

ASSESSING THE IMPACT OF A TRANSITIONAL CARE PROGRAM ON  
SYMPTOM RECOGNITION AND SELF-CARE IN HEART FAILURE PATIENTS

by

Carolyn Muller Hull

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As members of the DNP Project Committee, we certify that we have read the DNP Project prepared by Carolyn Muller Hull entitled “Assessing the Impact of a Transitional Care Program on Symptom Recognition and Self-Care in Heart Failure Patients” and recommend that it be accepted as fulfilling the DNP Project requirement for the Degree of Doctor of Nursing Practice.

\_\_\_\_\_  
Date: December 6, 2016  
Lori Martin-Plank, PhD, FNP-BC, NP-C, GNP-BC, FAANP, FNAP

\_\_\_\_\_  
Date: December 6, 2016  
Luz Wiley, DNP, RN, ANP-BC

\_\_\_\_\_  
Date: December 6, 2016  
Christy Pacheco, DNP, FNP-BC

Final approval and acceptance of this DNP Project is contingent upon the candidate’s submission of the final copies of the DNP Project to the Graduate College.

I hereby certify that I have read this DNP Project prepared under my direction and recommend that it be accepted as fulfilling the DNP Project requirement.

\_\_\_\_\_  
Date: December 6, 2016  
DNP Project Director: Lori Martin-Plank, PhD, FNP-BC, NP-C, GNP-BC, FAANP, FNAP

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SIGNED: Carolyn Muller Hull

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## DEDICATION

This project is dedicated to my children, may you always believe that with dedication, courage and perseverance, you can achieve your wildest dreams. And to my patients, who inspired this project.

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## ABSTRACT

**Background:** Heart failure (HF) is a complex, costly and debilitating chronic health condition. Symptom recognition and self-care are crucial components of heart failure management; however, many HF patients struggle to perform these behaviors and skills at a proficient level. A transitional care program in the Southwest provides services to heart failure patients. A primary program aim is to help facilitate enhanced symptom recognition and self-care among heart failure patients. This project focuses on the assessment of the impact of such a transitional care program on HF patients' ability to perform symptom recognition and self-care.

**Methods:** Demographic questionnaires were distributed to collect socioeconomic data and clinical characteristics of participants. A pre and post SCHFI survey was completed by participants, and analysis of data performed using a paired *t*-test.

**Results:** The 15 participants were primarily Hispanic, elderly, and male. The majority of participants reported an annual income less than \$10,000, lived in close proximity to the transitional care clinic, reported living with family and/or friends, and had at least one additional comorbidity. There was improvement in self-care maintenance scores following the initial transitional care encounter; however, participants did not achieve self-care adequacy in this domain. Participants also did not achieve self-care adequacy in self-management. Self-confidence scores improved to reach adequacy following the initial transitional care encounter; however, results were not statistically significant.

**Conclusion:** With the complexities of HF self-management, it is not alarming that these patients have continued to struggle with symptom recognition and self-care. Recommendations are made for future research and interventions.

## INTRODUCTION

### Background Knowledge

Heart failure is a chronic, multi-faceted syndrome often coupled with a myriad of co-morbidities (i.e., cardiorenal syndrome, COPD, diabetes mellitus) and complex treatment regimens resulting in a significant health burden to patients, their families, and the healthcare system (Coleman & Newton, 2005). Approximately 5.8 million people in the United States are afflicted with heart failure (Roger, 2013); furthermore, the prevalence is anticipated to increase significantly as the aging population continues to grow exponentially (Heidenreich et al., 2013). The American Heart Association (AHA) estimates more than eight million people in the United States will be afflicted with heart failure by 2030 assuming prevalence continues at the current rate. Costs related to heart failure were approximately \$31 billion in 2012 with an estimated projected increase to \$70 billion in 2030 (Heidenreich et al., 2013). In addition, heart failure results in more hospitalizations than any other medical condition in the United States (Heidenreich et al., 2013).

To address the significant health and economic burden of many health conditions including heart failure, the Centers for Medicare and Medicaid (CMS) (2014) established reimbursement restrictions for heart failure 30-day hospital readmissions in Section 3025 of the Hospital Readmissions Reduction program. These restrictions have prompted the U.S. healthcare system to develop and implement interventions to improve heart failure management. Transitional care programs focusing on readmission penalty diagnoses such as heart failure as well as other chronic conditions have been developed to improve care coordination, enhance disease management efforts, and reduce preventable hospital readmissions (Naylor, Aiken,

Kurtzman, Olds, & Hirschman, 2011). The incidence of heart failure and related morbidity and costs associated with this chronic illness is a prevailing topic of concern and emphasis.

### **Transitional Care**

Transitional care programs have been heavily endorsed by the Affordable Care Act (ACA) of 2010 and are designed to improve the transition for individuals with complex and chronic diseases from acute care settings to a variety of outpatient settings (Naylor et al., 2011). These programs promote quality of life and improve physical health and functional status while decreasing healthcare expenditures primarily by promoting health and wellness, decreasing the length of inpatient stay as well as decreasing the incidence of re-hospitalization (Feltner et al., 2014; Naylor & Sochalski, 2010; Naylor et al., 2011). One such model, the Transitional Care Model (TCM), emphasizes the negative impact that various ‘transitions’ have on the health outcomes of many chronic disease sufferers; furthermore, the model seeks to address the disparities in care and encourages the implementation of feasible and effective evidence-based interventions to foster consistency of care and promote health and wellness (Naylor et al., 2010; Naylor et al., 2011). Transitional care interventions typically include medication reconciliation, patient education facilitated by a nurse or advanced practice nurse, care coordination, behaviorist consults, nutritional support, and frequent monitoring (either telephonic, in-person or telemonitoring) (Feltner et al., 2011). Unfortunately, transitional care interventions vary greatly and standardization is needed to allow for reproduction of beneficial services (Feltner et al., 2011).

