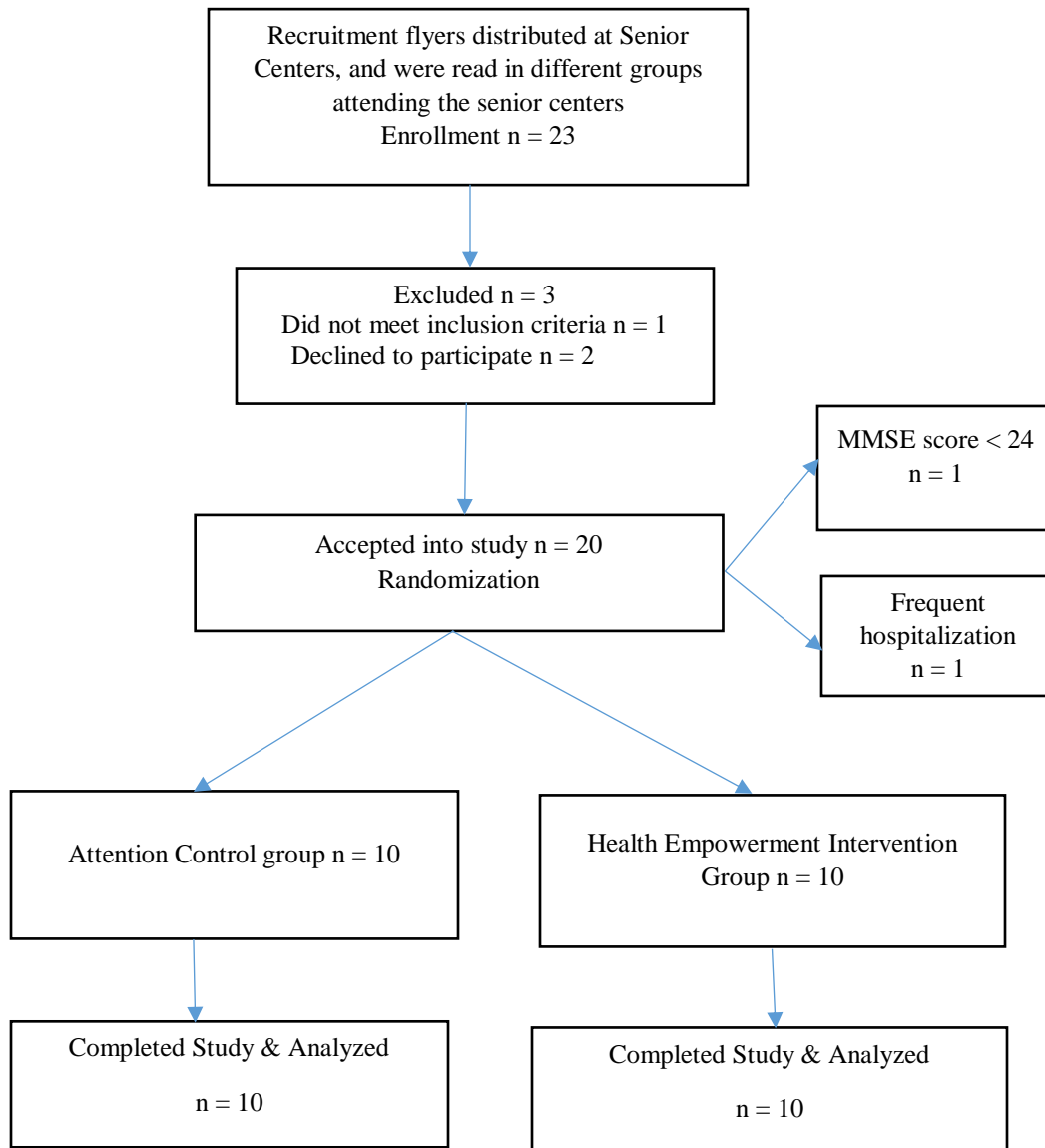


Figure 3. Recruitment Flowchart

### Screening of Participants

Participants were screened as per inclusion criteria: (1) diagnosed with heart failure for greater than 6 months, and New York Heart Association Functional (NYHA) class I, II, and III symptoms based on patient self-report; (2) able to read and understand English; (3) willing to give informed consent to participate in the study; (4) age 60 and above; (5) no cognitive impairment as measured by Mini Mental State Examination

(MMSE). The ability to read and understand English, and respond to questions was evaluated while interacting during the screening process. Screening for diagnosis of heart failure was based on self-report, and evaluation through functional classification of New York Heart Association.

**Functional Status Classification.** Participants were categorized in heart failure class as per criteria of New York Heart Association's Functional classification. Six participants were categorized in class 1, twelve participants were categorized in class II and two participants were categorized in class III.

**Cognitive Status.** The Mini-Mental State Examination (MMSE) questionnaire with a maximum score of 30 was used to evaluate cognitive health status. The mean score on the MMSE was  $M = 28.85$  ( $SD = 1.09$ ) with scores ranging from 26 to 30. Five participants scored 30, eleven scored 29, two scored 27 and remaining two 26 and 28 respectively.

### **Sample Description**

Demographic characteristics of the study participants are presented in Table 6. Age of participants ranged from 62 to 94 years, with mean age of 74.3 years ( $SD = 9.28$ ). The majority of participants (80%) were Caucasian/white, one participant (5%) was Hispanic/Latino (non-white), stated as "other", two participants (10%) were Asians, and one (5%) was African American. These proportions are similar to the demographics of Maricopa county, where 84.4% of older adults are white, 5.7% African Americans, and 4.1% Asian (United States Census Bureau, 2014).

**Table 6**  
*Demographic Characteristics of the Participants*

Characteristics	Attention Control Group (n=10)	HEI Group (n=10)	Total
<b>Age</b>			
Range of mean	67 - 94	62 -91	62-94
Mean (Standard Deviation)	76.4 (9.34)	72.2 (9.21)	74.3 (9.28)
<b>Race</b>			
Caucasian/white	6 (60%)	10 (100%)	16 (80%)
Hispanic/Latino (Non-white)	1 (10%)		1 (5%)
Other	3 (30%)		3 (15%)
<b>Gender</b>			
Male	1 (10%)	3 (30%)	4 (20%)
Female	9 (90%)	7 (70%)	16 (80%)
<b>Marital Status</b>			
Married	3 (30%)	2 (20%)	5 (25%)
Divorced	5 (50%)	5 (50%)	10 (50%)
Widowed	2 (20%)	3 (30%)	5 (25%)
<b>Monthly Household Income</b>			
Not enough money to meet monthly needs	9 (90%)	2 (20%)	11 (55%)
More than enough money to meet monthly needs	0 (0%)	8 (80%)	8 (40%)
More than enough money to meet my monthly needs	1 (10%)	0 (0%)	1 (5%)
<b>Primary Language spoken</b>			
English	8 (80%)	9 (90%)	17 (85%)
Chinese	1 (10%)		1 (5%)
Hindi	1 (10%)		1 (5%)
Polish		1 (10%)	1 (5%)
<b>Number of individuals living in the household</b>			
One	3 (30%)	7 (70%)	10 (50%)
Two	7 (70%)	3 (30%)	10 (50%)
<b>Years of schooling completed</b>			
11 to 14	7 (70%)	4 (40%)	11 (55%)
15 to 18	3 (30%)	3 (30%)	6 (30%)
19 to 22	0 (0%)	3 (30%)	3 (15%)

Eighty percent of participants were female. The majority of participants (55%), had 11 to 14 years of schooling; 30% had 15 to 18 years of schooling and 15% had 19 to 22 years of schooling. Level of educational attainment ranged from 11 to 22 years. Fifty

percent of the participants were divorced, 25% were married and 25% were widowed. Fifty-five percent of the participants stated that they did not have enough money to meet their monthly needs.

Eighty-five percent of the participants spoke English as their primary language, while 15% spoke Chinese, Hindi and Polish as their primary language. Fifty percent of participants were living alone, and 50% either were living with their spouses, sons or daughters. These findings are consistent with the Federal Interagency Forum on Aging-Related Statistics (2016), and Institute on Aging (2010), where 46 to 56% of older adults 65 years and above were reported to be living alone.

The HEI and the Attention Control groups were examined for systematic differences on baseline demographics conducting independent t-test. No significant differences were found in age, gender, educational status, marital status, number of individuals living in household, and income to meet monthly needs.

### **Psychometric Properties of Measures**

Table 7 presents a descriptive analysis including mean, standard deviation, skewness, kurtosis and Cronbach's alpha for measures including Ryff's Psychological Well-being Scale used to evaluate health empowerment, Self-Care in Heart Failure Index used to evaluate self-management, self-maintenance, and self-confidence in managing heart failure, Power as Knowing Participation in Change Tool used to evaluate purposeful participation, Minnesota Living with Heart Failure Questionnaire used to evaluate functional health, Well-Being Picture Scale used to evaluate well-being, and Goal Attainment Scale used to evaluate attainment of goals, had normal distribution. There were no problems with skewness as it was within the range of -1.0 to 1.0.

**Table 7**  
*Descriptive Statistics of Measurements at Baseline*

	Mean	Std. Deviation	Skewness	Kurtosis	Cronbach's Alpha
<b>Ryff's Psychological Well-being Scale</b>	128.00	24.16	-0.18	-0.67	.82
<b>Ryff Personal Growth</b>	31.95	7.01	-.46	-.84	.69
<b>Ryff Social Relations</b>	33.10	6.88	-.66	-.09	.70
<b>Ryff Purpose in Life</b>	31.55	7.20	.22	-1.68	.79
<b>Ryff Self-Acceptance</b>	31.16	7.03	-.16	-1.04	.79
<b>Self-Care of Heart Failure Index (SCHFI)</b>	59.55	8.54	0.51	0.38	.70
<b>SCHFI Self-Maintenance</b>	27.75	3.71	0.5	-0.36	.58
<b>SCHFI Self-Management</b>	13.6	4.26	0.49	-1.06	.55
<b>SCHFI Self-Confidence</b>	18.2	3.69	-0.5	-0.72	.85
<b>Power as Knowing Participation in Change Tool (PKPCT)</b>	252.78	43.22	-0.13	-1.32	.96
<b>PKPCT My Awareness</b>	61.43	10.74	-0.09	-1.33	.81
<b>PKPCT My Choices</b>	62.45	12.08	-0.02	-1.09	.89
<b>PKPCT Freedom to Act Intentionally</b>	65.45	11.302	-0.38	-0.57	.89
<b>PKPCT Participation in Creating Change</b>	63.45	13.02	-0.025	-1.64	.91
<b>Minnesota Living with Heart Failure Questionnaire</b>	34.36	23.68	0.19	-0.52	.94
<b>Well-Being Picture Scale</b>	53.1	10.39	0.36	-1.06	.83
<b>Goal Attainment Scale</b>	-0.75	1.88	0.14	-0.47	.84

Overall missing data ranged from 0 to 9%. Much of the missing data identified in the missing value analysis at baseline was within Ryff's Psychological Well-Being Scale,



including items such as “no improvement as a person over the years”, “pleased with how things have turned out in life”, and “feeling disappointed about achievements in life”, and within Power as Knowing Participation in Change Tool including items such as “avoiding – seeking”, “chaotic – orderly”, and “unintentional – intentional”.

At six weeks’ scores, much of the missing data was within Ryff’s Psychological Well-Being Scale including items “often feel lonely due to few close friends to share the concerns”, “trust friends and they trust me”, “pleased with how things have turned out in life”, and “my daily activities seem trivial and unimportant to me”. Within Self-Care of Heart Failure Index missing data items were “use of a Pillbox or reminders to remember the medicines” and “call your doctor or nurse for guidance”, and within Power as Knowing Participation in Change Tool missing data items were “valuable – worthless”, “unpleasant – pleasant”, “constrained – free”, “unintentional – intentional”, “expanding – shrinking”, “uninformed – informed”, “avoiding – seeking” and “leading - following”.

Missing values were replaced with the mean of the respective variable. The main reasons to consider the mean substitution were: (a) missingness being within 1 to 9%; (b) missing at random (MAR); and (c) no single item had abnormally large number of missing values. Data was compared for means with missing values and without missing, which resulted with hardly any difference. Missing value replaced with the mean score of the participant for the variable with missing value, offers some improvement over whole sample mean replacement (Bradley, et al., 2014). Means were calculated separately for missing values in the HEI and the Attention Control group rather than replacing the missing value with overall mean for the sample, which would be better estimate and

preserve more variance (Parent, (2012). This included all the cases in the analysis thus increased the internal validity of the study.

Cronbach's alpha for Ryff's Psychological Well-Being Scale was .82 and for subscales Personal Growth 0.69, Social Relations 0.70, Purpose in Life 0.79 and for Self-Acceptance 0.79. Items with limited distribution and skewness greater than 1.0 for Ryff's Psychological Scale included: (a) "I think, it is important to have new experiences that challenge how you think about yourself and the world", (b) "I have the sense that I have developed a lot as a person over time", (c) "for me, life has been a continuous process of learning, changing and growth", (d) "most, people see me as loving and affectionate", (e) "I enjoy personal and mutual conversation with family members or friends", (f) "people would describe me as a giving person, willing to share my time with others", (g) "I know that I can trust my friends, and they know they can trust me", (h) "I have a sense of direction and purpose in life", (i) "some people wander aimlessly through life, but I am not one of them", (j) "in general, I feel confident and positive about myself", (k) "when I compare myself to friends and acquaintances, it makes me feel good about who I am".

Cronbach's alpha for Self-Care of Heart Failure Index was .70, and for its subscales self-maintenance 0.58, self-management 0.55, and self-confidence 0.85. these reliabilities are in line with what Riegel and colleagues (2009) reported as alphas 0.55, 0.59 and 0.82 for the three subscales respectively. Shearer and colleagues (2007) reported alphas as 0.62, 0.86 and 0.88 for the subscales respectively.

The reason for unsatisfactory alpha on the 6 item self-management scale may be attributed to small sample size, small number of items, and availability of data only from the participants who were symptomatic one month prior to enrollment in the study

(Riegel et al., 2009). The majority of items in the scale had normal distribution. Items with limited distribution and skewness greater than 1.0 included: (a) “keep your doctor or nurse appointments”, (b) “forget to take one of your medicine”, (c) “use a system (pillbox, reminders) to help you remember your medicines”, (d) “reduce the salt in your diet”.

Cronbach’s alphas for total scale of Power as Knowing Participation in Change Tool (PKPCT) was .96 and for its four dimensions: (a) my awareness .81; (b) my choices .89; (c) freedom to act intentionally .89 and (d) involvement in creating change .91. Items with limited distribution, and skewness greater than 1.0 were “chaotic – orderly” for PKPCT awareness, “worthless and valuable” for PKPCT choices, “valuable – worthless”, and “chaotic - orderly” for PKPCT involvement in creating change.

Cronbach’s alpha for total score of Minnesota Living with Heart Failure Questionnaire (MLHFQ) was .94. Items with limited distribution or floor effect and skewness greater than 1.0 in MLHFQ included: (a) Making your sexual activities difficult, (b) Making you stay in a hospital, (c) Making you feel you are a burden to your family or friends. Cronbach’s alpha for Well-Being Picture Scale was 0.83. Gueldner, et al (2005) also reported Cronbach’s alpha between .88 to .94 for Well-Being Picture Scale. Items with limited distribution and skewness greater than 1.0 included “open eyes – closed eyes” “dark – bright”.

Cronbach’s alpha for goal attainment scale was 0.84. All the items had normal distribution.

**Specific Aim 1.** The first aim in this study was to examine the feasibility of the HEI in older adults with heart failure evaluated for acceptability, demand (attendance and attrition), and implementation fidelity.

**Acceptability.** Acceptability of the HEI was measured using survey responses and field notes. Participant evaluation of the HEI included seven questions rated on a four-point scale (“not at all” = 0, somewhat = 1, “pretty well” = 2, “very well” = 3) with a total score range of 7 – 21. The questionnaire was designed to elicit learnability, satisfaction and effectiveness of the intervention. Figure 3 presents the percentage of participants to what extent the HEI met their needs to attain their health goals.

In response to questions asking the extent to which sessions met their need for information and problem solving, and the usefulness of sessions in helping to recognize personal resources, 70% of participants responded very well and 30% as “pretty well”. Regarding the usefulness of sessions in helping to recognize people one could turn to for support, 60% participants responded very well and 40% “pretty well”. For usefulness of sessions in helping to identify and access needed social services, 80% participants rated “very well”, 10% “pretty well” and 10% as “somewhat”. Regarding usefulness of sessions in helping to progress towards the attainment of health goals, 90% rated “very well” and 10% as somewhat. For usefulness of the sessions in helping to identify resources to help attain your goals, 80% rated “very well” and 20% rated as “pretty well”. Response related to usefulness of educational materials given throughout the sessions, 100% of the participants rated as “very well”. Mean score for acceptability was 19.3 ( $SD = 1.64$ ).

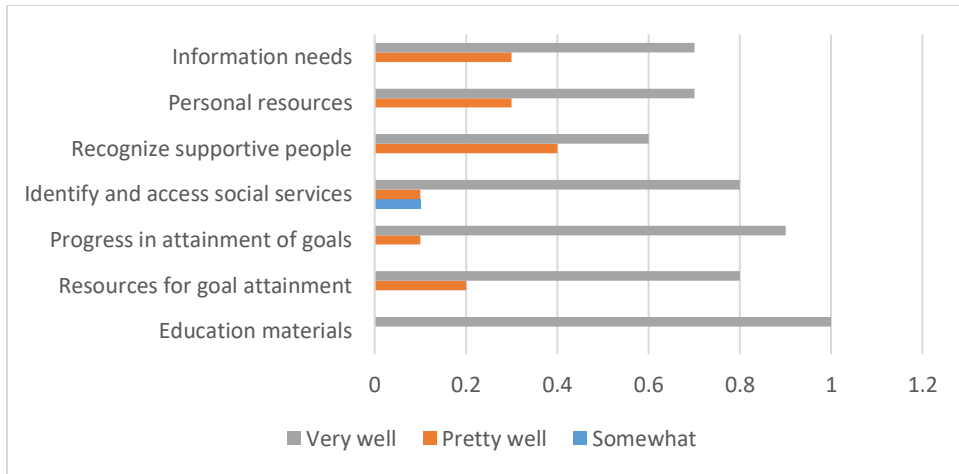


Figure 4. Intervention Acceptability: Usefulness of Sessions

**Demand.** Demand was evaluated by attendance rates in the HEI and the Attention Control group sessions, and was similar among participants in the HEI and the Attention Control groups. Figure 4 depicts the percentage of enrolled participants attending each session by treatment groups. Seventy percent of participants in the HEI, and 70% in the Attention Control group attended all the sessions. Ten percent in the HEI and 30% in the Attention Control Group attended five sessions. Ten percent in HEI group attended four sessions and 10% attended three sessions respectively. The reasons for missing the sessions included eye surgery for cataract, visit to the doctor, fire in the neighborhood, emergency call from relative, trip out of state to meet relatives, fall with injury, husband had a fall, and hip fracture, and later died. Participants in the HEI group attended 88.3% sessions and in the Attention Control group 95% sessions on an average out of six sessions.