### **Heart Failure Symptom Recognition and Self-Management**

Despite an array of multi-level interventions, heart failure outcomes are heavily dependent upon self-care, complex symptom recognition, and self-management (Baker et al., 2011; Riegel, Jaarsma & Stromberg, 2012). The ability of the patient to recognize and manage heart failure decompensation symptoms is integral to the prevention and management of heart failure decompensation (Baker et al., 2011). Baker et al. (2011) conducted a review of multiple heart failure disease management programs and found programs that included self-management training consisting of education emphasizing self-care skills such as early symptom recognition, weight monitoring, sodium restriction, exercise, medication adherence, and implementation of action plans in the event of an exacerbation, reduced heart failure related hospitalizations by 33%.

### **Barriers and Facilitators to Self-Care**

Self-care encompasses symptom recognition and the management of chronic illness. Adherence to self-care is challenging for many heart failure patients, but is crucial for improved health outcomes of chronic illness including illness stability, improved quality of life, and enhanced empowerment resulting from improved sense of control (Riegel et al., 2012). The following have been identified as both potential barriers and facilitators of self-care depending on the individual: experience and skill level, degree of motivation, confidence in one's abilities, habits, cultural beliefs, cognitive capacity and functional ability, degree of encouragement and support, and one's ability to obtain care (Riegel et al., 2012).

### **Educational Material and Health Literacy**

Early recognition of heart failure decompensation symptoms and self-care is crucial in heart failure management; however, heart failure patients with low health literacy levels often struggle with symptom recognition, rationale for treatment adherence, and self-care leading to poorer health outcomes and increased morbidity (Baker et al., 2011; Dennison, McEntee, Samuel, Johnson, Rotman & Kielty, 2011; DeWalt et al., 2006). Health literacy is not solely based on challenges associated with reading, but also includes problems related to comprehension of numerical information, material read, calculations, deficient memory, and limited baseline knowledge (Baker et al., 2011). Lower health literacy has been correlated with limited education, older age, racial/ethnic minorities, low socioeconomic status and comorbidities (Peterson et al., 2011). Although inadequate health literacy can negatively impact health outcomes, educational interventions designed to address lower health literacy levels have been effective at increasing quality of life and adherence to self-care (Peterson et al., 2011).

Baker et al. (2011) have identified the need for plain language and the use of images and pictures as an instrumental component of heart failure educational material for all literacy levels. Furthermore, they propose all individuals could benefit from exposure to basic educational material with the opportunity to build on knowledge as desired (Baker et al., 2011). Current recommendations encourage clinicians to use and reinforce appropriate teaching materials, and assess comprehension of education provided (Peterson et al., 2011).

### **Transitional Care Program of Interest**

The current transitional care program provided at an outpatient transitional care services clinic (TCS) in rural southwest Arizona includes a variety of heart failure management services

and evidence-based interventions to help enhance quality of life and reduce preventable 30-day hospital readmissions. A current aim is to help facilitate enhanced early heart failure symptom recognition leading to prompt medical evaluation and intervention; however, patients continue to struggle with symptom recognition and self-care measures which are crucial components of positive health outcomes (Riegel et al., 2012).

Hospitalized patients with a confirmed diagnosis of heart failure are referred to the transitional care services clinic (TCS) upon hospital discharge. The patient is scheduled for an initial TCS visit within seven days from hospital discharge. This visit includes a one hour, one-to-one educational session with a nurse practitioner (NP) that includes medication reconciliation, appointment scheduling (with PCP and specialists), the provision of monitoring equipment such as blood pressure machine and scale, assistance with insurance enrollment and access to medications, if appropriate, and the opportunity to meet with the onsite behaviorist and pharmacist. Behaviorist services include support and counseling on diet, exercise, smoking cessation, and anxiety. Weekly phone calls are conducted to allow for ongoing monitoring and to inquire about the onset of pertinent symptoms. Each personal and/or telephonic encounter reinforces symptom recognition and self-care measures (Appendix B). Symptoms inquired about include the following: new onset/unusual cough, struggling to breathe at night, gasping for air, dizziness, decreased appetite, fatigue, increased shortness of breath, weight gain (3 pounds in one day, 5 pounds in 1 week). Self-care measures emphasized include importance of medication adherence, appointment compliance, daily monitoring of weight and blood pressure, and a low sodium diet. Patients are encouraged to utilize the “Zones to Manage Heart Failure” tool distributed to them at their initial TCS visit (Appendix A).

### **Local Problem**

Despite the many services and interventions currently provided at TCS, problems with symptom recognition and consistency of self-care among heart failure patients continue to be identified. Many of the patients encountered in TCS are likely to have lower health literacy levels due to factors such as limited education, older age, racial/ethnic minorities, low socioeconomic status and comorbidities (Peterson et al., 2011). In response to the recognition that educational material presented at an inappropriate health literacy level may negatively impact the retention of education provided (e.g., poor symptom recognition), and impede activation of self-care (Baker et al, 2011; Dennison et al., 2011), heart failure educational material designed for low health literacy levels has been incorporated into the program. Current heart failure educational materials include the *Caring for Your Heart: Living Well with Heart Failure* booklet from the University of North Carolina (<http://www.acumentra.org/assets/HF-UNC-Guide-2011-07-19.pdf>) and the *Heart Failure Zone Tool* (Appendix A). This educational material was selected due to its specific design for populations with lower health literacy levels.

### **Stakeholders**

Key stakeholders include the transitional care team. The clinic team consists of two Family Nurse Practitioners (FNP), one Adult Nurse Practitioner (ANP), one RN, and two certified medical assistants. Additional stakeholders include patients, their families, the affiliated hospital, and community providers.

### **Purpose**

The purpose of this quality improvement project was to gain a better understanding of the impact of a transitional care program on heart failure symptom recognition and self-care among

heart failure patients. The aim was to help facilitate enhanced early heart failure symptom recognition leading to prompt medical evaluation and intervention resulting in decreased occurrence and/or severity of heart failure decompensation.

### **LITERATURE REVIEW**

The search strategy included utilization of multiple sites including Google Scholar, and EBSCO's CINAHL. A combination of key phrases were used for all sites including: "heart failure," "transitional care," "self-care," and "symptom recognition." The Google Scholar search yielded a large number of articles (over 1,000) which were scanned for applicability to the proposed study by perusal of the abstract and/or review of the title. The search was further refined by limiting the search strategy to the following phrases, "heart failure," "self-care," and "self-management." The search also was limited to articles published within the past five years. This yielded 13 articles. After reviewing the abstracts of these 13 articles, the search yielded five articles, of which two were retained. For the CINAHL search, the key phrases utilized were "heart failure," "self-care," and "self-management." The search was limited to adults, articles published within the past five years, English language, academic journals, and those articles with abstracts available. This yielded 24 articles which were reviewed for relevance to the project aim.

Although there is a plethora of literature pertaining to heart failure and related interventions utilized for chronic disease management, the studies identifying other interventions not currently in use by TCS were not reviewed as the aims of this project did not include the implementation of a new intervention.

Tung, Lin, Chen, Chang, Lin, and Chou (2012) conducted a study using a quasi-experimental design and convenience sampling. They sought to gain a better understanding of the impact of self-management interventions on Taiwanese heart failure patients' quality of life and self-care ability. They utilized three questionnaires to collect pertinent data: The Self-Care of Heart Failure Index (SCHFI), a demographic questionnaire, and the Minnesota Living with Heart Failure Questionnaire (MLHF). The self-management intervention included three components: a self-management booklet, self-management education and training, and a follow-up telephone encounter to assess adherence to self-care. The findings indicate that participants receiving the self-management interventions had better outcomes than the control group (Tung et al., 2012).

In contrast, Lee et al. (2014) conducted a study to determine the impact of regular heart failure symptom monitoring on self-care management. They divided participants into three groups, "adherent," "partially adherent," and "nonadherent" based on their responses to two questions pertaining to symptom recognition within the SCHFI. Self-care management was assessed using the self-care management component of the SCHFI. Effective self-care management was positively associated with adherent and partially adherent groups. The study results emphasize the importance of adequate symptom recognition (Lee et al., 2014)

Cockayne, Pattenden, Worthy, Richardson, and Lewin (2014) conducted an open parallel group randomized control trial (RCT) to evaluate the effectiveness of a self-management manual with additional review and education provided by a heart failure nurse in comparison to the manual with the opportunity for the participant to self-review information. Patient readmission (a 12 month timeframe) was evaluated to determine if there was a significant difference in this outcome between groups. Secondary outcomes were quality of life as measured by the

Minnesota Living with Heart Failure (MLHF) questionnaire, the EuroQOL five dimensions (EQ5D) questionnaire, the European heart failure self-care behavior scale, and the Hospital Anxiety and Depression scale (HAD). Results were indicative of a small albeit clinically insignificant difference in hospital readmission rates for those participants who received the nurse-led self-management intervention; however, this intervention did not have an impact on self-management behaviors. The secondary outcome results revealed a higher incidence of depression among the interventional group which researchers suggested may be due to increased awareness and knowledge of their chronic condition (Cockayne et al., 2014).

Shao, Chang, Edwards, Shyu, and Chen (2013) conducted a RCT to evaluate the impact of a self-management program on health-related outcomes of older adults with heart failure. The self-management program was conducted over the course of 12 weeks and emphasized symptom recognition, and self-management with specific focus on sodium and fluid intake among participants. The self-management program consisted of one home visit, multiple telephone encounters, completion of daily diary logging fluid and sodium intake, and daily weight monitoring. The self-management intervention was effective in improving self-efficacy pertaining to salt and fluid intake, behaviors of self-management, and in reducing heart failure related distress symptoms; however, insignificant benefit was observed in reducing utilization of health services (Shao et al., 2013).

Shively et al. (2013) conducted a study with a randomized two-group, repeated measures design to assess the effectiveness of targeted interventions on patient activation and improvement in self-management behaviors related to heart failure. The patient activation measure (PAM), the SCHFI and the Medical Outcomes Study (MOS) Specific Adherence Scale were utilized to

measure the outcomes. This was the first study to assess patient activation and heart failure self-management in a randomized design (Shively et al., 2013). Findings suggest that targeted interventions could have a positive impact on patient activation especially among individuals whose initial activation level fell in the “medium” category.