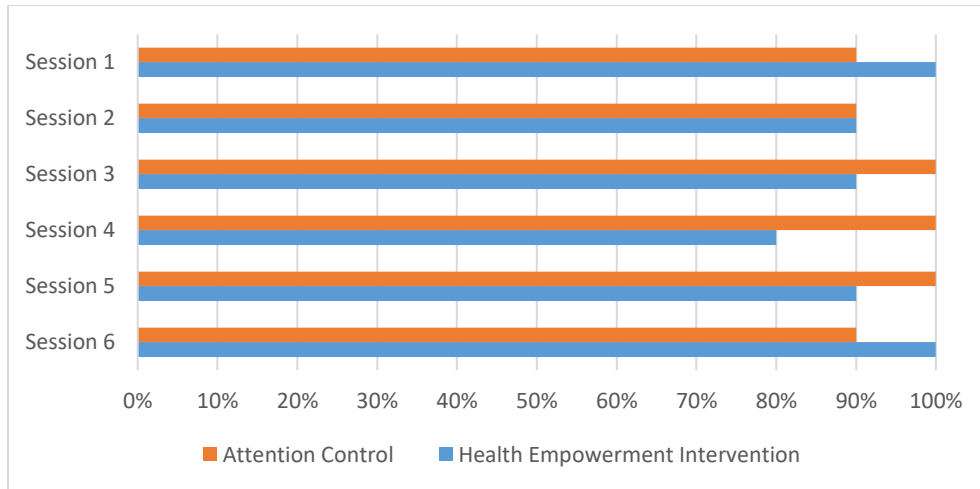


Figure 5. Attendance at HEI and Attention Control Group Sessions.

A reminder call was given to all the participants a day prior to each session, which may have enhanced the attendance rate. The participants also called the researcher if they were not able to attend a session.

**Implementation.** Implementation fidelity of the HEI in the senior center setting was evaluated using an Index of Procedural Consistency. The Index of Procedural consistency is a checklist using a three-point scale (“very little” = 1, “considerable degree” = 2, and “very well” = 3) to evaluate the extent to which the content in each session was delivered as planned. This Index of Procedural Consistency was completed by the interventionist after each HEI session. Each HEI session lasted approximately 60 minutes, included 9 to 10 participants, interventionist, and on occasion, the Director of the senior center. The study was conducted from July to August, 2016. Sessions were scheduled on Mondays for the HEI and on Fridays for the Attention Control groups from 10 am to 11 am, as preferred by the participants. An external reviewer with expertise in gerontological nursing and a trained intervention theorist evaluated 30% of the sessions via audiotape.

Figure 5 depicts implementation fidelity of HEI sessions; sessions were delivered as planned very well 90% and to a considerable degree 10% of the time. Reasons for addressing certain objectives to a considerable degree were due to the time limits of the session. In some sessions, the participants were deeply engaged in the content delivered, which took additional time. Sessions which included role playing as an activity

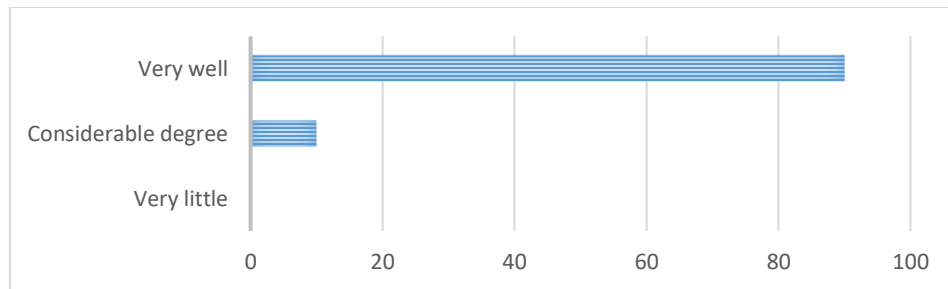


Figure 6. Implementation Fidelity of the HEI

to achieve the objectives, took a longer time to discuss, plan, and then role play. The participants brought a wealth of knowledge and experience to share, and listened to each other's perspective, how they faced challenges in their life, and succeeded in life. According to the external reviewer, the topics were delivered "very well" in all the sessions. The reviewer positively commented on the participants' engagement in the session, and facilitation of the sessions by the interventionist.

The content of the intervention was focused on identifying and building personal resources (self-capacity) and social networks, identifying social services, and how to access them, communicating assertively, problem solving, making decisions, and setting goals as well as focus on strategies to attain goals. For identifying personal resources, the participants shared their past experiences in facing challenging situations, identified strengths, made decisions to set personal health goals based on priorities, and participated

in the activities specified to attain these goals. Participants volunteered suggestions and recommendations to others in the sessions, and listened other's perspective as well as provided their own. While narrating their life stories, a hidden treasure of strengths was poured out by the participants, to be used to attain their personal health goals in the present situation, and in future.

Strengths used by the participants in the past to face challenging situations included: (a) active and engaged, (b) sense of humor, (c) believing in self, (d) positive thinking, (e) self-acceptance, (f) living in the present, (g) determination, (h) persistent, (i) listening, (j) volunteering, (k) friendly, (l) creative and innovative, (m) participating in change, (n) resourceful, (o) cartoonist, (p) singer, (q) writer, and (r) helpful.

After identifying strengths, the participants set goals according to their priorities in life. Goals included to: (a) do exercise routinely, and increase slowly day by day, (b) modify diet as per prescription of the health provider, (c) minimize stress, (d) be positive, (e) take herbal medicine in consultation with the health provider, (f) get relief from back pain, (g) lower A1c level near normal, (h) remain positive, (i) get social security benefit and insurance plan for free prescription drugs and to get driver's license, (j) connect with family and friends, (k) get help to file tax returns, (l) help others, (m) seek information about resources in the community, (n) attend church, (o) reduce nervousness, (p) stay out of high Wi-Fi, and (q) do grief counseling.

***Experiences shared by participants.*** One participant highlighted the importance of awareness of personal and social contextual resources. She shared her story: When she was young: her husband was mentally ill, and she had three children to look after along with her job. It was difficult for her to manage, so she tried to find out the resources to



get help. One day when she went to attend a PTA meeting in the school, she asked for help. She was guided to a person who was ready to take care of her children. This highlights the importance of seeking information and being aware about resources. One participant who developed fear of flying, and wanted to get rid of it, joined a program meant for desensitization of this fear, and he came out as winner when he flew from Scottsdale (Arizona) to Tucson. This reflects the determination which helped him to achieve his goal.

Another participant shared his experience: When he could not work due to hand injuries, he applied for social security, and his application for disability was rejected. Then one of his friends advised him to go to the counselor; on the advice of counselor he produced x-rays of his hands to the social security office, and was considered in a low-income group. Thus, he got social security benefits as well as medicare benefits. This experience shows the importance of social network (friend) and social service (counselor) resources which helped participant to face challenges in the present situation as well as would help in the future.

Another example of social network resources included, when one participant's friend helped her to clean her house and backyard. From the participant's point of view, such a, "friend is better than a family member". Some of the participants wanted to connect to their estranged friends or family members, but they were apprehensive as to whether they would be accepted after a long period of time. One participant shared his experience: in the past, his brother got upset with him, and it continued for months. But at last he called his brother without bringing up the past issue, and started the relationship again. So, he shared a strategy which could be used to build a social network. He also

shared the experience: he had a herniated disc, and did not work for long. Later, when he wanted to work, he was rejected, because he was not able to lift the specified weight. He took the help of a counselor, and she set him on the road with more confidence, and he got a job in a school to help the children during sports. Similarly, one participant had difficulty finding a job after heart surgery, and with the help of a counselor got an accounting job in the Marriot Hotel. Another participant was connected with the community's legal services with the help of a lawyer, to find out about home affordable plans. Some of the participants faced the challenges by being positive, and they emerged stronger after facing every challenge.

For one participant, attending school at the age of 65 years, helped her to relieve her anxiety about talking to friends and instructors. Another participant, who did not pay much attention to his education when he was young, had been going to school since 2010 continuously, and has taken courses in English, sociology, psychology and several other subjects. He shared that he is loved by others in his class. He has fulfilled his desire to have good education as well as to be active and connected. He did not like to be dependent on others. His goal is to live happily, and stay positive. One participant who is a volunteer in the senior center believes in self-acceptance, and shared her experience about how life changed when she accepted living with heart failure. Her goal was to be more active, so she became a volunteer in the senior center, and recently started reading for children in the district school. A sense of humor was mentioned as a critical strength by one of the participants while facing adverse situations in life.

***Goal attainment.*** Many participants were able to achieve their goals, and others were trying to achieve their personal health goals. One of the participants shared her

experience with trying to stop the negative thoughts by saying “STOP”. Another participant appreciated the intervention as a platform to listen and share with freedom, “I was able to share my experiences and thoughts, I was calm, and I was able to listen others as well. My nervousness has decreased as I progressed in the program.” One participant who wanted to connect with friends from the past, tried to contact many but only one responded, and his advice to the other participants was “have thick skin while trying to contact old friends, and be positive.” He went to meet his old friends where he used to work, and shared their reaction “are you still alive?” made everybody laugh.

One participant who tried to connect with her sister after a long period of time, was apprehensive that she would be rejected. She was advised to think positively and try to see what happened. Several participants achieved their goals of physical activity such as 20 to 30 minutes 4 to 5 times a week, and paid more attention to their diet. For one participant, going to church helped him to connect with more friends, and stated that he felt more confident now. Another participant connected with her family members, accessing help to attain her personal health goals. The role of family and friends and some social service agencies such as senior centers, was emphasized by participants as important for the attainment of personal health goals. The majority of the participants welcomed the participation in achieving their goals, and noticed the changes in themselves.

One participant underwent eye surgery; as she lived alone she contacted one cab agency to transport her to the facility, but they refused because it did not fit their schedule. Then one of her friends who was also one of the participants, helped her. Every time when she went for follow up, her friend transported her to and from and even

provided help at home. Her friend played an important role in attaining her personal health goal. One of the participants commented that “participating in the HEI program itself expanded our social network”. Another participant verbalized that HEI program has helped me to advocate for myself “I am advocating for myself as well as for others”. One participant who wrote in her journal everyday, shared the importance of journaling to reflect on yourself, and to know whether we are progressing, or regressing in our personal health goals.

***Social service utilization.*** Seventy five percent of the participants utilized senior center, church, Vista del Camino, and library services. Forty percent utilized the dollar ride, and twenty percent utilized physical, and occupational therapy services. Fifty percent of the participants used senior center/church/library one to three times/week, and twenty five percent four to six times/week. For the dollar ride 35% of the participants used the service one to three times/week and one participant used more than six times/week. Twenty percent of the participants used physical or occupational therapy one to three times /week. The utilization of social services was almost same in the HEI and the Attention control groups, however the participants who did not use the social services in the intervention group, wanted to join senior center services such as exercise program, and friendship group, motivated after attending the HEI and inspired by those attending the services. Information about social services was shared by the participants, and supplemented by the interventionist. To provide comprehensive information of available resources “Elder Resource Book” which was available with the Community Action Agency was procured, and distributed to the participants after the last session of the HEI.

**Specific Aim 2.** The second aim in this feasibility study was to evaluate the effect of the HEI on theoretical mechanisms; health empowerment and purposeful participation and outcomes; self-management, functional health and well-being among older adults with heart failure. The hypothesis to be tested was that older adults with heart failure who receive the HEI would have significant improvement in health empowerment, purposeful participation, self-management, functional health and well-being, compared to the Attention Control group at 6 weeks (post-intervention).

This section describes the results of primary analysis, follow up analysis and preliminary analysis to examine the intended effects of the HEI over time in health empowerment, purposeful participation in change, self-management, functional health and well-being within and between the HEI and the Attention Control groups. Primary analysis included ANCOVA to control for the effects of the confounding variable (covariate) by partitioning out the variation attributed to the covariate which is not the focal point or independent variable in the study.

Follow up ANCOVAs were conducted to assess the robustness of primary analysis by considering potential confounding factors that can influence the intended effects of the HEI on the outcomes. Potential confounding factors included; age, sex, education and income.

Preliminary analysis included t-tests to check for significant systematic differences across the HEI and the Attention Control group at baseline, Levene's test of variance equality, homogeneity of regression and correlations among the outcome variables to assess the magnitude and strength of relationship.

Table 8  
*Correlation Matrix of Measurements at Baseline*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
<b>1. Power as Knowing Participation in Change Tool (PKPCT)</b>	1															
<b>2. PKPCT awareness</b>	.91**	1														
<b>3. PKPCT Choices</b>	.91**	.81**	1													
<b>4. PKPCT Freedom to Act Intentionally</b>	.96**	.83**	.81**	1												
<b>5. PKPCT participation in Creating Change</b>	.90**	.71**	.71**	.87**	1											
<b>6. Ryff's Psychological Well-being Picture Scale</b>	.57**	.40	.61**	.46*	.59**	1										
<b>7. Ryff Personal Growth</b>	.52*	.48*	.62**	.41	.41	.85**	1									
<b>8. Ryff social Relations</b>	.41	.19	.54*	.29	.44	.85**	.64**	1								
<b>9. Ryff purpose in Life</b>	.49*	.29	.46*	.45*	.57**	.87**	.73**	.57**	1							
<b>10. Ryff Self-acceptance</b>	.51*	.39	.47*	.39	.60**	.88**	.62**	.71**	.73**	1						
<b>11. SCHFI Self-maintenance</b>	-.06	-.04	-.05	-.09	-.03	.22	-.07	.31	.15	.38	1					
<b>12. SCHFI Self-management</b>	.01	-.01	.00	.08	-.02	.07	-.05	-.10	.18	.13	.18	1				
<b>13. SCHFI Self-confidence</b>	.21	-.07	.23	.33	.26	.36	.09	.33	.43	.33	.31	.41	1			
<b>14. Minnesota Living with Heart Failure</b>	-.06	.04	-.14	-.12	-.00	-.26	-.29	-.41	-.13	-.08	-.15	.23	-.36	1		
<b>15. Well-Being Picture Scale</b>	.41	.45*	.43	.32	.33	.57**	.40	.42	.45*	.68**	.58**	.38	.36	.07	1	
<b>16. Goal Attainment Scale</b>	.32	.31	.44	.27	.15	.49	.41	.46	.38	.50	.49	.20	.17	.08	.54*	1

\*Correlation is significant at  $p \leq 0.05$  level

Table 8 indicates that significant positive correlations were observed between Self-Care of Heart Failure Index and its domains self-maintenance, self-management, and self-confidence ( $r = .66, .76, .77, p < .01$ , respectively). Strongest correlations were observed between Power as Knowing Participation in Change Tool and its four dimensions including awareness, choices, freedom to act intentionally, and participation in creating change ( $r = .91, .91, .96, .90, p < .01$ ). Power as Knowing Participation in Change Tool, and Well-being Picture Scale had significant correlations with Ryff's Psychological Well-being Scale ( $r = .57, .57, p < .05$ , respectively) and Ryff's dimensions purpose in life and self-acceptance ( $r = .45, .68, p < .05$ , respectively). Well-being Picture Scale also had significant correlations with Self-Care of Heart Failure Index ( $r = .59, p < .01$ ), with Self-Maintenance ( $r = .58, p < .01$ ), and Goal Attainment Scale ( $r = .54, p < 0.5$ ).

**Table 9**  
***Means and Standard Deviations of Theoretical Mechanisms and Outcomes***

	Baseline (T1)				Six weeks (T2)			
	Control (n=10)		Intervention (n=10)		Control (n=10)		Intervention (n=10)	
	Mean	Std.	Mean	Std.	Mean	Std.	Mean	Std.
<b>Ryff's Psychological Well-being Scale</b>	119.50	22.86	136.50	23.43	143.70	22.78	155.51	13.83
<b>Personal Growth</b>	29.80	7.60	34.10	5.97	28.90	6.14	35.90	4.82
<b>Social Relations</b>	32.50	6.49	33.70	7.56	33.60	7.16	34.59	6.51
<b>Purpose in Life</b>	27.60	6.48	35.50	5.72	28.90	5.67	34.10	5.57
<b>Self-Acceptance</b>	29.11	6.33	33.20	7.41	29.55	7.91	34.17	5.50
<b>Power as knowing Participation in Change Tool</b>	245.72	42.06	259.83	45.43	243.68	50.38	280.48	32.18
<b>My Awareness</b>	60.02	9.21	62.83	12.42	61.68	14.04	71.20	8.24
<b>My Choices</b>	61.30	13.0	63.60	11.67	59.96	15.17	70.98	6.12
<b>Freedom to Act Intentionally</b>	62.70	11.59	68.20	10.89	62.70	11.59	68.20	10.89
<b>Participation in Creating Change</b>	61.70	13.22	65.20	13.29	59.36	12.37	70.10	12.48
<b>Self-care of Heart Failure Index</b>	55.60	7.37	63.50	8.05	59.39	10.24	63.06	8.75
<b>Self-Maintenance in Heart Failure</b>	26.50	2.42	29.00	4.447	29.34	4.99	28.86	4.325
<b>Self-Management in Heart Failure</b>	12.20	4.185	15.00	4.056	12.85	4.267	14.90	4.38
<b>Self-Confidence in Heart Failure</b>	16.90	3.843	19.50	3.206	17.20	3.36	19.30	1.83
<b>Minnesota Living with Heart Failure Questionnaire</b>	32.01	22.28	36.70	25.98	28.99	21.80	35.10	20.84
<b>Well-being Picture Scale</b>	49.30	7.59	56.90	11.75	58.43	11.71	61.43	8.94
<b>Goal Attainment Scale</b>	-2.00	1.31	.50	1.512	-2.00	1.31	1.70	1.64

Table 9 depicts the mean scores with standard deviations on health empowerment measured using Ryff's Psychological Well-being Scale, purposeful participation measured using Power as Knowing Participation in Change Tool, self-management



measured using Self-care of Heart Failure Index, functional health measured using Minnesota Living with Heart Failure Questionnaire, well-being measured using Well-Being Picture Scale and personal health goal attainment measured using Goal Attainment Scale at baseline and six weeks for the HEI and the Attention Control group which were analyzed for change over time.

### **Univariate Analysis of Covariance**

A one-way analysis of covariance (ANCOVA) was conducted to determine whether significant differences were observed for health empowerment, purposeful participation, self-management, functional health, and well-being in older adults with heart failure. ANCOVA was conducted due to the potential for the confounding influence of the baseline scores (covariates) on six week scores (dependent variable). The independent variable group included two levels, the HEI and the Attention Control. The dependent variables were six week scores on outcome measures; baseline scores on these outcome measures were considered as covariates.

As a follow up analysis ANCOVA was conducted to assess the robustness of primary analysis by controlling for age, sex, number of schooling years, education, and income, to take into account their influence on six weeks' scores. ANCOVA partitioned out the variance explained by demographics from the dependent variable, thus reduced the error variance and enhanced the power of the study.