### **Strengths**

The studies reviewed supported a wide variety of interventions pertaining to symptom recognition and self-care in heart failure patients. The majority of studies supported tailored interventions reinforcing symptom recognition and self-care in heart failure patients.

### **Weaknesses**

Many of the studies were conducted in one setting or with a predominant sample limiting generalizability of research findings to a variety of settings and populations (Lee et al., 2014; Shao et al., 2013; Tung et al., 2012). The Lee et al. (2014) and Shively et al. (2013) study participants were comprised primarily of Caucasian, male participants. Another identified weakness is the lack of longitudinal data indicating effectiveness of interventions over longer periods of time (6 months to 1 year) (Tung et al., 2012). The Cockayne et al. (2014) study results may have been skewed due to a flaw in design where nurses answered questions for control participants. With studies utilizing multi-faceted interventions, there were challenges with identifying which aspects were effective. Attrition was also identified as a limitation (Shively et al., 2013).

### **Theoretical Framework**

The Theory of Self-Care of Chronic Illness was used as the theoretical framework guiding this project. The Theory of Self-Care in Chronic Illness is a middle range theory based

on the situation-specific theory of heart failure self-care that focuses on three essential components of self-care including “self-care maintenance,” “self-care monitoring,” and “self-care management” (Riegel et al., 2012). The theory was derived from clinical experience with adult heart failure patients and is pertinent to this project as the project aims were focused on gaining a better understanding of heart failure patients’ comprehension of symptom recognition and self-management. Self-care is defined as “a process of maintaining health through health promoting practices and managing illness...” (Riegel et al., 2012, p. 195). Self-care maintenance is defined as the behaviors performed by the chronically ill person to maintain stability of one’s illness. The behaviors may be independently determined or derived from recommendations. Self-care monitoring is defined as one’s ability to monitor oneself for specific symptoms, and self-care management comes into play when one recognizes a change in symptoms warranting the need for action. Self-care management also incorporates the evaluation of effectiveness of imposed interventions/action plan. There are seven predictions which have been proposed for this particular theory: 1) Specific similarities exist in self-care across a variety of chronic illnesses; 2) Self-care process is learned - those with previous experience in caring for another or in performing self-care perform better than those without similar experiences; 3) Those individuals that do not participate in the evaluation process of self-care are unable to achieve mastery of self-care; 4) Lack of or poor comprehension of chronic illness has a negative impact on self-care; 5) Expertise in self-care maintenance occurs before expertise in self-care management; 6) Effective self-care monitoring must occur to achieve competent self-care management; and, 7) Better outcomes are achieved for those practicing evidence-based self-care (Riegel et al., 2012).

## **METHODOLOGY**

### **Design**

Descriptive statistics and a paired t-test design were utilized to assess the impact of program utilization on heart failure symptom recognition and self-care adherence using the Self-Care of Heart Failure Index (SCHFI) tool, version 6.2 ([http://www.self-careofheartfailureindex.com/?page\\_id=6](http://www.self-careofheartfailureindex.com/?page_id=6)) and data collected from the Demographics Questionnaire. This tool assessed heart failure symptom recognition and self-care adherence for the heart failure patient, by using a paired sample t-test for a comparison of the initial SCHFI scores to scores obtained at the end of the transitional care program. For the purpose of this project, no control or comparison group was utilized. Data were collected per routine clinical practice. This type of project design is more practical for utilization in the intended setting as it does not divide patients into control and interventional groups; however, a significant potential research design flaw includes challenges in making causal inferences due to the possibility of other contributing factors (Polit & Beck, 2010). Data analysis was performed by the lead investigator (NP) using SPSS 24.

### **Setting**

This quality improvement project took place in an outpatient transitional care clinic in a southwestern U.S./Mexico border community. The transitional care clinic is an ambulatory clinic of the community hospital. There are three full-time nurse practitioners, one registered nurse, and two medical assistants. The clinic is overseen by a nurse practitioner with her Doctorate in Nursing Practice (DNP). According to 2013 American Community survey results, the targeted community, has an estimated population of 199,026. The Hispanic/Latino population is

estimated at 119,671 and non-Hispanic population at 79,355. The median household income is \$41,595. Approximately 71.9% are high school graduates. Approximately 40.3% of the population has public health insurance coverage and 21% lacks health insurance coverage. An estimated 16.7% of all families and 39.7% of single-parent families (female household) live below the poverty level (U.S. Census Bureau, 2013). The county ranks thirteenth out of fifteen counties in the “*Clinical Care*” domain. Additionally, 27% of the county population is uninsured. There is a significant healthcare provider shortage within the community. There are approximately 2,439 patients to every 1 primary care provider, 3,658 patients to every 1 dentist, and 1,880 patients to every 1 mental health provider (County Health Rankings, 2015). A review of this data identifies that the community struggles with poverty, limited health insurance coverage, lower levels of education, and decreased access to healthcare.

### **Participants**

Discharged heart failure patients are currently referred to the transitional care program - a transitional care appointment is scheduled for them prior to their hospital discharge. All heart failure program patients presenting to the transitional care clinic between September 1st and October 15th, 2016 were evaluated for possible inclusion in the project. Those meeting inclusion criteria were approached by the lead investigator (NP) and invited to participate. Inclusion criteria included patients at least 18 years of age, English and Spanish speaking, diagnosis of heart failure, and able to give consent. Exclusion criteria included major diagnosed psychiatric illness, major uncorrected hearing impairment, current resident at a skilled nursing facility (SNF) and current substance abuse. Based off a retrospective review of prior transitional care program heart failure participation data during the specified time frame, it was anticipated that

approximately 43 patients may be eligible for participation. The goal was to include at least 20 patients in the project after accounting for attrition due to mortality as well as other variables (i.e., relocating, disinterest in further participation, etc.). Based on a power analysis, a minimum sample size of 31 was required for correlational analyses.

### **Demographics Questionnaire**

Data on age, gender, ethnicity, co-morbidities (specifically CAD, COPD, diabetes mellitus, HTN), approximate time since diagnosis, marital status, highest level of education, living arrangements (i.e., living alone/lives with others), distance traveled to obtain healthcare services, method of transportation to clinic visit, and total household income was collected from self-report. A demographics questionnaire (Appendices G & H) was attached to the initial SCHFI survey and was distributed to each participant to obtain the self-reported data. Information collected from the demographics questionnaire was stored in a SPSS spreadsheet for data analyses.

### **Screening Tool**

The Self-Care Heart Failure Index (SCHFI), version 6.2 is a 22-item evidence-based survey (Appendices C & D) that was used to measure patients' ability to recognize heart failure symptoms and identify appropriate actions to take in the event heart failure decompensation symptoms are present. This tool also measured patient confidence in a third domain which allowed for assessment of patient engagement. The survey is available in the public domain in multiple languages (at <http://www.self-careofheartfailureindex.com/>). This tool has been identified as helpful to the healthcare provider involved with evaluating or improving self-care management (Riegel, Lee, Dickson, & Carlson, 2009). The tool takes approximately five

minutes to complete and can either be self-administered or completed by interview (Riegel, Carlson, Moser, Sebern, & Hicks, 2004). Riegel et al. (2004) conducted a study to test the reliability and validity of the SCHFI tool. Reliability was determined adequate which allowed for its utilization in research. Internal consistency in the self-confidence domain was lower than anticipated and desired, but not alarming as health behaviors often vary over time (Riegel et al., 2004). The study results led to marked revisions to refine the tool (Riegel et al., 2004).

The initial component of the SCHFI survey screens symptom monitoring and treatment adherence with a “self-care maintenance scale;” the second component screens for symptom recognition, actions related to heart failure self-care, subsequent responses when symptoms present, and implementation and evaluation of treatment. The third domain assesses patients’ perception of one’s ability to perform self-care. Three separate four-point self-report scales are utilized and separate scores are calculated for each section (maintenance, management, and confidence). The scores are based on a standardized 0-100 score (Vellone et al., 2013). A higher score is indicative of a higher degree of self-care (Riegel et al., 2009; Vellone et al., 2013). The Spanish version of the SCHFI was utilized for Spanish speaking participants. The Spanish version has three separate five-point Likert scales, one for each section (maintenance, management, and confidence).

### **Data Collection**

The lead investigator (NP) provided potential participants with a verbal explanation of the project as well as a written copy of the participant recruitment letter and disclosure form in their preferred language (either English or Spanish - Appendices E & F) when they presented to the clinic for their initial transitional care visit. They were given the opportunity to read and

review the participant recruitment letter and disclosure form, and ask questions. If assistance was needed with reading, the lead investigator read the letter and disclosure form to the potential participant.

The lead investigator/NP assigned a unique identification number to each participant packet to allow for confidential data collection. All of the documents contained within the participant packet were labeled with the designated participant identification number. The packet includes the demographics questionnaire, and the pre- and post-SCHFI surveys. The demographics and pre-SCHFI surveys were given to participants at their initial transitional care visit. The subsequent post-SCHFI survey was given to them to complete and return when they presented for their follow-up visit. The completed questionnaires and surveys were stored in a locked file cabinet in the lead investigator's office. The information obtained from data collection was stored in an electronic password protected file on the lead investigator's computer. The demographics questionnaire and SCHFI, version 6.2 tool were distributed to the patient by the lead investigator/ NP prior to the participant being "roomed." These surveys are self-reported surveys and therefore do not require an entity to officially administer them; however, they may be administered upon request. Upon completion, the surveys were turned into the lead investigator during the clinical encounter, and information was entered into the password protected SPSS file.

### **Data Analysis**

Demographic and SCHFI data was entered into a SPSS spreadsheet (version 24.0) by the lead investigator for data collection and analysis. Interpretation of survey results and calculation of scores was performed by the lead investigator using SPSS command formulas attained from

Riegel et al. (2009). For the SCHFI maintenance and confidence scores, at least half of the items must be answered to have accurate measurements of self-care. Furthermore, the self-care management component was scored only if the participant reported dyspnea or peripheral edema in the past month (Riegel et al., 2009). Participants were given the same SCHFI survey on their subsequent return (one to three weeks from initial encounter) to the transitional care clinic. Screening results coupled with demographic data may help identify potential barriers and/or factors contributing to self-care deficiencies leading to practice changes that may positively impact patient engagement.

### **Ethical Considerations**

The proposed quality improvement project was reviewed by the designated committee and submitted to the University of Arizona's Institution Review Board (IRB) for review and approval. The hospital affiliated with the clinic does not have an IRB; however, permission was obtained for this quality improvement project from the hospital (Appendix J).