A preliminary analysis was conducted to evaluate the equality of error variance which tests the null hypothesis that the error variance of the dependent variable is equal across groups in all the outcome measures. Homogeneity of regression assumption was

tested for all the variables to test whether the baseline score differ by group, and the results of these analyses were in favor of these assumptions.

Table 10 presents the significant results of ANCOVA for the theoretical mechanisms of change and outcomes variables. For the dimension “freedom to act intentionally” of Power as Knowing Participation in Change Tool the mean scores at baseline and at six weeks were same for the HEI and the Attention Control group with zero difference.

**Table 10**  
*ANCOVA For Theoretical Mechanisms and Outcome Variables*

Outcome measures	F	p-value	Eta squared
Ryff's Psychological Well-being Scale	.24	.63	.01
Ryff's Personal Growth	5.50	.03*	.25
Ryff's Social Relations	.02	.90	.00
Ryff's Purpose in life	.02	.91	.00
Ryff's Self-Acceptance	.59	.45	.03
Power as knowing Participation in Change Tool	6.21	.023*	.27
PKPCT My Awareness	3.31	.08*	.16
PKPCT My Choices	7.07	.02*	.29
PKPCT Freedom to Act Intentionally	00	00	00
PKPCT Participation in Creating Change	3.76	.06*	.18
Self-care of Heart Failure Index	.29	.60	.02
Self-Maintenance in Heart Failure	.43	.52	.03
Self-management in Heart Failure	.04	.85	.00
Self-confidence in heart failure	1.13	.30	.06
Minnesota Living with Heart Failure Questionnaire	.22	.65	.01
Wellbeing Picture Scale	.68	.42	.04
Goal Attainment Scale	8.03	.01*	.38

**Health Empowerment.** Health empowerment was measured using Ryff's Psychological Well-being Scale, with four dimensions including personal growth, purpose in life, social relations, and self-acceptance. ANCOVA was statistically significant ( $F = 5.51, df = 1, p = .03$ ) for personal growth, indicating that the HEI group had higher personal growth scores as compared to the Attention Control group. Personal growth reflects continuous development, growth and expansion of self, openness to experiences, realizing personal strengths, and change reflected through more knowledge. Further analysis revealed that personal growth was significantly higher for females ( $F = 7.56, df = 1, p = .02$ ) as compared to males.

Follow up ANCOVA to evaluate significant differences across intervention and control groups was conducted by controlling for potential confounding factors. ANCOVA was significant for personal growth with age ( $F = 7.986, df = 1, p = .01$ ), education ( $F = 9.672, df = 1, p = .00$ ), and gender ( $F = 7.216, df = 1, p = .02$ ) indicating that the HEI group had high scores on personal growth as compared to the Attention Control group after controlling for confounding factors. ANCOVA was significant for purpose in life with age ( $F = 4.613, df = 1, p = .046$ ), education ( $F = 5.084, df = 1, p = .038$ ) and income ( $F = 7.99, df = 1, p = .01$ ) indicating that the HEI group had high scores on purpose in life as compared to Attention Control group after controlling for confounding factors, which was insignificant in the primary analysis. Purpose in life reflects that person has goals in life, sense of directedness, values present and past life and has aims for living.

There were no significant differences between the HEI and the Attention Control groups for social relations and self-acceptance. However, mean scores were higher for

social relations and self-acceptance for the HEI group ( $M = 34.59$ ,  $SD = 6.51$  &  $M = 34.17$ ,  $SD = 5.50$  respectively) as compared to the Attention Control group ( $M = 33.60$ ,  $SD = 7.16$  &  $M = 29.55$ ,  $SD = 7.91$  respectively). For the total scale scores, ANCOVA approached significance ( $F = 3.11$ ,  $df = 1$ ,  $p = .09$ ) between groups after controlling for education as well as income ( $F = 3.48$ ,  $df = 1$ ,  $p = .07$ ).

Figure 7 illustrates that adjusted marginal means for health empowerment were higher in the HEI group, compared to the Attention Control group at six weeks, beyond the effect of covariate. Cohen’s effect size ( $d = .63$ ) is consistent with the moderate practical importance of the HEI effect on personal growth, social relations, purpose in life and self-acceptance, measured using the Ryff’s Psychological Well-being Scale.

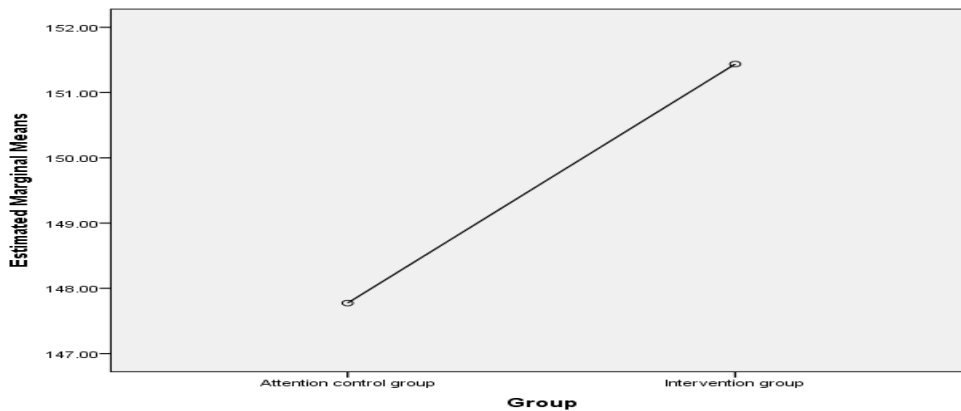


Figure 7. Adjusted Marginal Mean Scores Ryff’s PWS at Six week for HEI and the Attention Control Groups

**Purposeful Participation in Change.** Purposeful participation was measured using Power as Knowing Participation in Change Tool, with four dimensions including awareness, choices, freedom to act intentionally, and involvement in creating change. ANCOVA was statistically significant ( $F = 6.209$ ,  $df = 1$ ,  $p = .023$ ) for purposeful participation in change indicating that the HEI group had higher scores as compared to

the Attention Control group. Further ANCOVA was significant for females ( $F = 4.719$ ,  $df = 1$ ,  $p = .05$ ) on purposeful participation as compared to males.

Follow up ANCOVA was statistically significant for awareness, and choices, ( $F = 5.102$ ,  $df = 1$ ,  $p = .037$ , &  $F = 5.768$ ,  $df = 1$ ,  $p = .028$  respectively) after controlling for income, and for choices ( $F = 5.40$ ,  $df = 1$ ,  $p = .033$ ) after controlling for education, which means the HEI group had higher scores in awareness, and choices as compared to the Attention Control group. Purposeful participation was statistically significant ( $F = 8.66$ ,  $df = 1$ ,  $p = .033$ ) for participants in the HEI group who had enough money to meet their monthly needs.

Figure 8 illustrates that adjusted marginal means for purposeful participation in change were higher for the HEI group, compared to the Attention Control group at six weeks, beyond the effect of covariate. Figure 9 presents the change in the mean scores at baseline and six weeks across four dimensions of the scale including awareness, choices, freedom to act intentionally and participation in creating change. Cohen's effect size ( $d = .87$ ) is consistent with the high practical importance of the HEI effect on awareness, choices, freedom to act intentionally and participation in creating change, measured using the Power as Knowing Participation in Change Tool.

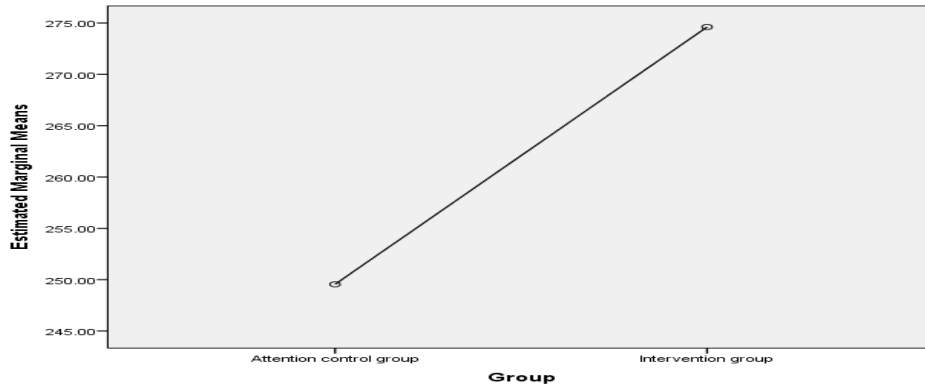


Figure 8. Adjusted Marginal Mean Scores PKPCT at Six-week for the HEI and the Attention Control Groups

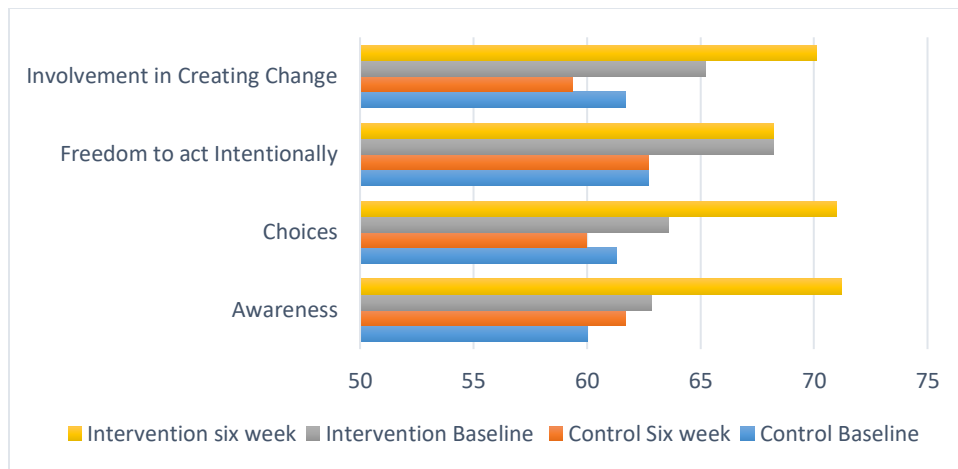


Figure 9. Mean Scores PKPCT Subscales at Baseline and Six weeks for the HEI and the Attention Control groups

**Self-Management.** Self-care management of heart failure which was measured using Self-care of Heart Failure Index, including three dimensions of self-maintenance, self-management, and self-confidence. ANCOVA was not found statistically significant for the HEI and the Attention Control groups. However, 30% of the participants had adequate scores ( $\geq 70$ ) for self-maintenance at baseline and 45% had adequate scores at six weeks, in both the groups. Adequacy scores for self-management and self-confidence were almost similar at baseline, and six-weeks. Fifty percent of the participants had

adequate score on self-confidence ( $\geq 70$ ) at baseline as well as at six-weeks, and 20% of the participants had adequate scores on self-management both at baseline and six-weeks. Significant effect of baseline scores for self-management and self-maintenance ( $F = 6.530, df = 1, p = .02$  &  $F = 5.056, df = 1, p = .038$  respectively) was observed at six week scores by explaining 28% and 23% of the variance respectively. The baseline scores had strong intent toward significance level for self-confidence ( $F = 3.327, df = 1, p = .08$ ) by explaining 16% of the variance at six weeks' scores.

Follow up analyses with ANCOVA after controlling for education, and age were significant for group for self-confidence ( $F = 4.593, df = 1, p = .047$  &  $F = 4.604, df = 1, p = .047$  respectively), indicating higher self confidence in the HEI group as compared to Attention Control group, thus rejects the null hypothesis. Figure 10 illustrates that adjusted marginal means for self-management were higher for the HEI group, compared to the Attention Control group at six weeks, beyond the effect of covariate. Cohen's effect size ( $d = .78$ ) is consistent with a large practical importance of the HEI effect on self-confidence, and ( $d = .47$ ) is consistent with moderate practical importance of the HEI on self-management, measured using Self-care of Heart Failure Index.

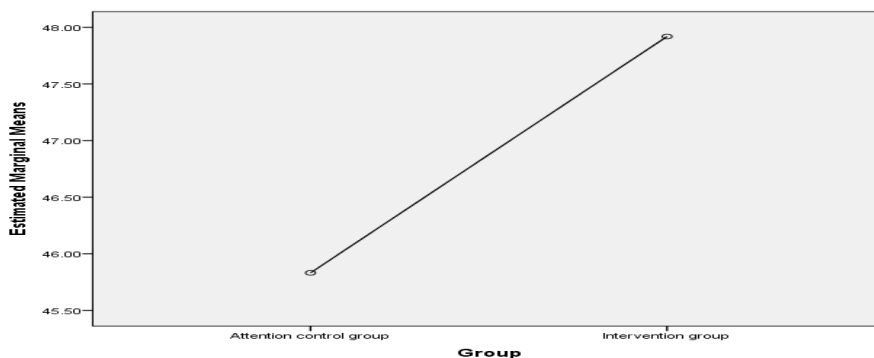


Figure 10. Adjusted Marginal Mean Scores of Self-Mangement at Six-weeks for the HEI and the Attention Control Group

**Functional Health.** Functional health was measured using Minnesota Living with Heart Failure Questionnaire (MLHFQ). Analysis of covariance conducted to examine the effect of the HEI on functional health over time resulted with no significant difference across the HEI and the Attention Control groups. However, mean scores at baseline were higher for the HEI group ( $M = 36.70$ ,  $SD = 25.98$ ) as compared to the Attention Control group ( $M = 32.01$ ,  $SD = 22.28$ ). Both groups had decrease in the mean scores from baseline to six weeks, indicating improvement in functional health, as higher scores indicate poor quality of functional health. Decrease in functional health scores for the HEI group ranged from 6 to 30 and for the Attention Control group ranged from 4 to 32 reflecting improvement in functional health across both the groups. One participant in each group had increase in functional health scores (60 & 25 respectively) indicating deterioration in functional health.

No significant difference across groups was observed for physical dimension and emotional dimension of MLHFQ. Overall, functional health scores for emotional dimension ranged from 0 to 23 and 0 to 17, at baseline and six weeks respectively indicating improvement in emotional dimension of functional health. However, significant effect of baseline scores of physical and emotional dimensions ( $F = 4.422$ ,  $df = 1$ ,  $p = .05$  &  $F = 14.47$ ,  $df = 1$ ,  $p = .001$ , respectively) was observed at six weeks' scores by explaining 21% and 46% of the variance respectively. Figure 9 depicts that there was decrease in mean scores of the HEI and the Attention Control groups over time. Cohen's effect size ( $d = .30$ ) is consistent with a small to medium practical importance of



the HEI's effect on the functional health measured using the Minnesota Living with Heart Failure questionnaire.

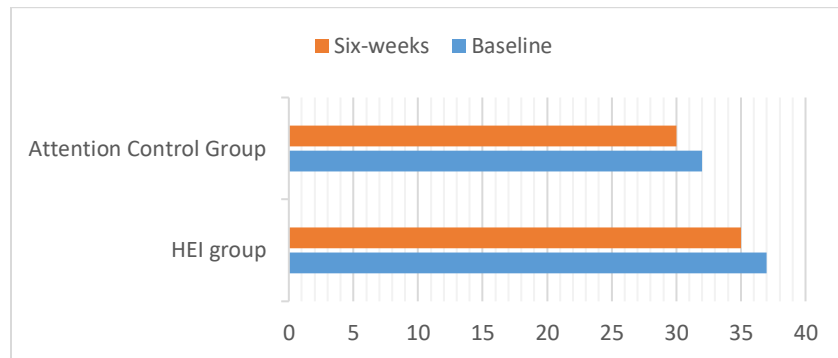


Figure 11. Mean Scores MLHFQ at Baseline & Six weeks for the HEI and the Attention Control Group

**Goal Attainment.** Attainment of personal health goals was measured using Goal Attainment Scale. ANCOVA was statistically significant for group ( $F = 14.805$ ,  $df = 1$ ,  $p = .00$ ); attainment of personal health goals was higher in the HEI group as compared to the Attention Control group. Majority of goals which were attained by the participants included exercise, modifying diet, reducing stress, building network, thinking positive, volunteering, cleaning the house and backyard, helping others, getting driver's license, assertive communication, and being active. Statistically significant difference across groups were observed after controlling for age, education and income. Figure 11 depicts that adjusted marginal means for goal attainment were higher for the HEI group, compared to the Attention Control group at six weeks, beyond the effect of covariate. Cohen's effect size ( $d = .76$ ) is consistent with the moderate to high practical importance of the HEI effect on attainment of personal health goals. No movement of goals was assumed in the Attention Control group.

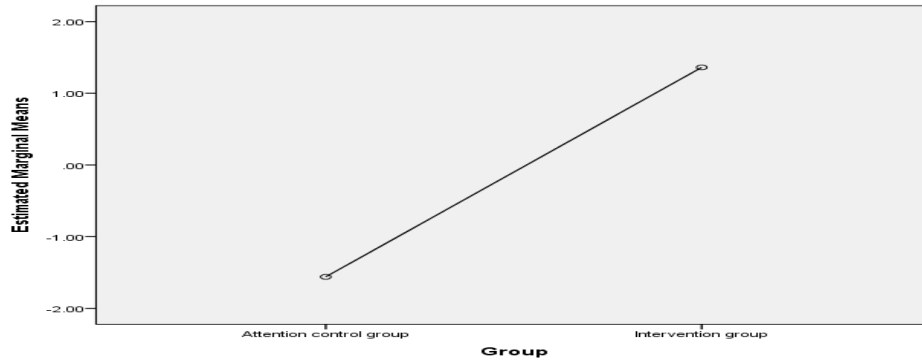


Figure 12. Adjusted Marginal Mean Scores of Goal Attainment at Six week for the HEI and the Attention Control Group

**Perceived Well-being.** Perceived well-being was measured using Well-Being Picture Scale. ANCOVA resulted with significant effect ( $F = 19.996$ ,  $df = 1$ ,  $p = .000$ ) of baseline scores at six-week scores by explaining 54% of variance. However, no significant difference was observed between the HEI and the Attention Control group; the mean scores at six weeks were higher in the HEI group ( $M = 61.16$ ) as compared to Attention Control group ( $M = 58.70$ ), depicted in figure 10. Cohen’s effect size ( $d = 30$ ) is consistent with small to moderate practical importance of the HEI effect on perceived well-being, measured using Well-Being Picture Scale.

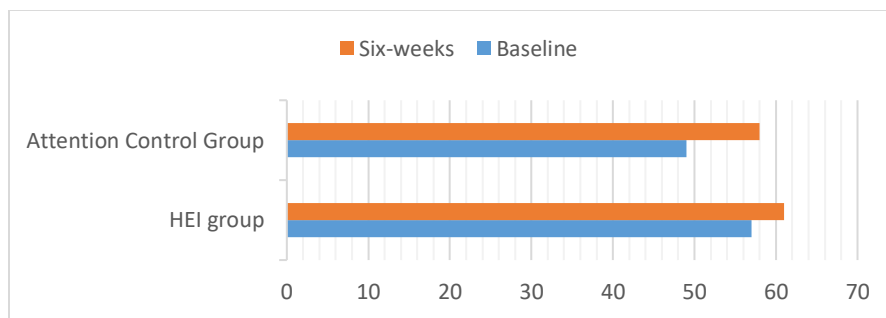


Figure 13. Mean Scores WPS at Baseline and Six-Week for the HEI and the Attention Control Group

## **Summary**

Study findings support the feasibility (acceptability, demand, implementation fidelity) of the HEI, in older adults with heart failure in the senior center settings. The Acceptability survey revealed that the HEI was found to be acceptable. Regular attendance in the sessions, and limited attrition depicted the demand of the intervention. Results of ANCOVA using General Linear Model, to evaluate changes over time in health empowerment, purposeful participation, self-management, functional health, goal attainment, and well-being, indicated that there were significant changes over time in the HEI group as compared to the Attention Control group. Statistically significant differences were observed across the HEI and the Attention Control groups related to personal growth, purpose in life, purposeful participation in change, awareness, choices, self-management, and attainment of personal health goals. The mean scores were higher for the HEI as compared to the Attention Control group for functional health, self-maintenance, social relations and perceived well-being.

## **Chapter 5**

### **DISCUSSION**

This feasibility study of the HEI supports its acceptability, demand and implementation among older adults with heart failure in senior center settings. Findings provided support for the effects of the HEI on theoretical mechanisms of change; health empowerment including personal growth, social relations, purpose in life and self-acceptance, and purposeful participation in change including awareness, choices, freedom to act intentionally and involvement in creating change for goal attainment to optimize outcome variables of self-management, functional health, and well-being.

Research findings have important implications for theory, nursing science, future research, and practice. In this chapter, the results are summarized and tied to the research aims and literature. The findings are discussed within the context of heart failure to optimize self-management, functional health, and well-being in older adults, organized as per specific aims in this study. Strengths and limitations of the study are addressed as well as suggestions for future research. Finally, recommendations for research and practice are formulated from the study results.

Participants were categorized in heart failure functional class according to New York Heart Association Functional Classification. Participants belonging to class I, II, and III were included in the study. Interventions targeting class I, II and III may reduce heart failure exacerbations by increasing awareness of personal and social contextual resources to foster decision making for purposeful participation in the attainment of personal health goals. Similarly, Riegel, Carlson, Glaser and Hoagland (2000) reported in their study to test the effectiveness of a multidisciplinary disease management intervention in heart failure that acute care resource use was lower in class II intervention patients. Higher class was associated with poor outcomes in a group of ambulatory chronic heart failure patients in a retrospective follow-up trial (Ahmed, et al., 2006). Thus, NYHA functional classification can be used to design interventions for heart failure patients.

Specific aims of the study included: (a) to examine the feasibility of the HEI, and (b) to evaluate the effect of the HEI on theoretical mechanisms; health empowerment and purposeful participation and outcomes; self-management, functional health and well-being. Specific aim 1 was achieved by evaluating the acceptability of the intervention in

older adults, demand through participant attrition rate and attendance in the sessions, and implementation fidelity of the HEI as measured through Index of Procedural Consistency. Specific aim 2 was achieved by measuring theoretical mechanisms; health empowerment and purposeful participation, and outcomes; self-management, functional health and well-being at baseline and six weeks using valid and reliable measures.

### **Specific Aim 1**

**Acceptability.** The HEI was evaluated as acceptable by the older adults with heart failure enrolled in this study.

**HEI acceptability.** Based on participant' evaluation, and interventionist field notes, the content, activities, and role plays in the six week sessions were very well accepted by most of the participants regarding usefulness of sessions to recognize personal resources, recognize people they can turn to for support, identify and access social services, and progress toward attainment of health goals. Acceptability findings in this study are consistent with those reported in other HEI studies. Shearer, Fleury and Belyea (2010) reported acceptability as “very well” among home bound older adults in their randomized controlled trial to explore the impact of the HEI on theoretical mediating variables. Duffy and colleagues (2010) in their study ‘improving outcomes for older adults with heart failure a randomized controlled trial using a theory-guided nursing intervention’ also reported about patient participation and acceptability, none of the participant discontinued their participation, and all participated in the discussions and decisions related to their health. Community stakeholders and participants were involved in all the phases of the intervention, which may have contributed in enhancing acceptability of the intervention. Dickson and colleagues (2015) highlighted the

importance of community stakeholders in making the intervention feasible and acceptable. Acceptability is a key element to evaluate in research and practice (Bowen, et al., 2009), however it has not been reported systematically in studies advancing an empowerment perspective among heart failure patients. Understanding the extent to which the intervention is suitable, and satisfying to the participants, is extremely important for designing, testing, translating to practice, and examining sustainability of the intervention.

***Demand.*** Demand of the HEI was evaluated through the attendance rate of the participants in the sessions, as well as absence of attrition in this study. The reasons for which participants missed sessions included illness, fall, surgery, fire in the neighborhood, visit to a relative, and emergency in the family. Very good attendance in the HEI may have been influenced by: (a) relevance and usefulness of the HEI to the target population; (b) face to face interaction during the recruiting process including distribution of flyer, introduction of the health program, screening of the participants, consent process, and administering pretest; (c) involvement of the participants in the planning process, considering their priorities, and their convenience to schedule the health program; (d) reminder calls to all the participants one day prior to each session; (e) positive feedback during and after every session; (f) setting for delivery of intervention was familiar to a number of the participants because they were already attending the senior centers.

A reminder call one day before each session may have been the key element in enhancing the attendance, because older adults may forget and miss the sessions without reminders. Telephone reminders and face to face contact enhanced recruitment and

attendance in studies by Shearer, Fleury and Belyea (2010) and Ford, Havstad, and Davis (2004). Face to face contact has been supported as more effective than other approaches to recruitment and reduced the feeling of uncertainty about participation (Gonzalez, et al., 2007; Adams et al., 1997). The recruitment flyer for this study described the health program as designed to increase the awareness of personal and social contextual resources for optimizing self-management, functional health and well-being for older adults with heart failure. The consent form provided an overview of the health program, which also reduced the uncertainty about the program. The participants were assured about transportation in collaboration with the senior center management, if they needed, to attend the program sessions; lack of transportation has been reported as a barrier for older adults to participate in the health programs (Shearer, Fleury & Belyea, 2010; Resnick, et al., 2003).

***Implementation fidelity.*** The HEI in this study was delivered as planned. A meticulous plan of the intervention implementation, including manual, training of interventionist, and list of standard supplies for each session ensured that interventionist and site were well prepared for each session. Evaluation of fidelity to intervention delivery, receipt, and enactment through field notes, the Index of Procedural Consistency, audiotaping the intervention sessions, and an external review allowed the PI and research team to correct any deviation from the intervention protocol. Fidelity monitoring throughout the implementation process might foster replication of the HEI in future research, and may contribute substantially in developing quality improvement approaches while translating the HEI into practice. According to Frank and colleagues (2008),

interventions are more effective when they are modified in response to implementation feedback.

Intervention fidelity assists in generalization of results with effective interventions, what worked, for whom, and under what conditions, and therefore what should be replicated in future (Nelson et al., 2012). Intervention fidelity is a critical element in valid interpretation of outcomes of research, and for improving the usability of theory based intervention in future research (Glasgow & Emmons, 2007; Nelson, et al., 2012; Corley & Kim, 2016). Intervention fidelity may serve as a moderator of the relationship between interventions and their intended effects (Carroll, et al., 2007). Implementation fidelity strengthens the validity of a study, and requires systematic evaluation of implementation quality (Breitenstein, et al., 2010).

The content of the HEI was focused on identifying personal and social contextual resources, and building upon them, problem solving, decision making and goal setting as well as strategies to attain personal health goals (Shearer, 2009). Participants shared the strengths and values that have guided them to purposefully participate in changes and life events to realize their potential, which may help them to achieve well-being consistent with self-management of heart failure. Reminiscing about past experiences is crucial to realize the personal strengths, which can be utilized for problem solving in the present situation (Webster, Bohemeijer & Westerhof, 2010; Shearer, 2009). Participants identified several personal strengths by sharing their past experiences, including determination, being persistent, positive thinking, being active, sense of humor, friendly, helpful, listener, writer, singer, creative and innovative, and resourceful. In a qualitative analysis of living with heart failure, Zambroski (2003) found that participant experiences,



input from others, being active, and belief in God, helped the patients to cope with the challenges of self-management of heart failure. From the perspective of Lundman and colleagues (2012), inner strength is a key to promoting well-being and maintaining health, with both inner and environmental resources as important. However, most research on self-management interventions for heart failure patients is focused on identifying symptoms, making decisions to take actions, and evaluating the effects of actions (Moser, et al., 2012), rather than an empowerment focus on self-capacities, values, and priorities of older adults with heart failure (Shearer, 2009).

Intervention study designed to improve awareness of personal resources such as personal responsibility over daily activities and feelings of choice have proved effective in initiating both activity level and sociability among older adults in the nursing homes (Rodin & Langer, 1977). In the present study, awareness of personal resources included perception of self as growing and expanding, realizing potential, and learning from the new and past experiences to improve and change, was reflected through purposeful participation in attainment of personal health goals. These findings are consistent with the findings of qualitative studies by Shearer (2007 & 2008). After identifying strengths, participants set goals consistent with their own priorities in life. Participant understanding of their strengths and needs is fundamental to engagement in the change process, rather than responding to an outside decision maker (Brock & Pettit, 2007). The goals set by the participants included to minimize stress, do exercise, be positive, get relief from back pain, lower A1c level, connect with family and friends, help others, seek information, attend church, and reduce nervousness. From the perspective of an empowerment

approach, people have inherent power, which can be realized and used for decision making and attaining their health goals (Dunst & Trivette, 1996, Shearer, 2009).

Past experiences of participants also highlighted the importance of social network and social service agencies to manage the life situations. The importance of effective and assertive communication to build social networks, accessing social service agencies, as well as strategies to break communication barriers were shared by the participants. The majority of the participants built their social network by connecting with their family and friends; some were yet trying to reconnect. One participant said “for me a friend is better than the family members, he is cleaning my house and backyard and painting my house as well”. One participant’s husband had fallen and suffered a hip fracture; her friends assisted in shifting her husband to the hospital, and provided needed help.

Similarly, in a study of participants in a congregate meal program, Shearer and Fleury (2006) reported that social resources fostered health empowerment by being continuously available, and providing support to face life situations. Social networks have been found to influence self-management by assisting in symptom management and evaluation of symptoms (Quinn, et al., 2010), and assisting in dietary and medication adherence. Dunbar and colleagues (2005) assessed the role of family support regarding adherence to low sodium diet in heart failure patients, and found significant differences across experimental and control groups.

Social support is positively associated with subjective well-being (Pinquart, 2001). The importance of a social network for consultation and advice about symptoms of disease and making decisions has been highlighted by American Heart Association (AHA Meeting Report, April 29, 2015).

Field notes from the HEI revealed that the participants supported each other during the sessions, and some of the participants had supportive family members who transported them to participate in the sessions. Some of the participants lived away from their families, and were dependent on their friends, and social service agencies for social support. Similarly, Sayers and colleagues (2008) highlighted the significance of emotional support, direct assistance and fostering healthy behaviors by family and friends for day to day management of heart failure.

Most of the participants could access social services, and were utilizing them. For example, senior center services including lunch program, music classes, Karaoke, gymnasium, exercise classes, Bingo, library, art classes, and computer lab were utilized by most of the participants. Other agencies whose services were availed by the participants were physical, and occupational therapy, animal food bank, free cab and trolley service, Dial a Ride, church, and temple. As the participants wanted more information about resources, they were provided with the “Elder Resource Book” which was available with the community agency, containing comprehensive information about the social resources, after the last session of the program.

Some of the HEI participants who were not availing services of senior center decided to attend the exercise, and friendship group during the health program. The participants in the HEI group were using more social services when compared to the Attention Control group. Thus, information on how to access social services is crucial for their utilization by older adults with heart failure.

## **Specific Aim 2.**

The effect of the HEI was evaluated on theoretical mechanisms; health empowerment and purposeful participation and outcomes; self-management, functional health and well-being of older adults with heart failure in the senior center settings. The hypothesis that older adults with heart failure who receive the HEI will have significant improvement in health empowerment, purposeful participation, self-management, functional health and well-being, compared to the attention control group at 6 weeks (post-intervention) was tested.

**Theoretical mechanisms of change.** Theoretical mechanism of change processes in the HEI include health empowerment and purposeful participation for goal attainment.

**Health empowerment.** Empowerment is a relational and inherent process which encompasses more than providing information when utilized with a patient (Shearer, et al., 2007; Rogers, 1970). Sharing knowledge, identifying resources and building upon them, identifying opportunities for change, decision making to attain the personal health goals consistent with the values and priorities of older adults are fundamentals of the person-environment process (Shearer et al., 2007). Health empowerment includes four dimensions: personal growth, social relations, purpose in life, and self-acceptance, measured using Ryff's Psychological Well-being Scale. A statistically significant increase was observed in personal growth in the HEI participants as compared to the Attention Control group and females had higher personal growth as compared to males. Higher personal growth in women may be attributed to social role quality, and involvement which is linked to psychological well-being (Ryff, 2014; Plach, 2007). Personal growth was reflected through growth, and expansion of self by seeking more

information, and listening to others' perspectives, identifying personal strengths, and participating in change. After controlling for age, education and income purpose in life was significantly improved in the HEI as compared to the Attention Control group. Purpose in life was reflected through goals in life and direction, as well as learning from past and present situations.

Participants shared experiences during the sessions and used these experiences for decision making in goal setting and attaining those goals. Differences in scores for health empowerment between groups approached significance for the total scale score after controlling for education and income. Although there were no statistically significant differences between groups for social relations and self-acceptance, the mean scores were higher for the HEI group. Shearer (2007), Shearer, Fleury and Belyea (2010), and Shearer and Fleury (2006) noted the importance of social support and network building in the promotion of well-being. However, in this study, the baseline scores of participants were high for social relations, leaving hardly any room for improvement. Moderate effect size of 0.6 indicates that 73% of the Attention Control group scores would be below the average score in the HEI group; a 0.66 probability that scores in the HEI group would be higher than scores in the Attention Control group, data support the practical importance of the HEI effect on personal growth, social relations, purpose in life, and self-acceptance (Coe, 2002). Similar findings were reported by Shearer, Fleury and Belyea (2010), Shearer and Fleury (2006), Shearer and colleagues (2007) in their studies related to the HEI.

***Purposeful participation.*** Patient participation in care has become the goal of health care, based on people's right for self-determination (WHO, 2013). From the

perspective of empowerment, the older adult with heart failure is an active participant in self-care, rather than being a passive recipient, who makes informed decisions to participate purposefully to attain personal health goals (Shearer, et al., 2010; Shearer, et al., 2007). Purposeful participation includes four dimensions: awareness, choices, freedom to act intentionally, and involvement in creating change, operationalized through Power as Knowing Participation in Change Tool. Statistically significant differences were observed for purposeful participation; the HEI group had higher scores on awareness, choices, and purposeful participation in change when compared to the Attention Control group.

Significant differences were observed for awareness and choices, after controlling for income and education. Purposeful participation was significantly higher for female participants in the HEI group, and for participants who had enough money to meet their monthly needs. Thus, when income is adequate to meet expenses, participants can participate more fully in change. Similar findings were reported by Shearer, Fleury and Belyea (2010) in their randomized controlled trial of the HEI; while main effects were not found for purposeful participation, significant differences were observed after controlling for age, income, and education.

Laschinger and colleagues (2010) noted that participation of patients in their own care may be enhanced by facilitating their awareness that they have potential to participate, providing information and opportunities to grow, facilitating collaboration with family, friends and providers, and providing autonomy in decision making, thus supporting findings regarding purposeful participation in change. Shearer and colleagues (2007) in their study “a telephone- delivered empowerment intervention with patients

diagnosed with heart failure” reported that participants with heart failure purposefully participated in identifying and attaining their health goals; one patient located a mail order pharmacy to get prescription medications at lower cost. In the present study, to get free prescription drugs some of the participants had their health insurance through ACCESS, whereas some were trying to get it. Large effect size of 0.9 indicates that 82% of the Attention Control group scores would be below the average score in the HEI group, with 0.74 probability that scores from the HEI group would be higher than scores in the Attention Control group. Findings support the practical importance of the HEI effect on purposeful participation in change measured using the PKPCT (Coe, 2002).

**Outcomes.** Outcomes in the HEI for older adults with heart failure include self-management, functional health and well-being.

**Self-management.** Self-care is crucial to improve patient outcomes in heart failure. Self-management of heart failure was measured using Self-Care of Heart Failure Index (SCHFI). The focus of the HEI was to optimize self-management of older adults with heart failure. While no significant effects were found for the outcome variable self-maintenance in heart failure across groups, baseline scores strongly predicted the six week scores explaining almost 28% of the variance. The participants scored higher for keeping their doctor and nurse appointments, with a mean score of 3.80. Thirty percent of the participants had adequate self-maintenance score ( $\geq 70$ ) at baseline, which increased to 45 % at six weeks in both the groups. However, mean scores for the three subscales were less than the adequacy score of 70 in this study and similar findings were noted by Riegel, and colleagues (2009), in an update on SCHFI. Similarly, Tung and colleagues (2014), and Conceicao and colleagues (2015), reported mean scores for three sub scales

of less than 70. In this study, females had higher mean scores on self-management as compared to males in the HEI group. This may be attributed to preferences to make decisions related to participation in the self-care which are positively associated with female gender (Bos-Touwen, 2015). Findings revealed that females who were suffering with heart failure paid more attention to the symptoms of heart failure, salt intake, fluid intake, and calling the doctor or nurse for guidance.

Self-confidence for self-management was significantly higher in the HEI group as compared to the Attention Control group after controlling for age, and education. Increase in self-confidence indicates that older adults with heart failure in the intervention group developed skills to manage heart failure symptoms, follow treatment advice, evaluate importance of symptoms, recognize changes, try remedies, and evaluate the effect of remedies. Similar findings were reported by Shearer, Cisar and Greenberg (2007), testing a telephone delivered empowerment intervention for heart failure patients, also reporting significant improvement in checking for edema and following a low-salt diet. Fifty percent of all participants had adequate scores ( $\geq 70$ ) on self-confidence at baseline as well as at six-weeks, and 20% had adequate scores for self-management at baseline as well as at six weeks.

Cronbach's alpha on the self-maintenance, self-management and self-confidence in this study were .58, .55 and .85 respectively, consistent with the Cronbach's alphas reported by Riegel and colleagues (2009) as .54, .59 and .82 respectively. However, no specific item was problematic and deletion of a single item would not have changed the Cronbach's alphas in all the three scales. For enhancing reliability of SCHFI researchers have noted a need to revise the content of the scale; Tung and colleagues (2014) made



similar recommendations in their study testing the effectiveness of a self-management intervention in patients with heart failure. The three scales were not highly correlated (none  $> .41$ ), which indicates that they measure different constructs. Riegel and colleagues (2009) reported similar inter-correlation across three scales. In this study, Cohen's effect sizes for SCHFI ranged from .5 to .8. Moderate to large effect sizes (0.5 to 0.8) indicate that 66% to 79 % of the Attention Control group scores would be below average score in the HEI group, with probability ranging from 0.64 to 0.71 that scores from the HEI group would be higher than scores from the Attention Control group, supporting the practical importance of the HEI effect on the self-care of heart failure (Coe, 2002).