Heart failure transitional care program patients were informed of the study both verbally and in written format. The participant recruitment form and disclosure letter (Appendices E & F) was provided to each potential participant. Completion and submission of the demographics questionnaire and SCHFI surveys implies consent. Participation is voluntary and participants were made aware that they are able to withdraw from the study at any time without penalty. There are no risks associated with project participation

Data were collected as described in Methodology. Data were de-identified, collected, and stored in a password protected, locked SPSS spreadsheet. Original completed demographics questionnaires and SCHFI surveys are kept in a locked file cabinet in the NP's office.

## **RESULTS**

### **Data Management**

Demographic information was collected on all participants who consented to be a part of this project inquiry (N=28) after receiving approval from the University of Arizona Institution Review Board (Appendix J). English and Spanish speaking participants received written demographic questionnaires and SCHFI surveys in their preferred language (English or Spanish). Responses from the demographic questionnaires and SCHFI surveys were entered into SPSS 24 for data analysis.

### **Sample Demographics**

A total of 28 participants completed demographics questionnaires and the SCHFI survey; however, participants' who submitted incomplete data on SCHFI surveys were removed from data analyses (N=13). Of the 13 participants whose data was removed, three participants reported not having had either shortness of breath or lower extremity edema as specified in Section B of the Self-Care Management section, and therefore, did not have self-care management scores calculated. Two of the participants did not complete and/or submit post SCHFI surveys, and eight of the participants skipped multiple questions causing the self-maintenance, self-management and/or self-confidence scores not to be calculated. The data analyses were then limited to 15 participants. Of these 15 participants, 53.3% were English speaking and 46.7% were Spanish speaking only. Forty-six percent of patients were 75 years or older, 26.7% were 65-74 years, 26.7% were 55-64 years, 6.7% were 45-54%, and 6.7% were 18-34 years. Thirty-three percent of participants were white, 60% were Hispanic, and 6.7% were black or African American. The majority of participants were male (80%). Thirteen percent of participants had no

formal education, 13.3% finished eighth grade, 13.3% completed some high school, 26.7% were high school graduates, and the remaining 33.3% had some level of higher education or vocational training. Sixty-six percent of participants traveled less than 5 miles to their appointment, 13.3% traveled ten miles, and 20% traveled more than 20 miles to their appointment. All of the participants traveled by car (100%). Less than half of participants (46.4%) were married. Six percent of participants were divorced, 20% separated and 6.7% were widowed. The majority of participants reported living with family or friends (67.9%) while 26.7% reported living alone, and 26.7% reported living with their spouse. Sixty percent of participants reported an annual income of less than \$10,000, 13.3% reported \$10,000-\$20,000, and 20% reported an annual income between \$20,000-40,000. All participants (100%) reported at least one co-morbidity. Forty-five percent of participants reported a new diagnosis of HF within six months while 27.3% reported at least 1-2 years since diagnosis, 9.1% reported 2-5 years since diagnosis, and 18.2% reported more than seven years since diagnosis. Table 1. provides a summary of the demographic characteristics of project participants.

TABLE 1. *Demographic Characteristics of Project Participants*

Characteristics	Frequency	%
<i>Age (years)</i>		
18-34	1	6.7
45-54	1	6.7
55-64	4	1.3
75 or older	2	46.7
<i>Ethnicity of Origin</i>		
White	5	33.3
Hispanic	9	60.0
Black or African American	1	6.7
<i>Gender</i>		
Male	12	80
Female	3	20

TABLE 1 - *Continued*

Characteristics	Frequency	%
<i>Highest Level of Education Completed</i>		
No schooling	2	13.3
8 <sup>th</sup> Grade	2	13.3
Some high school, no diploma	2	13.3
High school graduate, diploma	4	26.7
Some college	2	13.3
Trade/tech/vocational	1	6.7
Grad school	2	13.3
<i>Distance Travelled to Appointment (miles)</i>		
5	10	66.7
10	2	13.3
20 or more	3	20.0
<i>Method of Transportation</i>		
Car	15	100
<i>Marital Status</i>		
Single, never married	3	20
Married or domestic partnership	7	46.7
Widowed	1	6.7
Divorced	1	6.7
Separated	3	20
<i>Living Arrangements</i>		
With family	6	40.0
With spouse	4	26.7
With friends	1	6.7
Alone	4	26.7
<i>Household Income (annual)</i>		
Less than \$10,000	9	60
\$10,000-\$20,000	2	13.3
\$20,000-\$40,000	3	20
Missing	1	
<i>Other Health Conditions (CAD, HTN, DM or COPD)</i>		
Yes	15	100
No	0	
<i>Time Since HF Diagnosis</i>		
Less than 6 months	5	33.3
1-2 years	3	20
2-5 years	1	6.7
More than 7 years	2	13.3
Missing	4	

### SCHF I Surveys

Self-care maintenance, management and confidence were measured using the SCHFI survey. A total of 15 completed SCHFI surveys were received (English SCHFI N=8, Spanish SCHFI N=7). The SCHFI survey includes ten questions pertaining to self-care maintenance, and

six questions each addressing self-care management and confidence, for a total of 22 questions. Pre and post SCHFI scores were calculated based on participants' responses to the three subsets of the SCHFI survey (self-care maintenance, self-care management, and confidence). The possible score for each subset section was 100. A score of 70 or greater is associated with self-care adequacy; however, lower scores may still represent benefit (Riegel et al., 2009).

SPSS command codes were obtained from Riegel et al. (2009) for the English version. The command formulas varied slightly between English and Spanish versions as the Spanish version had a five-point Likert scale in lieu of the English version (four-point Likert scale). Instructions for the scoring of the Spanish SCHFI survey were not available through a literature search. Command formulas were reconfigured using simple algebra for the Spanish SCHFI scores.

Prior to calculating the self-care maintenance scores, question #8, "*Forget to take one of your medications,*" was recoded (reversely scored), using the following command, RECODE SCHFI8 (1=4) (2=3) (3=2) (4=1) for the English version, and RECODE SCHFI8 (1=5) (2=4) (3=3) (4=2) (5=1) for the Spanish version. The following SPSS command was used to calculate the maintenance score: COMPUTE SCHFI Maintenance=(SUM(SCHFI1,SCHFI2,SCHFI3,SCHFI4,SCHFI5,SCHFI6,SCHFI7,SCHFI8,SCHFI9,SCHFI10)-10)\*3.333, for the English SCHFI surveys. The SPSS command COMPUTE SCHFI Maintenance=(SUM(SCHFI1,SCHFI2,SCHFI3,SCHFI4,SCHFI5,SCHFI6,SCHFI7,SCHFI8,SCHFI9,SCHFI10)-10)\*2.5 was used for the Spanish SCHFI maintenance calculations. Scoring guidelines, provided by Riegel et al. (2009), advised to disregard scores for the management

section if the initial question in Section B, “*In the past month, have you had trouble breathing or ankle swelling?*,” was answered with a “*No*” or “*0*,” regardless if survey responses had been provided for subsequent management questions. The following command was utilized in SPSS to calculate management scores for English surveys with a “*Yes*” response,  $IF (BreathAnkl=1) SCHFIManagement=(SUM(SCHF111,SCHF112,SCHF113,SCHF114,SCHF115, SCHFI116)-4)*5$  (Riegel et al., 2009). The command,  $IF (BreathAnkl=1) SCHFIManagement=(SUM(SCHF111,SCHF112,SCHF113,SCHF114,SCHF115, SCHFI116)-4)*3.84$ , was utilized for calculation of management scores for Spanish surveys. The answer to this question had to be entered as “1” which reflected either “*Yes*” or “*Si*” in order for the self-management score to be calculated (Riegel et al., 2009).

To compute the English confidence score, the following command was used in SPSS, `COMPUTE`  
 $SCHFIConfidence=(SUM(SCHF117,SCHF118,SCHF119,SCHF120,SCHF121,SCHF122)-6)*5.56$ . For the Spanish confidence score, the command, `COMPUTE`  
 $SCHFIConfidence=(SUM(SCHF117,SCHF118,SCHF119,SCHF120,SCHF121,SCHF122)-6)*4.1666$  (Riegel et al., 2009). More than half of the questions in the confidence section had to be answered in order for the confidence score to be considered accurate (Riegel et al., 2009).

Once pre- and post-scores were calculated in all three sections (maintenance, management and confidence), the scores were compared using a paired t-test to determine the impact of the transitional care program on HF patients’ self-care maintenance, self-care management and self-confidence. The p value was set at <0.05 for statistical significance.

### Self-Care Maintenance

The pre- and post-mean self-care maintenance scores were 49.93 ( $SD=19.181$ ) and 59.53 ( $SD=13.627$ ), respectively (Table 2). The paired  $t$  test revealed a statistically significant difference ( $t=-3.505$ ,  $p=0.004$ ) between the SCHFI self-care maintenance scores from pre- to post-testing. This result suggests that participants scored higher on self-care maintenance after participating in the transitional care program. Only 20% of the participants attained scores associated with self-care adequacy (70 or higher) on both the pre- and post-SCHFI self-care maintenance section. Although there was improvement in the overall scores from pre- to post-testing, the average scores remained at a level of self-care inadequacy (score of less than 70).

TABLE 2. Mean, Standard Deviation, Score Range and Meaning of Pre and Post Maintenance Scores

	M ( <i>SD</i> )	N	Possible Range	Self-Care Adequacy
Pre-Maintenance Scores	49.93 ( <i>19.181</i> )	15	0-100	Not Adequate
Post-Maintenance Scores	59.53 ( <i>13.627</i> )	15	0-100	Not Adequate

### Self-Care Management

The pre- and post-mean SCHFI self-care management scores were 54.33 ( $SD=25.198$ ) and 58.27 ( $SD=21.671$ ) respectively (Table 3.). Although there was a small improvement in scores following the transitional care program, the improvement was not statistically significant ( $t=-.645$ ,  $p=0.529$ ). Twenty-six percent of pre-survey and 40% of post-survey self-care management scores were above the established self-care adequacy level ( $>70$ ). These results indicate that participants struggle with symptom recognition; furthermore, participation in the transitional care program did not make a statistically significant difference in their ability to recognize heart failure-related symptoms and perform self-care management at an adequate level.