***Functional health.*** Functional health is the ability to perform normal daily activities for meeting basic needs, fulfilling usual roles, and maintaining health and well-being. Functional health can be influenced by physiological impairment, symptoms, mood, as well as the health perceptions of the individual (Leidy, 1994). Functional health, measured using Minnesota Living with Heart Failure Questionnaire (MLHFQ,) showed no significant difference between the HEI and the Attention Control groups. Scores on functional health decreased for both the groups from baseline to six weeks showing improvement, however one participant in the Attention Control group had deterioration in her functional health, as her husband had fall and later passed away. Similarly, one participant in the HEI group had deterioration in her functional health due to ankle and feet swelling. Scores for the total scale ranged from 0 to 86 at baseline and 0 to 75 at six weeks, which shows change of 11 points over time. Mean scores were higher for the HEI group at baseline, indicating poorer functional health when compared to the

Attention Control group; the same trend continued at six weeks' scores. Number of individuals living in the household was a strong predictor of six week scores; indicating the importance of social interactions for older adults with heart failure.

Shearer and Fleury (2006) and Ryan and Willits (2007) reported a positive association between social support from family members and feeling of well-being among older adults with heart failure. Living with family members provide emotional, appraisal, instrumental and informational support which help older adults to improve their functional health. Shearer and colleagues (2007) measured functional health using the SF-36, and reported that it was not sensitive to capture changes over time, suggesting the Minnesota Living with Heart Failure Questionnaire (MLHFQ) in future studies. However, use of MLHFQ in this feasibility study indicates that results were almost the same as with SF-36. Consensus is lacking on which measure is best when assessing the functional health status of older adults. The SF-36 and MLHFQ are self-report instruments; this may have resulted in patients answering the questions in a socially desirable manner, affecting the validity of responses.

Rather than attributing the results to the insensitivity of outcome measures used, it may be that the complexity of self-management in heart failure among older adults is not amenable to change in six weeks. A small to moderate Cohen *d* effect size (0.3) indicates that 62% of the Attention Control group scores would be below the average score in the HEI group, with a 0.58 probability that scores in the HEI group would be higher than scores from the Attention Control group. These findings support the practical importance of the HEI's effect on the functional health (Coe, 2002).

***Goal attainment.*** Attainment of personal health goals was measured using the Goal Attainment Scale (Kiresuk & Sherman, 1968). Significant differences were observed for goal attainment across the HEI and the Attention Control groups, indicating that purposeful participation in attainment of personal health goals was higher in the HEI group following the intervention, when compared to the Attention Control group. Goals attained included, doing exercise, thinking positive, connecting with family and friends, reducing stress, communicating effectively, helping others, volunteering and being active. Although older adults have multiple health issues, participants engaged in identifying resources, making decisions to set health goals, and worked for the attainment of personal health goals.

Shearer, Fleury and Belyea (2010) reported significant increase in purposeful participation in goal attainment, measured using the Goal Attainment Scale. In a study, “an ethnographic approach to understanding the illness experiences of patients with congestive heart failure and their family members” by Mahoney, (2001), older adults with heart failure described ways to reconcile living with heart failure, such as finding purpose in life, and meaning in the illness experience through caring for loved ones and believing in God. In this study, participants found purpose in life such as volunteering, helping friends, and attending church to attain their personal health goals. A large effect size (0.8) indicates that 79% of the Attention Control group scores would be below the average score in the HEI group, with a 0.71 probability that scores from the HEI group would be higher than scores in the Attention Control group. These findings support the practical importance of the HEI effect on the goal attainment. (Coe, 2002).

***Perceived well-being.*** Perceived well-being was measured using the Well-Being Picture Scale (Gueldner, et al., 2005). No significant main effect was observed between the HEI and the Attention Control group. However, baseline mean scores were strong predictors of six week scores, and explained almost fifty percent of the variance. Mean scores at six weeks were higher for the HEI group, as compared to the Attention Control group. A small to moderate Cohen d effect size (0.3) indicates that 62% of the Attention Control group scores would be below the average score in the HEI group, with a 0.58 probability that scores from HEI group would be higher than scores from the Attention Control group (Coe, 2002). Similar findings were reported by Shearer, Fleury and Belyea (2010) in their randomized trial of the HEI.

### **Limitations**

Limitations of this study include: (a) small sample size, (b) inability to measure long term effects, (c) self-report measures, (d) diagnosis of heart failure based on self-report and the NYHA classification, and (e) homogeneity of the sample, where the majority of the participants were Caucasian. The sample size of this feasibility study was 10% of the projected sample size of 200 for the future randomized controlled trial, as suggested by Treece and Treece (1982). Hill (1998) also suggested 10 to 30 participants for pilot studies and Julious (2005) suggested sample size of 12 per group for pilot study. An adequate sample size increases power by decreasing likelihood of Type II error and increases the precision about intended effects of the treatment (Stallard, 2012). Although small, the sample size was representative of the population of older adults with heart failure living in Scottsdale, Arizona.

Designed as a feasibility study, the study did not include evaluation of long term effects of the HEI. Evaluation of long term effects is necessary for determining continued awareness of personal and social contextual resources, their utilization for decision making and goal setting, purposeful participation in change process, and attainment of personal health goals. Sustainability of the long-term effects of intervention will enhance external validity and help in identifying best practices for self-management. Longitudinal study design as well as larger sample size will enable researchers to measure the long-term effects of the HEI on self-management, functional health and well-being, which may not be evident in a six-weeks period.

Most of the outcome measures used were based on self-report, although the measures were non-invasive and feasible. Self-report measures are useful for gaining insight into the level of health empowerment, purposeful participation, self-management, functional health and well-being of older adults with heart failure. However, they may over-estimate or under-estimate the results related to issues of recall and response bias, and may not sensitively capture the changes over time (Prince, et al., 2008). The diagnosis of heart failure was based on the NYHA functional classification, and self-report by the participants, with limited documentation of clinical data.

The majority of the participants were Caucasians, limiting the generalizability of the research findings in other ethnic groups of older adults with heart failure. Shearer and colleagues (2007) reported similar findings about the ethnicity of participants in a telephone delivered health empowerment intervention for older adults with heart failure. However, African Americans who share the large burden of heart failure with higher

mortality and hospitalization rates compared to white populations (Alexander, et al., 1999; Bahrami, et al., 2008), need attention in the future research.

### **Strengths**

Strengths of this study included: (a) a randomized controlled design, (b) use of a theoretical framework to guide the research, (c) strength based perspective, and (d) no attrition of older adults. Increases in health empowerment, purposeful participation, self-management, functional health, and attainment of personal health goals support the replication of the HEI in similar populations of older adults in diverse settings using a large sample size. The randomized controlled design allowed estimation of effect sizes, which are extremely important for future research, as effect size emphasizes the most important aspect of an intervention, allowing the best evidence to be translated in practice (Coe, 2002). Effect sizes for theoretical mechanisms (health empowerment, purposeful participation) ranged from .63 to .87, whereas for outcomes (self-management, functional health, well-being and goal attainment) ranged from .30 to .76.

This feasibility study of the HEI was guided by a theoretical perspective, which facilitated the development, testing, and explication of the linkages between the problem being studied, intervention critical content to guide intervention design, implementation, and evaluation, theoretical mechanism underlying change process, and outcomes (Sidani & Braden, 2011). A theoretical perspective is critically important to generate knowledge about what, when, where and for whom an intervention is effective by explaining linkages among the theory of problem, theory of intervention, theoretical mechanisms underlying change process, and outcomes (Whittemore & Grey, 2002).

In the literature review for this study, theoretical perspectives were used to guide the research in most of the studies, however insufficient detail was provided to understand the conceptualization and operationalization of the key concepts in the interventions. The mechanisms underlying the change process were not explicated adequately, thus limiting the applicability of existing interventions to practice. The majority of interventions focused on social relationships, with limited attention to personal resources of older adults with heart failure, which are crucial for the self-management. Further, the conceptualization of personal and social contextual resources as primary elements of the HEI is critical to understand the mechanism of underlying change, because limited awareness of resources has resulted in poor outcomes. Without considering that older adults have the necessary abilities to participate in health-related decisions puts them in jeopardy (Schultz & Nakamoto, 2013).

This study provided needed attention to the specific elements of theory-based intervention such as conceptualization and operationalization, explication of mechanisms of change process, and description of details of quantification of implementation fidelity to the planned protocol. The Theory of Health Empowerment fosters health empowerment as a mechanism of change, leading to transformation in older adults, reflected through recognition of their ability to purposefully participate in the attainment of personal health goals (Shearer, 2009). The use of the Theory of Health Empowerment in this study facilitated identification of a specific problems (lack of awareness of personal and social contextual resources in older adults with heart failure) which were addressed by implementing the HEI.

Lack of awareness of personal and social contextual resources among older adults with heart failure guided the identification of relevant theoretical mechanisms, outcome variables, and critical content of the HEI. Rather than focusing on weaknesses, the HEI focus on strengths of older adults, facilitated identification of personal strengths and building upon them, decision making and goal setting, and purposeful participation of older adults in attainment of their personal health goals. Therefore, older adults participated actively rather than being passive recipient of the delivery of intervention.

The relevance of concepts in the Theory of Health Empowerment for older adults with heart failure is supported in literature reviews, empirical studies, and theory as a practical guide for health empowerment (Shearer, Fleury & Belyea, 2010; Shearer, 2009, Shearer, Fleury, Ward, & O'Brien, 2012, Shearer & Reed, 2004). The identification of personal and social contextual resources led to awareness of choices, freedom to make decisions and set goals, as well as to participate purposefully in attaining personal health goals.

Health empowerment reflected through personal growth (growth and expansion of self, openness to experiences, realizing personal strengths, and change reflected through more knowledge), purpose in life (goals in life, sense of directedness, values past and present life and have aims for living), self-acceptance (positive attitude toward accepting the self with disease) and social relations (positive relations with others, concern for wellbeing of others, understanding of give and take). The field notes and narrative of sharing experiences from past support the theoretical mechanisms of underlying change process including: identifying resources, building social network, and accessing social



services, making decisions, setting goals, and purposeful participation to attain personal health goals.

Building relationships with the stakeholders in the community included gaining understanding of the context. Shared decision making as a critical element of relation building in the community was followed for the implementation of the HEI in the senior center of Tempe Community Action agency. The research team met the Executive Director and Director of the Senior Centers, to know their interests, and was open to their ideas about how they might benefit from the research.

Information about the study was presented to the stakeholders including Executive Director, Director, Managers, volunteers in the senior center and potential participants during several different meetings. In addition, information was also shared at local events in the senior centers such as friendship group, art class, yoga class, exercise class, open lounge and music class. Suggestions regarding recruitment, and study setting were welcomed, and incorporated into the study protocol. Findings will be disseminated to the stakeholders and participants after dissertation approval.

### **Implications for Theory/Nursing Science**

Findings from this study provide empirical support for the HEI as optimizing self-management, functional health and well-being in older adults with heart failure through awareness of personal and social contextual resources, choices, decision making and goal setting, and purposeful participation in change process. Results amplify the role of awareness of personal and social contextual resources, promoting personal growth, purpose in life, building social network, and self-acceptance through decision making and goal setting as well as purposeful participation in attaining personal health goals, thus

transforming the goals into desired outcomes. Linkages across theory of problem, theory of intervention are clearly explicated in this study to enhance the conceptual and methodological understanding of the HEI for its translation into practice.

The primary focus of the HEI is on strengths rather than weaknesses, implying that individual has inherent power; helping the older adults with heart failure to realize this power facilitated their participation in the change process to attain their goals (Shearer, Fleury & Belyea, 2010; Shearer, 2007, 2009). Findings of the study support the applicability of a strength-based middle range theory optimizing self-management in chronic conditions such as heart failure, and significantly contributing to achieve the mission and visionary goals of the American Academy of Nursing (Strategic Goals 2014-2017), American Nurses Association, as well as of the National Institute of Nursing Research (2011).

Findings of the study are consistent with the empowerment perspective in the HEI as an ongoing process of change, and innovative. Older adults faced challenges in the past, took actions to change the situation by deciding on specific actions that reflected their strengths. Realizing their strengths, building social network and awareness of social resources, decision making and participation in the change process to attain their goals reflected innovation in the present study. Every individual's experience is contextual and unique and is a valuable resource to be considered while developing interventions. This study has also contributed in minimizing the theory practice gap through implementation of the HEI in the senior centers settings.

Testing of the theory based HEI in older adults with heart failure fostered linkages between theory, practice and research. From the practical perspective, findings of this

study may inform approaches to improve self-management of older adults with heart failure thus, might reduce burden on patients, and health care system. The results of the study are supportive of important role played by personal resources (self-capacity) and social contextual resources (social network) in optimizing self-management of heart failure, evidenced in the narrative pieces of the participants in the HEI. The findings are in concert with the findings of a qualitative study that older adults have personal strengths by Shearer (2008) and role of social contextual resources by Shearer and Fleury, (2006). As the patient is a key person in decision making regarding self-management in heart failure thus, ignoring patient's preferences and experiences might be a reason for poor outcomes of interventions targeted at self-management in the past (Barrett, 2002, Shearer, Fleury, Ward & O'Brien, 2012).

### **Implications for Future Research and Practice**

For translation of research findings into practice, future trials with the HEI are needed, integrating and modifying the design and methodologies based on the feedback from the present study to enhance internal and external validity (Bowen, et al., 2009). Specific considerations for future research include: (a) maintaining consistent community partnerships with the Community Action Agency; (b) expanding feasibility research of the HEI in additional diverse populations including older adults attending clinics, home health agencies, and long term care facilities; (c) examining the sustainability of the HEI effects; and (d) designing innovative research methods focusing on the personal and social contextual resources that may impact positively self-management in heart failure.

Findings from this study have implications for practice, including developing an intervention based on health empowerment perspective optimizing self-management,

functional health and well-being in older adults with heart failure in the rural and clinic settings. The strategies used in the HEI are focused on facilitating person-centered approaches, that are manualized, and are amenable for use by nurses and other disciplines. Critical content promoting self-management, functional health and well-being in older adults with heart failure, guides nurses and interventionists to identify and build upon personal and social contextual resources, facilitating decision making and goal setting, and purposeful participation in the attainment of personal health goals.

To achieve the maximum benefits of the Health Empowerment Interventions targeted at older adults with heart failure, collaborative relationships among researchers, clinicians and stakeholders in the community agencies are crucial. Overall, the findings of this study support a theory driven strength-based approach to facilitate health empowerment in older adults with heart failure. This study reflects continued development and testing of the theory-based HEI with a variety of patients diagnosed with heart failure. The findings of this study confirm previous studies in establishing the HEI as an effective approach to optimize health empowerment, purposeful participation in goal attainment, self-management, functional health and well-being. The key elements of the Theory of Health Empowerment may guide clinicians in the translation of feasible approaches to optimize self-management, functional health and well-being in older adults with chronic conditions consistent with their priorities, values, goals and resources.

### **Summary**

In summary, this study supports the feasibility and efficacy of the HEI in older adults with heart failure. The HEI delivery was feasible as reflected through acceptability, demand and implementation fidelity. The HEI was effective as evident through increased

awareness of personal strengths and social networks, social services utilization, health empowerment, purposeful participation in change, self-management, functional health and well-being in older adults with heart failure. With the disproportionate increase in population of older adults 65 years and above in the U. S., there is a corresponding increase in the population with heart failure, as heart failure is most common chronic condition in older adults. Theory based interventions that focus on personal and social contextual resources to optimize self-management, functional health and well-being in older adults may significantly minimize the burden on the individual, as well as health care system, because it is the individual who is responsible for the self-management of chronic conditions.

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APPENDIX A  
PERMISSION LETTERS



To: Ramesh Devi Thakur  
ASU Doctoral Student

March 23, 2016

From: Jan Nicpon  
Director of Senior Services  
Tempe Community Action Agency

Re: Project Support/Seniors

As Director of Senior Services with Tempe Community Action Agency, I will survey participants at our centers to identify those who meet the requirements for your research project. They will be encouraged to participate in one of the study groups: Intervention or Attention Control. The classes will be held in one of our senior center locations once a week for six weeks the end of April – May.

Jan Nicpon  
Director of Senior Services  
Tempe Community Action Agency  
[jann@tempeaction.org](mailto:jann@tempeaction.org)

EXEMPTION GRANTED

Julie Fleury  
CONHI - PhD  
602/496-0773  
Julie.Fleury@asu.edu

Dear Julie Fleury:

On 5/3/2016 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Feasibility study of the Health Empowerment Intervention to evaluate the effect on self-management, functional health and well-being
Investigator:	Julie Fleury
IRB ID:	STUDY00004225
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> <li>• IRB_References 1.pdf, Category: Other (to reflect anything not captured above);</li> <li>• Intervention fidelity, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions);</li> <li>• Attendance Sheet.pdf, Category: Technical materials/diagrams;</li> <li>• Healthy Aging, Category: Technical materials/diagrams;</li> <li>• Recruitment Flyer HEI.pdf, Category: Recruitment Materials;</li> <li>• Telephone reminder.pdf, Category: Recruitment Materials;</li> <li>• Addressing the Gathering, Category: Recruitment Materials;</li> <li>• Introductory Card.pdf, Category: Recruitment Materials;</li> <li>• Interventionist Manual.pdf, Category: Technical</li> </ul>

	materials/diagrams; • Appendix B (variables & measures).pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • letter of support, Category: Off-site authorizations (school permission, other IRB approvals, Tribal permission etc); • Protocol, Category: IRB Protocol; • Appendix A Consent Form, Category: Consent Form; • Participant Health Notebook.pdf, Category: Participant materials (specific directions for them);
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The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 4/30/2016.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc: Ramesh Devi Thakur  
 Nelma Shearer  
 Michael Belyea  
 Ramesh Devi Thakur

## **Permission Letters to use instruments**

Self-Care of Heart Failure Index and Goal attainment scales are in the public domain, therefore can be used without permission of the concerned authors.

RE: Re - Permission to use Power as Knowing Participation in Change Tool (PKPCT)

Violet Malinski

Wed 4/27/2016 11:44 AM

To: Ramesh Devi Thakur <rameshdthakur@hotmail.com>;

Hello,

Do you need a copy of the tool and scoring guide or do you already have them? If not, let me know and I will forward to you. This constitutes permission to use the tool.

The only question I have concerns the use of "empowerment" rather than "power as knowing participation in change intervention." If you can change at this point, I suggest that you do, as empowerment is not what Barrett is talking about or measuring.

Her view is that we all already have power and do not need another person to "empower" us.

Good luck with your study, and let me know what, if anything, you need.

Dr. Violet Malinski

On Wed, Apr 27, 2016 at 11:41 AM, Ramesh Devi Thakur wrote:

Dear Dr. Malinski,



Re: Re - Permission to use Well-Being Picture Scale

Sarah Gueldner  
Sun 6/19, 11:55 AM  
You

Hello Ramesh --- I would absolutely love for you to use the Well-Being Picture Scale in your research!!

Sarah Gueldner

PS I'm sorry for being slow getting back to you -- my computer was .working well

On Thu, May 26, 2016 at 5:48 PM, Ramesh Devi Thakur  
<rameshdthakur@hotmail.com> wrote:  
Dear Dr. Gueldner,

Good evening. I Ramesh Devi Thakur, PhD student from College of Nursing and Health Innovation, Arizona State University, seek your permission, for using Well-Being Picture Scale (WPS) in my research “Feasibility Study of Health Empowerment Intervention to Evaluate the Effect on Self-management, Functional Health and Well-being in Older Adults with Heart Failure”. Kindly permit me to use the scale. Thanks for your time and consideration in advance.

With best regards  
Ramesh Devi Thakur  
PhD student & Hartford Scholar  
College of Nursing & Health Innovation  
Arizona State University

**License to use Minnesota Living With Heart Failure**

**Full License Agreement**



Following is the full and final license agreement text.

**Please read the terms and conditions of this license agreement ("Agreement") carefully. By**

**clicking "Accept" on the "Review and Accept Agreement" page during the licensing process, you are agreeing to the following terms and conditions on behalf of the Licensee identified below, and you represent and warrant that you are authorized to do so.**

The Minnesota Living with Heart Failure® Questionnaire can be used with the following educational project:

As a student project to assess the quality of life of heart failure patients

**License Fee:**

License Fee is \$0.00 USD, payable upon checkout.

**Licensee:** Ramesh Thakur

**Company -** Arizona state University

**Contact Email -** ramesh.thakur@asu.edu

**Contact Phone -**

**And residing or doing business at -**

1850 s Alma School Rd 3244

Mesa, AZ 85210

US

APPENDIX B

TABLE: SYNTHESIS OF INTERVENTIONS FOCUSING ON HEALTH  
EMPOWERMENT

Table 2

*Synthesis of Interventions Focusing on Self-Care Behaviors, Self-Management, Quality of life (Concepts of Empowerment)*

Author/Year Title	Setting & Sample Characteristics	Conceptualization of self-management as Concept of Empowerment & Theoretical Framework	Intervention Components & Dosage	Outcome measures	Key findings of health outcomes
<b>Shearer, Cisar &amp; Greenberg (2007). A telephone delivered empowerment intervention to promote self-management of heart failure A Randomized controlled trial, follow up 3 months</b>	<ul style="list-style-type: none"> <li>a. Home based setting</li> <li>b. RCT pretest-posttest design</li> <li>c. N=87, (IG=42, CG=45)</li> <li>d. Age: (mean)=76.03 years</li> <li>e. Gender: female=31 (35.6%)</li> <li>f. Ethnicity: Native American=1(1.1%) Black=2(2.3%), Hispanic =3 (3.4%) and white =81(93.1%)</li> </ul> Inclusion criteria <ul style="list-style-type: none"> <li>a. Diagnosis of HF doc. By Health care provider</li> <li>b. Ability to read and understand English</li> <li>c. Access to telephone</li> </ul>	<ul style="list-style-type: none"> <li>a. Empowerment is conceptualized as a relational, dynamic human health process in which the patient recognizes that he or she can purposefully participate in change consistent with heart failure self-management.</li> <li>b. It is a complex participatory process of changing oneself and one's environment, recognizing patterns and engaging inner resources for well-being.</li> <li>c. Theoretical perspective guided by Rogers' Science of Unitary Human beings.</li> </ul>	<ul style="list-style-type: none"> <li>a. Providing information</li> <li>b. Identifying strengths</li> <li>c. Building strengths</li> <li>d. Nurse clinician interveners, Experience in HF care</li> <li>e. Delivery &amp; dosage</li> </ul> Delivered through six telephone calls over 12 weeks CG received usual care and standardized HF education. IG received empowerment intervention (EI) through telephone. Aim of the intervention was to enhance purposeful participation in goal attainment, self-management of HF and perceptions of functional health.	<ul style="list-style-type: none"> <li>a. Purposeful participation in in attaining health goals self-management and functional health was measured through Power as Knowing Participation in change tool (PKPCT)</li> <li>b. Functional health was measured through SF-36</li> <li>c. Self-Management of HF Scale was used to measure self-care maintenance behaviors and self-management of symptoms</li> </ul>	SMHF scores significantly higher in IG group ( $t/28 = 4.03, p < 0.001$ ) compared with CG. The participants were better able to manage their HF through self-care as compared to CG.
<b>Tomita, et al. (2009) Multidisciplinary internet based program on management of heart failure. A Randomized</b>	<ul style="list-style-type: none"> <li>a. Home based setting</li> <li>b. RCT Pretest-posttest design</li> <li>c. N= 40 (IG=16, CG=24)</li> <li>d. Gender male=32.5%</li> </ul>	<ul style="list-style-type: none"> <li>a. Empowerment is a process that progresses through stages from contemplation, preparation, and action</li> </ul>	<ul style="list-style-type: none"> <li>a. Informational support</li> <li>b. Instrumental support</li> <li>c. Appraisal support</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge questionnaire</li> <li>a. Nominal Scale for frequency of breathing stretching, walking exercise</li> </ul>	Significant improvement in IG group in knowledge, exercise, QOL ( $p < 0.05$ ), Reduction in symptoms, fatigue, emotional function, & BP ( $p < 0.001, p < 0.011, p$

Author/Year Title	Setting & Sample Characteristics	Conceptualization of self-management as Concept of Empowerment & Theoretical Framework	Intervention Components & Dosage	Outcome measures	Key findings of health outcomes
<b>controlled trial 12 months follow up study.</b>	<ul style="list-style-type: none"> <li>e. Age (mean) = 76.2 years.</li> <li>f. Ethnicity = 2.5% Asian, 12.5% African American/ Black, and 85% were Caucasian.</li> </ul> <p>Inclusion criteria</p> <ul style="list-style-type: none"> <li>a. Living at home, 60 years &amp; above</li> <li>b. &gt; One visit to the emergency room in the last year.</li> <li>c. NYHA classification II &amp; III.</li> </ul> <p>Exclusion criteria;</p> <ul style="list-style-type: none"> <li>a. Scheduled for heart surgery</li> <li>b. Cognitive impairment (MMSE) &lt;24.</li> </ul>	<ul style="list-style-type: none"> <li>b. A conceptual framework, Model Toward Optimal Independence through Technological Adoption, based on transtheoretical model, social support theory and mass communication theory was developed.</li> <li>c. From the perspective of model empowerment process progresses from contemplation, preparation, action and maintenance.</li> </ul>	<ul style="list-style-type: none"> <li>d. Emotional support</li> <li>e. Geriatric physician, geriatric nurse, occupational therapist, exercise physiologist</li> <li>f. Experienced multidisciplinary team</li> </ul> <p>Delivery &amp; dosage</p> <p>Delivered through internet and emails</p> <p>Participants trained in basic computer skills.</p> <p>Information on heart failure, drugs, effects of alcohol, depression exercise, nutrition and weight management through video, simple online system to record answers about their condition and emotional support whenever needed for one year</p> <p>Aim of the intervention to enhance knowledge of HF, adherence, perceived QOL and to reduce specific HF symptoms and ER visits</p>	<ul style="list-style-type: none"> <li>b. Congestive Heart Failure questionnaire to measure HF-specific symptoms</li> <li>c. QOL (50 item age relevant questionnaire) to measure perceived quality of life</li> </ul>	= 0.001, & $p = 0.10$ ) respectively. Significant decrease in emergency room visits.
<b>Duffy, Hoskins &amp; Dudley-Brown (2010) Improving outcomes for older adults with</b>	<ul style="list-style-type: none"> <li>a. Home based setting</li> <li>b. RCT, pretest-posttest design</li> </ul>	<ul style="list-style-type: none"> <li>a. Empowerment concept quality of life and satisfaction not defined</li> </ul>	<ul style="list-style-type: none"> <li>a. Symptom Monitoring</li> <li>b. Education</li> </ul>	<ul style="list-style-type: none"> <li>a. The Outcomes and Assessment Information Set (OASIS) was used to extract information about</li> </ul>	Improvement of scores in QOL in IG of 8.6% although not significant. More

Author/Year Title	Setting & Sample Characteristics	Conceptualization of self-management as Concept of Empowerment & Theoretical Framework	Intervention Components & Dosage	Outcome measures	Key findings of health outcomes
<b>heart failure: randomized controlled trial using a theory guided intervention follow up 2 months</b>	<ul style="list-style-type: none"> <li>c. N=32 IG=15, CG=17 Females=59.4%</li> <li>d. Age=80s mostly Minority= 35%</li> </ul> Inclusion criteria <ul style="list-style-type: none"> <li>a. 65 years of age and older,</li> <li>b. Alert and oriented</li> <li>c. Primary diagnosis of class IIIorIV HF</li> <li>d. Recently referred to a home health agency</li> <li>e. English speaking and have telephone access.</li> </ul>	<ul style="list-style-type: none"> <li>b. The Quality-Caring Model used as theoretical framework that emphasizes patient –provider and patient-healthcare team relationships are the foundation of care. Patients and families mutually interact with healthcare providers to advance health thus improving quality of life.</li> </ul>	<ul style="list-style-type: none"> <li>c. Emotional support</li> <li>d. Intervention nurses. Trained in the study protocol.</li> <li>e. Delivery &amp; dosage</li> </ul> Intervention nurses used designated area to make phone calls and cared for the same patients consistently. They maintained a telephone log. Aim of the intervention was symptom monitoring, education and emotional support, patient’s participation and response to intervention. CG group received usual care.	<ul style="list-style-type: none"> <li>b. Short Portable Mental Status Questionnaire was completed by the patients during enrollment</li> <li>c. The Living with HF Questionnaire operationalized to measure the quality of life</li> <li>d. Home Care Client Satisfaction Instrument was used to measure patient satisfaction</li> </ul>	readmission, reasons for hospitalization, length of stay and length of time prior to transfer. <ul style="list-style-type: none"> <li>b. Short Portable Mental Status Questionnaire was completed by the patients during enrollment</li> <li>c. The Living with HF Questionnaire operationalized to measure the quality of life</li> <li>d. Home Care Client Satisfaction Instrument was used to measure patient satisfaction</li> </ul> satisfaction with home care services in IG. The number of in home visits, length of stay in home care was higher in IG. Intervention effective and efficient for symptom monitoring, facilitating learning and providing emotional support.
<b>Baker et al. (2011) Progressive reinforcing telephone education and counseling / brief educational intervention to improve knowledge, self-care behaviors and heart failure symptoms, Randomized controlled trial one month follow up</b>	<ul style="list-style-type: none"> <li>a. General Internal Medicine and Cardiology clinic</li> <li>b. RCT pre-post design</li> <li>c. N=605 TTG= 303 BEI= 302)</li> <li>d. Age: Mean 60.7 years</li> <li>e. Males: 52%</li> <li>f. Ethnicity: &gt; 50% non-white, Low literacy = 37%</li> </ul> Inclusion criteria <ul style="list-style-type: none"> <li>a. Diagnosis of HF</li> <li>b. NYHA class II-IV</li> <li>c. Current use of a diuretic</li> <li>d. Speak English and Spanish</li> </ul>	<ul style="list-style-type: none"> <li>a. Self-care not defined.</li> <li>b. Described self-care training that teaches self-management skills and reinforce behaviors associated with better outcomes, including symptom recognition, weight monitoring, dietary salt restriction, exercise, medication adherence and a plan what to do when symptoms worsen.</li> <li>c. Intervention based on social cognitive theory and adult learning theory</li> </ul>	<ul style="list-style-type: none"> <li>a. Information support</li> <li>b. Education support</li> <li>c. Reinforcement through telephone calls</li> <li>d. Health educator Master’s degree</li> <li>e. Delivery &amp; dosage</li> </ul> Both groups received initial education session of 40 minutes. IG received 5 to 8 telephone calls for 4 weeks for	<ul style="list-style-type: none"> <li>a. NHYA classification to categorize heart failure severity</li> <li>b. S-TOFHLA was used to measure health literacy level of patients</li> <li>c. Improving Chronic Illness Care Evaluation was used to measure health related quality of life</li> <li>d. Heart Failure Symptom Scale (HFSS) heart failure knowledge and self-care behavior</li> </ul>	Significant Increase in salt knowledge in TTG group as compared to BEI (0.90 vs 0.37, $p < 0.001$ ) self-efficacy (0.4 vs. 1.0, $p < 0.006$ ) & SCB (1.8 vs. 3.2, $p < 0.001$ ). Significant change in heart related quality of life (-0.6 versus 6.7) respectively for BEI and TTG ( $p < 0.001$ ).

Author/Year Title	Setting & Sample Characteristics	Conceptualization of self-management as Concept of Empowerment & Theoretical Framework	Intervention Components & Dosage	Outcome measures	Key findings of health outcomes
	e. Adequate cognition		reinforcement each call lasted for 10 minutes. Aim of the intervention was to improve knowledge of HF, self-care behaviors and HF specific quality of life		
<b>Brandon, et al. (2009)</b> <b>Effects of an advanced practice nurse led telephone intervention on outcomes of patients with heart failure Randomized controlled trial 3 months follow up</b>	<ul style="list-style-type: none"> <li>a. Cardiology clinics</li> <li>b. N=20, settings rural Cardiology clinics.</li> <li>c. Age= 49-69 years</li> <li>d. Gender=females 11, male =9</li> <li>e. Ethnicity Black= 12 (60%) White= 8(40%)</li> </ul> Inclusion criteria <ul style="list-style-type: none"> <li>a. Living with HF for more than 6 months</li> <li>b. Capable of self-care</li> <li>c. Telephone access</li> </ul>	<ul style="list-style-type: none"> <li>a. Self-care is the requisite for maintaining functionality in HF patients. Self-care deficits may occur due to lack of HF symptom knowledge, poor dietary selection or lack of social support.</li> <li>b. Through educative and supportive strategies these deficits can be addressed which can empower the patients to practice healthy self-care behaviors</li> <li>c. Theoretical basis of study is Orem's self-care deficit theory. It is fundamental for the people to gain knowledge specific to their context, reflect on their meaning to healthy functioning, identify the course of action and determine the effectiveness of these actions.</li> </ul>	<ul style="list-style-type: none"> <li>a. Education</li> <li>b. Reinforcement through telephone calls</li> <li>c. Advance Practice Nurse, (APN) and Cardiologist</li> <li>d. APN with 10 years' experience in intensive care and coronary care units</li> <li>e. Delivery &amp; dosage</li> </ul> CG group was provided education in the clinic whereas IG group received telephone delivered intervention weekly for 2 weeks, then every week for 10 weeks, call lasted for 5 to 30 minutes. Aim of the intervention was to improve quality of life and self-care behaviors and reduce hospital readmissions.	<ul style="list-style-type: none"> <li>a. NYHA classification to measure severity of heart failure</li> <li>b. Minnesota Living with Heart Failure (MLHFQ) to measure heart failure and effect of treatment on physical and emotional aspect</li> <li>c. Self-Care Behavior Scale to measure 21 behaviors listed on the scale</li> </ul>	Significant decrease in hospital readmissions ( $F = 7.63, p = 0.013$ ), Improvement in SCB and QOL ( $p < 0.001$ & $p < 0.026$ ) respectively at three months
<b>Bakan &amp; Akyol, (2008)</b> <b>Theory guided interventions for adaptation to heart</b>	<ul style="list-style-type: none"> <li>a. Cardiac and internal disease polyclinic</li> <li>b. RCT pre-post design</li> <li>c. Age: Mean 62.67 years</li> </ul>	<ul style="list-style-type: none"> <li>a. Health related quality of life reflects the response of adaptive</li> </ul>	<ul style="list-style-type: none"> <li>a. Counseling &amp; education</li> <li>b. Crossword puzzle about HF</li> </ul>	<ul style="list-style-type: none"> <li>a. Patient identification form for demographic information</li> </ul>	Significant increase in QOL (physical and emotional dimension), social support

Author/Year Title	Setting & Sample Characteristics	Conceptualization of self-management as Concept of Empowerment & Theoretical Framework	Intervention Components & Dosage	Outcome measures	Key findings of health outcomes
<b>failure Randomized controlled trial 3 months follow up</b>	<ul style="list-style-type: none"> <li>d. Females: 61.9%</li> <li>e. Married: 52.4%</li> <li>f. Ethnicity not specified</li> </ul> Inclusion criteria <ul style="list-style-type: none"> <li>a. Living with HF for more than 6 months</li> <li>b. Capable of self-care</li> <li>c. Telephone access</li> </ul>	<ul style="list-style-type: none"> <li>b. The modes of adaptation include physical functioning, emotions, social functioning and interpersonal support.</li> <li>c. Adaptation to these modes increase participation in self-care thus empower the patients.</li> <li>d. Theoretical framework Roy's adaptation model is based on assumptions of general system theory and adaptation level theory. Focus of theory is on environmental stimuli and biopsychosocial response to stimuli. Stimuli that contribute to adaptation include focal, contextual and residual.</li> </ul>	<ul style="list-style-type: none"> <li>c. Reinforcement through telephone calls</li> <li>d. Researchers, qualification not specified.</li> <li>e. Delivery &amp; dosage</li> </ul> IG received one-to-one counseling session and heart failure education and booklet on "how can I learn to live with Heart failure". Telephone calls to verify the health status, proper use of medications. Group education session at one month. CG maintained their daily activities and clinic visits. Aim of intervention included to enhance quality of life, functional capacities and social support.	<ul style="list-style-type: none"> <li>b. Assessment form for physiological data for body mass index, cholesterol, high density and low density lipoproteins, smoking, alcohol consumption</li> <li>c. Minnesota Living with Heart Failure Questionnaire to measure quality of life heart failure impact on physical, social interaction, sexual activity and emotions</li> <li>d. Interpersonal support list to measure tangible, appraisal and belonging support</li> <li>e. 6-Minute walking test was used to measure the functional status</li> </ul>	and 6-minute walk distance in IG as compared to CG.



Author/Year Title	Setting & Sample Characteristics	Conceptualization of self-management as Concept of Empowerment & Theoretical Framework	Intervention Components & Dosage	Outcome measures	Key findings of health outcomes
<b>Westlake, et al. (2007)</b> <b>Evaluation of web-based education and counseling pilot program for older heart failure patients</b> <b>Randomized trial with 3 months follow up</b>	<ul style="list-style-type: none"> <li>a. Quasi experimental pre-post design</li> <li>b. Cardiology clinic</li> <li>c. N= 80 IG= 40 CG = 40</li> <li>d. Age: Mean 65.7± .5.7 years, Female=28.7%</li> <li>e. Ethnicity: White = 72.5%, non-white = 27.5%, Black = 10%, Hispanic = 3.75% Others = 13.75%</li> </ul> <p>Inclusion criteria</p> <ul style="list-style-type: none"> <li>a. Ability to communicate verbally</li> <li>b. Diagnosis of HF</li> <li>c. NYHA class II &amp; III</li> <li>d. Ejection fraction &lt;40</li> <li>e. No hearing, visual or mental disorder</li> <li>f. Remain in city during study and can be contacted by phone</li> </ul> <p>Exclusion criteria</p> <ul style="list-style-type: none"> <li>a. Life threatening conditions</li> </ul>	<ul style="list-style-type: none"> <li>a. Optimal self-care include adherence to medical regimen, self-assessment of signs and symptoms, and appropriate decision making about therapeutic and caregiving actions.</li> <li>b. Participatory Action Research model as theoretical framework.</li> <li>c. Base of the model that is worldviews of critical theory and constructivism not identified</li> </ul>	<ul style="list-style-type: none"> <li>a. Informational support</li> <li>b. Psycho-social and spiritual support</li> <li>c. Encouragement</li> <li>d. Cardiovascular Clinical Nurse Specialist with PhD</li> <li>e. Delivery &amp; dosage</li> </ul> <p>Intervention delivered through modules. First module focusing on Pathophysiology, and self-management of heart failure was available at the time of enrollment to 12 weeks, 2<sup>nd</sup> module focusing on risk factors modification such as diet exercise, smoking and alcohol was available one week after enrollment, 3<sup>rd</sup> module focusing on psychosocial and spiritual issues was available after 2<sup>nd</sup> week of enrollment. Aim of intervention included enhancement of quality of life and perceived control.</p>	<ul style="list-style-type: none"> <li>a. SF-12 to measure quality of life physical (physical function, role limitations, bodily pain and general health) and mental health (vitality, social functioning emotional problems)</li> <li>b. The Control Attitude Scale to measure the degree of control the patient feels related to his/her health</li> </ul>	QOL (mental component) & perceived control ( $p > 0.0001$ , & $p = 0.001$ ) respectively improved significantly over 3 months for web based group than the control.
<b>Caldwell, Peters &amp; Dracup (2005). A simplified education program improves knowledge, self-care behavior, and disease</b>	<ul style="list-style-type: none"> <li>a. Cardiology clinic &amp; home based</li> <li>b. RCT pre-post design</li> <li>c. N= 36, IG=16, CG= 20</li> <li>d. Gender: Female=11(31%)</li> </ul>	<ul style="list-style-type: none"> <li>a. Described self-monitoring and timely response by HF patients to worsening symptoms caused by fluid overload are</li> </ul>	<ul style="list-style-type: none"> <li>a. Counseling &amp; education</li> <li>b. Reinforcement through telephone call</li> </ul>	<ul style="list-style-type: none"> <li>a. HF questionnaire was adapted from REACT study in the acute myocardial infarction</li> <li>b. Heart Failure Self-Care Behavior Scale to</li> </ul>	Knowledge, self-care behavior improved significantly at 3 months in IG ( $p=0.01$ & $0.03$ ) respectively.

Author/Year Title	Setting & Sample Characteristics	Conceptualization of self-management as Concept of Empowerment & Theoretical Framework	Intervention Components & Dosage	Outcome measures	Key findings of health outcomes
<b>severity in heart failure. Randomized controlled trial with 3 months</b>	<p>e. Ethnicity: Caucasian=34(94%)</p> <p>Inclusion criteria</p> <p>a. Age= no age range NYHA class II-IV patients</p> <p>b. Trip to physician or admission in emergency department within one year</p> <p>c. Read, write and understand English</p> <p>d. Living independently</p> <p>Exclusion criteria</p> <p>a. Neurological disorder with impaired cognition</p> <p>b. Untreated malignancy</p> <p>c. Part of formalized heart failure program</p>	<p>corner stone of care in this population.</p> <p>b. Disease management program based intervention focusing on symptom recognition and management of fluid weight.</p> <p>c. No theoretical framework specified.</p>	<p>c. Registered nurse, non-cardiac trained</p> <p>Patients in the IG group received one-on-one education and counseling session in the physician's office and a phone call at one month to reinforce the education and symptom's status. Follow up questionnaire was administered at 3 months. Patients in the CG group received a printed brochure published by American Heart Association. Aim of intervention was to improve knowledge of HF, patient reported self-care behavior and HF severity.</p>	<p>measure self-care behaviors</p> <p>c. B- Natriuretic peptide to measure heart failure severity, a blood test.</p>	
<b>Brodie, Inoue &amp; Shaw, (2008). Motivational interviewing to change quality of life for people with heart failure, Randomized controlled trial with 5 months follow up.</b>	<p>a. Hospital settings</p> <p>b. RCT pre-post design with three groups (standard care, motivational interviewing and both</p> <p>c. N=60, (IG1 = 18, IG2=22, IG3=20)</p> <p>d. Age: mean 76, 78 and 79 years respectively for three groups.</p> <p>e. Ethnicity not specified</p> <p>Inclusion criteria:</p> <p>a. Age 65 years &amp; above</p> <p>b. Able to walk</p>	<p>a. Motivational interviewing is a method of facilitating decision making for behavior change. Health professional stimulates thoughts and then support the patient through the process of decision making and behavior change.</p> <p>b. Patient is expert on his behaviors, their maintaining factors and context and take</p>	<p>a. Information about daily physical activity</p> <p>b. Motivation to set goals and take decisions</p> <p>c. Researcher with no clinical qualifications</p> <p>d. Delivery &amp; dosage</p> <p>Standard care package on information of physical activity, motivational</p>	<p>a. SF-36 to measure health related quality of life, however its self-completion version is difficult for older adults</p> <p>b. Minnesota Living with Heart Failure Questionnaire (MLHFQ) to measure heart failure specific quality of life (severity of perceived measurement.</p> <p>c. Readiness to Change Ruler to measure the ambivalence related to</p>	<p>Significant improvement in physical functioning, social functioning, and changes in health status in three groups (<math>p &lt; 0.05</math>).</p> <p>Specific quality of life related to HF improved significantly (<math>p = 0.03</math>).</p> <p>Ninety-eight participants were in the pre-contemplation stage at baseline at the end of follow up 21 % of the patients were in contemplation stage 13% in action and 8% in pre-contemplation.</p>

Author/Year Title	Setting & Sample Characteristics	Conceptualization of self-management as Concept of Empowerment & Theoretical Framework	Intervention Components & Dosage	Outcome measures	Key findings of health outcomes
<b>Smeulders, et al. (2010) Nurse led self-management group program for patients with congestive heart failure Randomized Controlled Trial follow up 12 months</b>	<ul style="list-style-type: none"> <li>c. Able to give written informed consent</li> <li>d. NYHA class II, III, &amp; IV</li> <li>e. Left ventricular dysfunction (echo)</li> </ul> <p>Exclusion criteria</p> <ul style="list-style-type: none"> <li>a. Normal systolic function</li> <li>b. Living in residential home</li> <li>c. Living outside catchment area</li> <li>d. Expectancy less than intervention period</li> </ul>	<ul style="list-style-type: none"> <li>c. responsibility for changes.</li> <li>c. Theoretical framework not specified</li> </ul>	<p>interviewing consisted of eight 1 hour weekly session patients encouraged to set their own goals.</p> <p>Aim of intervention was to improve health related QOL, HF specific QOL and intentional behavior change.</p>	<p>behavior change at different stages of change process</p>	
	<ul style="list-style-type: none"> <li>a. Cardiology clinics</li> <li>b. RCT pre-post design</li> <li>c. N= 317 IG = 186, CG = 131</li> <li>d. Age: Mean 66.7%</li> <li>e. Females: 27.4%</li> <li>f. Ethnicity not specified</li> </ul> <p>Inclusion criteria</p> <ul style="list-style-type: none"> <li>a. Ejection fraction &lt;40%</li> <li>b. NYHA class II &amp; III</li> <li>c. Hospitalization atleast once after diagnosis</li> <li>d. Diagnosed atleast six-month back</li> <li>e. Understand, write and speak English</li> <li>f. Willing to give informed consent</li> </ul> <p>Exclusion criteria</p> <ul style="list-style-type: none"> <li>a. Impaired cognition</li> <li>b. Participating in other studies</li> </ul>	<ul style="list-style-type: none"> <li>a. Chronic Disease Self-Management Program is a generic cognitive-behavioral based on the assumptions that patient with different chronic conditions can learn from each other.</li> <li>b. Increasing self-management skills can influence quality of life, self-care behaviors, psychosocial attributes, and health related quality of life.</li> <li>c. Theoretical framework is based on Bandura's self-efficacy theory. Self-efficacy refers to the confidence to achieve certain behaviors.</li> </ul>	<ul style="list-style-type: none"> <li>a. Skill mastery</li> <li>b. Reinterpretation of symptoms</li> <li>c. Modelling</li> <li>d. Social persuasion</li> <li>e. Cardiac nurse specialist and a patient with HF</li> <li>f. Delivery &amp; dosage</li> </ul> <p>Patients in the IG group received the six weeks' self-management group program in addition to usual care, 8 participants required for each class.</p> <p>Aims of the intervention were to enhance self-efficacy expectations, skill mastery, reinterpretation of symptoms, modelling and social persuasion</p>	<ul style="list-style-type: none"> <li>a. General Self-Efficacy Scale to measure general self-efficacy expectancies</li> <li>b. Cardiac Self-Efficacy Questionnaire to measure cardiac specific self-efficacy</li> <li>c. Coping with symptoms Scale to measure cognitive symptoms management</li> <li>d. Mastery Scale was used to measure perceived control</li> <li>e. Heart Failure Self-Care Behavior Scale to measure self-care behavior</li> <li>f. RAND-36 to measure general quality of life</li> <li>g. Hospital Anxiety and Depression Scale to measure anxiety and depression</li> <li>h. Kansas City Cardiomyopathy</li> </ul>	<p>Significant short term effects on improvement of cognitive symptoms management (<math>P &lt; 0.001</math>) self-care behavior (<math>p &lt; 0.011</math>) &amp; cardiac specific quality (<math>p &lt; 0.004</math>)</p> <p>The significant effect of the intervention continued at 6 months (<math>p = 0.010</math>, <math>d = 0.18</math>) and 12 months (<math>p = 0.031</math>, <math>d = 0.19</math>).</p> <p>No significant difference at 6 months and 12 months in self-efficacy expectancies and perceived control</p>

Author/Year Title	Setting & Sample Characteristics	Conceptualization of self-management as Concept of Empowerment & Theoretical Framework	Intervention Components & Dosage	Outcome measures	Key findings of health outcomes
			to motivate the patients to change their behaviors and beliefs.	Questionnaire (KCCQ) to measure cardiac specific quality of life i. Perceived autonomy was measured through visual analogue scale.	

**APPENDIX C**  
**INFORMED CONSENT AND SCREENING INSTRUMENTS**

**Informed Consent**  
**Arizona State University**

**Health Empowerment Intervention for Older Adults with Heart Failure**

**Introduction**

A PhD student from the College of Nursing and Health Innovation at Arizona State University is inviting you to participate in a research study. The purpose of this form is to provide you information that may affect your decision as to whether or not to participate in this research and to record the consent of those who agree to participate in the study. Approximately 30 older adults will be invited to participate.

**Study Purpose**

The purpose of this study is to test a nurse delivered health program that promotes the use of personal and social contextual resources that help older adults with heart failure to promote self- management, functional health and well-being.

**Description of Research Study**

You are invited to participate if you are 60 years of age or older, are diagnosed with heart failure understand and are able to read, and speak English. You will be randomly assigned (similar to a coin toss) to one of two groups of the health program.

For group one the program will focus on identifying and building upon personal and social contextual resources to help older adults with heart failure to promote self-management, functional health and well-being. The program will consist of weekly session of one hour for six weeks. Some sessions will be audio taped to evaluate the delivery of the program as planned. You may decide not to be audio recorded at any time. You will be asked to fill questionnaires before the first session and after the last session of the program. The questionnaires ask about your health and well-being, your participation in care and attainment of personal health goals. The time to fill the questionnaires will take approximately one hour.

For group two the program will focus on general health topics which will help you to improve your well-being. The researcher will deliver the program each week for six weeks. Each session will last for one hour. You will be asked to fill questionnaires before the first session and after the last session of the program. The questionnaires ask about your health and well-being, your participation in care and attainment of personal health goals. The time to fill the questionnaires will take approximately one hour.

**Risks**

A possible risk is that you may be uncomfortable talking about your health. There are no other known risks, however as with any research, there is some possibility that you may be subject to risks that have not yet been identified.

**Benefits**

Although there may be no direct benefits to you, the possible benefits of your participation in the research are that you may increase your own health awareness, and knowledge about promoting self-management, functional health and well-being.

**New Information**

If the researchers find new information during the study that would reasonably change your decision about participating, then they will provide this information to you.

**Confidentiality**

All information obtained in this study is confidential unless disclosure is required by law. The results of this research study may be used in reports, presentations, and publications, but the researcher will not identify you. In order to maintain confidentiality of your records, the researcher will store all data in research office on the campus of ASU. Any audio tape will be destroyed after evaluation without personal identifying information that would disclose your identity. Only the researcher will have access to the data, which will be retained in accordance with the ASU policy, until completion of data analysis and publication of findings.

**Withdrawal Privilege**

It is ok for you to say no to study participation. Even if you say yes now, you are free to withdraw from the study at any time.

Your decision will not affect your relationship with Arizona State University or the Area Agency on Aging or otherwise cause a loss of benefits to which you might otherwise be entitled.

**Costs and Payments**

The researcher wants your decision about participating in the study to be absolutely voluntary. Yet they recognize that your participation may utilize your time and pose some inconvenience. You will receive \$20.00 gift card at the beginning and end of the health program (\$40.00 total)

**Voluntary Consent**

Any questions you may have concerning the research study or your participation in the study, before or after your consent, will be answered by principal investigator, Julie Fleury ([Julie.Fleury@asu.edu](mailto:Julie.Fleury@asu.edu) Phone: 602-496-0773) or researcher, Ramesh Thakur ([Ramesh.Thakur@asu.edu](mailto:Ramesh.Thakur@asu.edu) Phone: 602-430-8966) College of Nursing & Health Innovation.

If you have questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk; you can contact the chair of Human Subjects Institutional Review Board, through the ASU Research Compliance Office, at 480-965-6788.

This form explains the nature, demands, benefits and any risk of the program. By signing this form, you agree knowingly to assume any risks involved. Remember, your participation is voluntary. You may choose not to participate or to withdraw your consent and discontinue participation at any time without penalty or loss of benefit. In signing this consent form, you are not waiving any legal claims, rights, or benefits to you.

Your signature below indicates that you consent to participate in the above study

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-----  
-----  
Subject's Signature                      Printed Name                                      Date

**Researcher's Statement**

"I certify that I have explained to the above individual the nature and purpose, the potential benefits and possible risks associated with participation in this research study, have answered any questions that have been raised, and have witnessed the above signature. These elements of Informed Consent conform to the Assurance given by Arizona State University to the Office of Human Research Protections to protect the rights of human subjects. I have provided (offered) the subject/participant a copy of this signed consent document."

Signature of Researcher----- Date-----  
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**Screening Measures**

**New York Heart Association's Functional Classification**

**Patient Name**-----

**Date of Screening**-----

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**Please tick one box containing the description which best summarizes your ability to engage in day to day activity**

- 
- I can perform all day to day activity without getting short of breath or tired, or having palpitations.
  
  - I get short of breath or tired, or have palpitations when performing more strenuous activities for example walking on steep inclines or walking up several flights of steps.
  
  - I get short of breath or tired, or have palpitations when performing day to day activities. For example, walking on the flat.
  
  - I feel breathless at rest, and am mostly housebound. I am unable to carry out any day to day activity without getting short of breath or tired, or having palpitations.

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SA-NYHA, self-assigned New York Heart Association. (Holland, Rechel, Stepien, Harvey & Brooksby

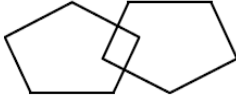
2010).

## Mini-Mental State Examination (MMSE)

Patient's Name: \_\_\_\_\_

Date: \_\_\_\_\_

**Instructions: Score one point for each correct response within each question or activity.**

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)  
30		TOTAL

APPENDIX D  
DATA COLLECTION PACKET

**Demographic Information:**  
**ID:**

1. Year of Birth:
2. Present Marital Status: (1) Married  
(2) Separated  
(3) Divorced  
(4) Widowed  
(5) Never Married
3. Number of individuals living in your household:
4. Number of years of schooling you have completed:
5. Your home zip code:
6. Nationality or ethnic group you identify with:  
(1) \_\_\_\_\_Caucasian/White  
(2) \_\_\_\_\_African American/Black  
(3) \_\_\_Hispanic/Latino (non-white)  
(4) \_\_\_\_\_Native American Indian  
(5) \_\_\_\_\_Asian  
(6) \_\_\_\_\_Other\_\_\_\_\_
7. Monthly Household Income:

I **do not** have enough money to meet my monthly needs.

I **do** have enough money to meet my monthly needs.

I **have more** than enough money to meet my monthly needs.

8. Have you been diagnosed with heart failure? \_\_\_yes \_\_\_no If so please specify the date you were diagnosed: \_\_\_\_\_

9. What is the primary language spoken in your home? \_\_\_\_\_

10. Primary Contact Person and telephone number: \_\_\_\_\_

ID-----

Evaluation Date-----

**Ryff's Psychological Well-being Scales (PWB), 28 Item version**

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**Please Indicate your degree of agreement (using a score ranging from 1-6 (strongly disagree to strongly agree) to the following sentences.**

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	Strongly disagree	Disagree somewhat	Disagree slightly	Agree slightly	Agree Somewhat	Strongly Agree	Code	Score
<b>1</b> I am not interested in activities that will expand my horizons.	1	2	3	4	5	6	RYFF_1_t1	
<b>2</b> I think, it is important to have new experiences that challenge how you think about yourself and the world.	1	2	3	4	5	6	RYFF_2_t1	
<b>3</b> When I think about it, I have not really improved much as a person over the years.	1	2	3	4	5	6	RYFF_3_t1	
<b>4</b> I have the sense that I have developed a lot as a person over time.	1	2	3	4	5	6	RYFF_4_t1	
<b>5</b> I do not enjoy being in new situations that require me to change my old familiar ways of doing things.	1	2	3	4	5	6	RYFF_5_t1	

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<b>6</b>	For me, life has been a continuous process of learning, changing and growth.	1	2	3	4	5	6	RYFF_6_t1
<b>7</b>	I gave up trying to make big improvements or changes in my life a long time ago.	1	2	3	4	5	6	RYFF_7_t1
<b>8</b>	Most people see me as loving and affectionate.	1	2	3	4	5	6	RYFF_8_t1
<b>9</b>	Maintaining close relationships has been difficult and frustrating for me.	1	2	3	4	5	6	RYFF_9_t1
<b>10</b>	I often feel lonely, because I have few close friends with whom to share my concerns.	1	2	3	4	5	6	RYFF_10_t1
<b>11</b>	I enjoy personal and mutual conversation with family members or friends.	1	2	3	4	5	6	RYFF_11_t1
<b>12</b>	People would describe me as a giving person, willing to share my time with others.	1	2	3	4	5	6	RYFF_12_t1
<b>13</b>	I have not experienced many warm and trusting relationships with others.	1	2	3	4	5	6	RYFF_13_t1

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<b>14</b>	I know that I can trust my friends, and they know they can trust me.	1	2	3	4	5	6	RYFF_14_t1
<b>15</b>	I live life one day at a time and don't really think about the future.	1	2	3	4	5	6	RYFF_15_t1
<b>16</b>	I have a sense of direction and purpose in life.	1	2	3	4	5	6	RYFF_16_t1
<b>17</b>	My daily activities often seem trivial and unimportant to me.	1	2	3	4	5	6	RYFF_17_t1
<b>18</b>	I don't have a good sense of what it is I am trying to accomplish in life.	1	2	3	4	5	6	RYFF_18_t1
<b>19</b>	I enjoy making plans for the future and working to make them a reality.	1	2	3	4	5	6	RYFF_19_t1
<b>20</b>	Some people wander aimlessly through life, but I am not one of them.	1	2	3	4	5	6	RYFF_20_t1
<b>21</b>	I sometimes feel as if I have done all there is to do in life.	1	2	3	4	5	6	RYFF_21_t1
<b>22</b>	When I look at the story of my life, I am pleased with how things have turned out.	1	2	3	4	5	6	RYFF_22_t1
<b>23</b>	In general, I feel confident and positive about myself.	1	2	3	4	5	6	RYFF_23_t1

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<b>24</b>	I feel like many of the people I know have gotten more out of life than I have.	1	2	3	4	5	6	RYFF_24_t1
<b>25</b>	I like most aspects of my personality.	1	2	3	4	5	6	RYFF_25_t1
<b>26</b>	In many ways, I feel disappointed about my achievements in life.	1	2	3	4	5	6	RYFF_26_t1
<b>27</b>	My attitude about myself is probably not as positive as most people feel about themselves.	1	2	3	4	5	6	RYFF_27_t1
<b>28</b>	When I compare myself to friends and acquaintances, it makes me feel good about who I am.	1	2	3	4	5	6	RYFF_28_t1

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**ID---**

**Evaluation date----**

**All answers are confidential.**

**Think about how you have been feeling in the last month or since we last spoke as you complete these items.**

**Section A:**

**Listed below are common instructions given to persons with heart failure. How routinely do you do the following?**

		<b>Never or Rarely</b>	<b>Some times</b>	<b>Frequentl y</b>	<b>Always or Daily</b>	<b>Code</b>	<b>Score</b>
1	Weigh yourself	1	2	3	4	SMAIN-1_t1	
2	Check your ankles for swelling	1	2	3	4	SMAIN-2_t1	
3	Try to avoid getting sick (eg. flu shot, avoid ill people)	1	2	3	4	SMAIN-3_t1	
4	Do some physical activity	1	2	3	4	SMAIN-4_t1	
5	Keep your doctor or nurse appointments	1	2	3	4	SMAIN-5_t1	
6	Eat a low-salt diet	1	2	3	4	SMAIN-6_t1	
7	Exercise for 30 minutes	1	2	3	4	SMAIN-7_t1	

8	Forget to take one of your medicine	1	2	3	4	SMAIN-8_t1	
9	Ask for low-salt items when eating out or visiting others	1	2	3	4	SMAIN-9_t1	
10	Use a system (pillbox, reminders) to help you remember your medicines	1	2	3	4	SMAIN-10_t1	
<p><b>Section B:</b>  <b>Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure. In the past month, have you had trouble breathing or ankle swelling? Circle one.</b>  <b>(0) No</b>  <b>(1) Yes</b>  <b>(11) if you had trouble breathing or ankle swelling in the past month...(Circle one number)</b></p>						SM_11_t1	
	<b>Have not had these</b>	<b>I did not recognize it</b>	<b>Not quickly</b>	<b>Somewhat quickly</b>	<b>Quickly</b>	<b>Very quickly</b>	
How quickly did you recognize it as a symptom of heart failure?	N/A	0	1	2	3	4	SM_11A_t1

<b>Listed below are remedies that people with heart failure use. If you have trouble breathing or ankle swelling, how likely are you to try one of these remedies? (Circle one number for each remedy)</b>							
		<b>Not likely</b>	<b>Somewhat likely</b>	<b>Likely</b>	<b>Very likely</b>		
12	Reduce the salt in your diet	1	2	3	4	SM_12_t1	
13	Reduce your fluid intake	1	2	3	4	SM_13_t1	
14	Take an extra water pill	1	2	3	4	SM_14_t1	
15	Call your Doctor or nurse for guidance	1	2	3	4	SM_15_t1	
<b>16</b>	<b>Think of a remedy you tried the last time you had trouble breathing or ankle swelling, (circle one number)</b>						
	<b>I did not try anything</b>	<b>Not sure</b>	<b>Somewhat sure</b>	<b>Sure</b>	<b>Very sure</b>		
	How sure were you that the remedy helped or did not help?	0	1	2	3	4	SM_16_t1
<b>Section C:</b> <b>In general, how confident are you that you can</b>							

		<b>Not confident</b>	<b>Somew hat confide nt</b>	<b>Very confident</b>	<b>Extremely confident</b>		
17	keep yourself free of heart failure symptoms?	1	2	3	4	SCONF_17_t1	
18	follow the treatment advice you have been given?	1	2	3	4	SCONF_18_t1	
19	evaluate the importance of your symptoms?	1	2	3	4	SCONF_19_t1	
20	recognize changes in your health if they occur?	1	2	3	4	SCONF_20_t1	
21	do something that will relieve your symptoms?	1	2	3	4	SCONF_21_t1	
22	evaluate how well a remedy works?	1	2	3	4	SCONF_22_t1	

**ID-----**  
**Evaluation date-----**

**MINNESOTA LIVING WITH HEART FAILURE® QUESTIONNAIRE**

The following questions ask how much your heart failure (heart condition) affected your life during the past month (4 weeks). After each question, circle the 0, 1, 2, 3, 4 or 5 to show how much your life was affected. If a question does not apply to you, circle the 0 after that question.

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<b>Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by-</b>	<b>Not</b>	<b>Very little</b>	<b>Little</b>	<b>Moderate</b>	<b>Much</b>	<b>Very much</b>	<b>Code</b>	<b>Score</b>
1. causing swelling in your ankles or legs?	0	1	2	3	4	5	MLHFQ_1_t1	
2. making you sit or lie down to rest during the day?	0	1	2	3	4	5	MLHFQ_2_t1	
3. making your walking about or climbing stairs difficult?	0	1	2	3	4	5	MLHFQ_3_t1	
4. making your working around the house or yard difficult?	0	1	2	3	4	5	MLHFQ_4_t1	
5. making your going places away from home difficult?	0	1	2	3	4	5	MLHFQ_5_t1	
6. making your sleeping well at night difficult?	0	1	2	3	4	5	MLHFQ_6_t1	

<b>Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by-</b>	<b>Not</b>	<b>Very little</b>	<b>Little</b>	<b>Moderate</b>	<b>Much</b>	<b>Very much</b>	<b>Code</b>	<b>Score</b>
7. making your relating to or doing thing with your friends or family difficult?	0	1	2	3	4	5	MLHFQ_7_t1	
8. making your working to earn a living difficult?	0	1	2	3	4	5	MLHFQ_8_t1	
9. making your recreational pastimes, sports or hobbies difficult?	0	1	2	3	4	5	MLHFQ_9_t1	
10. making your sexual activities difficult?	0	1	2	3	4	5	MLHFQ_10_t1	
11. making you eat less of the foods you like?	0	1	2	3	4	5	MLHFQ_11_t1	
12. making you short of breath?	0	1	2	3	4	5	MLHFQ_12_t1	
13. making you tired, fatigued, or low on energy?	0	1	2	3	4	5	MLHFQ_13_t1	
14. making you stay in a hospital?	0	1	2	3	4	5	MLHFQ_14_t1	
15. costing you money for medical care?	0	1	2	3	4	5	MLHFQ_15_t1	
16. giving you side effects from treatments?	0	1	2	3	4	5	MLHFQ_16_t1	
17. making you feel you are a burden to your family or friends?	0	1	2	3	4	5	MLHFQ_17_t1	

<b>Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by-</b>	<b>Not</b>	<b>Very little</b>	<b>Little</b>	<b>Moderate</b>	<b>Much</b>	<b>Very much</b>	<b>Code</b>	<b>Score</b>
18. making you feel a loss of self-control in your life?	0	1	2	3	4	5	MLHFQ_18_t 1	
19. making you worry?	0	1	2	3	4	5	MLHFQ_19_t 1	
	Not	Very little	Little	Moderate	Much	Very much		
20. making it difficult for you to concentrate or remember things?	0	1	2	3	4	5	MLHFQ_20_t 1	
21. making you feel depressed?	0	1	2	3	4	5	MLHFQ_21_t 1	

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- There are no right or wrong answers.

Record your first impression for each pair of words.

- You can place an “X” in any space along the line that best describes the meaning the indicator has for you at this time.
- Mark only one “X” for each pair of words.
- Mark an “X” for every pair of words.

**PLEASE BEGIN TO MARK YOUR X’S ON BARRETT’S PKPCT**

(Please go the NEXT PAGE and continue)

## BARRETT PKPCT, Version II

MARK AN "X" AS DESCRIBED IN THE INSTRUCTIONS

### MY AWARENESS IS

<b>Profound</b>	7	6	5	4	3	2	1	<b>Superficial</b>	PKPCT_AWA1_t1
<b>Avoiding</b>	1	2	3	4	5	6	7	<b>Seeking</b>	PKPCT_AWA2_t1
<b>Valuable</b>	7	6	5	4	3	2	1	<b>Worthless</b>	PKPCT_AWA3_t1
<b>Unintentional</b>	1	2	3	4	5	6	7	<b>Intentional</b>	PKPCT_AWA4_t1
<b>Timid</b>	1	2	3	4	5	6	7	<b>Assertive</b>	PKPCT_AWA5_t1
<b>Leading</b>	7	6	5	4	3	2	1	<b>Following</b>	PKPCT_AWA6_t1
<b>Chaotic</b>	1	2	3	4	5	6	7	<b>Orderly</b>	PKPCT_AWA7_t1
<b>Expanding</b>	7	6	5	4	3	2	1	<b>Shrinking</b>	PKPCT_AWA8_t1
<b>Pleasant</b>	7	6	5	4	3	2	1	<b>Unpleasant</b>	PKPCT_AWA9_t1
<b>Uninformed</b>	1	2	3	4	5	6	7	<b>Informed</b>	PKPCT_AWA10_t1
<b>Free</b>	7	6	5	4	3	2	1	<b>Constrained</b>	PKPCT_AWA11_t1
<b>Unimportant</b>	1	2	3	4	5	6	7	<b>Important</b>	PKPCT_AWA12_t1
<b>Unpleasant</b>	1	2	3	4	5	6	7	<b>Pleasant</b>	PKPCT_AWA13_t1

MARK AN "X" AS DESCRIBED IN THE INSTRUCTIONS

**MY CHOICES ARE**

<b>Shrinking</b>	1	2	3	4	5	6	7	<b>Expanding</b>	PKPCT_CHO1_t1
<b>Seeking</b>	7	6	5	4	3	2	1	<b>Avoiding</b>	PKPCT_CHO2_t1
<b>Assertive</b>	7	6	5	4	3	2	1	<b>Timid</b>	PKPCT_CHO3_t1
<b>Important</b>	7	6	5	4	3	2	1	<b>Unimportant</b>	PKPCT_CHO4_t1
<b>Orderly</b>	7	6	5	4	3	2	1	<b>Chaotic</b>	PKPCT_CHO5_t1
<b>Intentional</b>	7	6	5	4	3	2	1	<b>Unintentional</b>	PKPCT_CHO6_t1
<b>Unpleasant</b>	1	2	3	4	5	6	7	<b>Pleasant</b>	PKPCT_CHO7_t1
<b>Constrained</b>	1	2	3	4	5	6	7	<b>Free</b>	PKPCT_CHO8_t1
<b>Worthless</b>	1	2	3	4	5	6	7	<b>Valuable</b>	PKPCT_CHO9_t1
<b>Following</b>	1	2	3	4	5	6	7	<b>Leading</b>	PKPCT_CHO10_t1
<b>Superficial</b>	1	2	3	4	5	6	7	<b>Profound</b>	PKPCT_CHO11_t1
<b>Informed</b>	7	6	5	4	3	2	1	<b>Uninformed</b>	PKPCT_CHO12_t1
<b>Timid</b>	1	2	3	4	5	6	7	<b>Assertive</b>	PKPCT_CHO13_t1

**MARK AN "X" IN ANY SPACE ALONG THE LINE THAT BEST DESCRIBES THE MEANING THE INDICATOR HAS FOR YOU AT THIS TIME**

**MY FREEDOM TO ACT INTENTIONALLY IS**

<b>Timid</b>	1	2	3	4	5	6	7	<b>Assertive</b>	PKPCT_FREE1_t1
<b>Uninformed</b>	1	2	3	4	5	6	7	<b>Informed</b>	PKPCT_FREE2_t1
<b>Leading</b>	7	6	5	4	3	2	1	<b>Following</b>	PKPCT_FREE3_t1
<b>Profound</b>	7	6	5	4	3	2	1	<b>Superficial</b>	PKPCT_FREE4_t1
<b>Expanding</b>	7	6	5	4	3	2	1	<b>Shrinking</b>	PKPCT_FREE5_t1
<b>Unimportant</b>	1	2	3	4	5	6	7	<b>Important</b>	PKPCT_FREE6_t1
<b>Valuable</b>	7	6	5	4	3	2	1	<b>Worthless</b>	PKPCT_FREE7_t1
<b>Chaotic</b>	1	2	3	4	5	6	7	<b>Orderly</b>	PKPCT_FREE8_t1
<b>Avoiding</b>	1	2	3	4	5	6	7	<b>Seeking</b>	PKPCT_FREE9_t1
<b>Free</b>	7	6	5	4	3	2	1	<b>Constrained</b>	PKPCT_FREE10_t1
<b>Unintentional</b>	1	2	3	4	5	6	7	<b>Intentional</b>	PKPCT_FREE11_t1
<b>Pleasant</b>	7	6	5	4	3	2	1	<b>Unpleasant</b>	PKPCT_FREE12_t1
<b>Orderly</b>	7	6	5	4	3	2	1	<b>Chaotic</b>	PKPCT_FREE13_t1

**MARK AN "X" IN ANY SPACE ALONG THE LINE THAT BEST DESCRIBES  
THE MEANING THE INDICATOR HAS FOR YOU AT THIS TIME**

**MY INVOLVEMENT IN CREATING CHANGE IS**






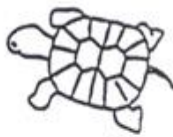




<b>Unintentional</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Intentional</b>	PKPCT_CHAN1_t1
<b>Expanding</b>	<b>7</b>	<b>6</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>	<b>Shrinking</b>	PKPCT_CHAN2_t1
<b>Profound</b>	<b>7</b>	<b>6</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>	<b>Superficial</b>	PKPCT_CHAN3_t1
<b>Chaotic</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Orderly</b>	PKPCT_CHAN4_t1
<b>Free</b>	<b>7</b>	<b>6</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>	<b>Constrained</b>	PKPCT_CHAN5_t1
<b>Valuable</b>	<b>7</b>	<b>6</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>	<b>Worthless</b>	PKPCT_CHAN6_t1
<b>Uninformed</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Informed</b>	PKPCT_CHAN7_t1
<b>Avoiding</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Seeking</b>	PKPCT_CHAN8_t1
<b>Leading</b>	<b>7</b>	<b>6</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>	<b>Following</b>	PKPCT_CHAN9_t1
<b>Unimportant</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Important</b>	PKPCT_CHAN10_t1
<b>Timid</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Assertive</b>	PKPCT_CHAN11_t1
<b>Pleasant</b>	<b>7</b>	<b>6</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>	<b>Unpleasant</b>	PKPCT_CHAN12_t1
<b>Superficial</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Profound</b>	PKPCT_CHAN13_t1

# Wellbeing Picture Scale

Subject ID \_\_\_\_\_ Date of evaluation \_\_\_\_\_

### Instructions:

Look at the scale between each pair of pictures. Mark [ X ] at the place on the scale that best describes how you feel now.

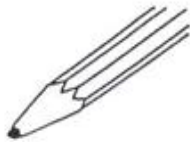
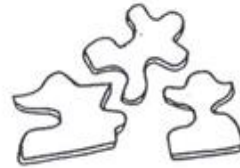
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**Instructions:**

Look at the scale between each pair of pictures. Mark [ X ] at the place on the scale that best describes how you feel now.



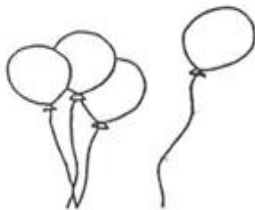
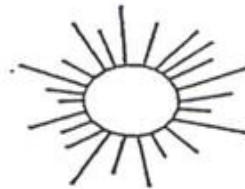
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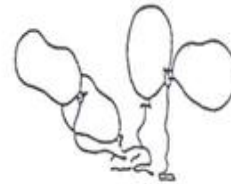
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**ID** \_\_\_\_\_  
**Evaluation date**

**Goal Attainment Scale**  
 Kiresuk & Sherman (1968)

Goal Statement 1	Outcome Value	Time 1	<b>GS_1_t1</b>
	Least favorable outcome (-2)		
	Less than expected outcome (-1)		
	Expected outcome (0)		
	More than expected outcome (+1)		
	Most favorable outcome (+2)		
Goal Statement 2	Outcome Value	Time 1	<b>GS_2_t1</b>
	Least favorable outcome (-2)		
	Less than expected outcome (-1)		
	Expected outcome (0)		
	More than expected outcome (+1)		
	Most favorable outcome (+2)		
Goal Statement 3	Outcome Value	Time 1	<b>GS_3_t1</b>
	Least favorable outcome (-2)		
	Less than expected outcome (-1)		
	Expected outcome (0)		
	More than expected outcome (+1)		
	Most favorable outcome (+2)		





**ID** \_\_\_\_\_

**Evaluation date** \_\_\_\_\_

### **Social Services Utilization Data Sheet**

List all the social service agencies you have utilized within the past six weeks

<b>Agency Name</b>	<b>Number of Times Used per Week</b>		
<b>1.</b>		Agency_1	Agency_1_TPW
<b>2.</b>		Agency_2	Agency_2_TPW
<b>3.</b>		Agency_3	Agency_3_TPW
<b>4.</b>		Agency_4	Agency_4_TPW
<b>5.</b>		Agency_5	Agency_5_TPW
<b>6.</b>		Agency_6	Agency_6_TPW
<b>7.</b>		Agency_7	Agency_7_TPW
<b>8.</b>		Agency_8	Agency_8_TPW
<b>9.</b>		Agency_9	Agency_9_TPW