TABLE 3. *Mean, Standard Deviation, Score Range and Meaning of Pre- and Post-Management Scores*

	M (SD)	N	Possible Range	Self-Care Adequacy
Pre-Management Scores	54.33 (25.198)	15	0-100	Not Adequate
Post-Management Scores	58.27 (21.671)	15	0-100	Not Adequate

### Self-Confidence

SCHFI Self-confidence scores improved from pre- to post-testing (mean pre SCHFI=68.73, *SD*=19.991; mean post SCHFI=78.80, *SD* 19.875); however, the difference was not determined to be statistically significant ( $t=-1.738$ ,  $p=.104$ ). Forty percent of pre- and 60% of post-confidence scores were above the established self-care adequacy level (>70). These results suggest that patients were fairly confident in their abilities to perform self-care; however further testing is needed to strengthen the statistical significance.

TABLE 4. *Mean, Standard Deviation, Score Range and Meaning of Pre- and Post-Confidence Scores*

	M (SD)	N	Possible Range	Self-Care Adequacy
Pre-Confidence Scores	68.73 (19.991)	15	0-100	Not Adequate
Post-Confidence Scores	78.80 (19.875)	15	0-100	Adequate

### DISCUSSION

This quality improvement project sought to gain a better understanding of the impact of a transitional care program on heart failure patients' ability to perform symptom recognition and self-care. Results from the project suggest that participating heart failure patients are not adequately able to perform self-care maintenance measures such as daily weights, monitoring for ankle edema, consuming a low salt diet, and compliance with their medication regimen; however, statistically significant improvement did occur in their self-care maintenance scores following the transitional care program. The participants also did not perform self-care

management at an adequate level; furthermore, the improvement after the transitional care program was not statistically significant. Heart failure patients often struggle with the integration and implementation of self-care (Dickson, Buck, & Riegel, 2011). When overwhelmed with multiple self-care instructions, their ability to perform certain skills may actually decrease. In addition, their confidence may also decline (Dickson et al., 2011). Further research is needed to determine the impact of the transitional care program on heart failure patients' symptom recognition and self-care as an enhanced understanding may lead to the implementation of innovative interventions that may help promote better health outcomes.

### **Limitations**

This project has several limitations. A purposive sampling method was utilized to focus on one specific population; therefore, the generalizability of findings is limited. Multiple participants' survey data (N=13) was eliminated from analyses due to missing information which resulted in a smaller sample size (N=15) that may not accurately reflect heart failure patients encountered at the transitional care clinic. The project was not powered to determine all significant relationships. The sample was made up primarily of Hispanic, elderly males; therefore, other populations were poorly represented. The English and Spanish SCHFI surveys had different Likert scales which presented challenges when calculating and comparing English and Spanish participants' scores.

### **Implications for Practice**

The findings from this quality improvement project are meaningful because a better understanding of the transitional care program impact on heart failure patients' symptom recognition and self-care was achieved. Research indicates that enhanced heart failure self-care

leads to better outcomes (Dickson et al., 2012); however, little was known about the impact of a transitional care program on heart failure patients' self-care prior to this project. Qualitative studies such as focus groups may be helpful in understanding additional challenges and barriers heart failure patients experience in regards to self-care.

### **CONCLUSION**

HF patients participating in a transitional care program demonstrated improvement in SCHFI scores on self-care maintenance, self-management and self-confidence; however, overall, the scores are not indicative of a consistent level of adequacy in self-care. Post-test SCHFI confidence levels were adequate which suggests participants felt comfortable making decisions related to heart failure management, but possibly lacked the ability to perform behaviors and skills needed to reach adequate levels of self-care maintenance and management. Further emphasis needs to be placed on identifying educational interventions and methods that may help improve HF patients' symptom recognition and self-management leading to enhanced self-care.

APPENDIX A:  
HEART FAILURE ZONE TOOL

## ZONES TO MANAGE HEART FAILURE

Discharge Weight: \_\_\_\_\_ Doctor's Name: \_\_\_\_\_

First weight at home: \_\_\_\_\_ Doctor's Phone: \_\_\_\_\_



### **GREEN ZONE**

#### **You have:**

- ♥ No shortness of breath
- ♥ No weight gain more than 3 pounds per day
- ♥ No swelling of feet, ankles, legs or stomach
- ♥ No chest pain

#### **What to do:**

- ♥ Keep up the good work!
- ♥ Take your medicine
- ♥ Eat a low salt diet
- ♥ Weigh yourself every day



### **YELLOW ZONE**

#### **You have:**

- ♥ Weight gain of 3 pounds in 1 day or 5 pounds in one week
- ♥ More shortness of breath
- ♥ More swelling in your feet, ankles, legs, or stomach
- ♥ Feeling more tired
- ♥ New or unusual coughing
- ♥ Dizziness
- ♥ Hard to breathe lying down – need to sleep sitting in chair

#### **What to do:**

- ♥ **Call your doctor or nurse**
- ♥ **Call Transitional Care Services (928)336-2165**



### **RED ZONE**

#### **You have:**

- ♥ Hard time breathing
- ♥ Struggling to breathe even at rest
- ♥ Chest pain or discomfort
- ♥ Feeling faint

#### **What to do:**

- ♥ **Call 911 or**
- ♥ **Get help, go to Emergency Room**

APPENDIX B:  
TRANSITIONAL CARE WEEKLY MONITORING PROGRAM

## TRANSITIONAL CARE WEEKLY MONITORING PROGRAM

Patient contacted as part of the transitional weekly monitoring program:

Inquired about the following heart failure symptoms:

- Fatigue Y/N
- New onset/ unusual cough Y/N
- Leg swelling Y/N
- Abdominal distension Y/N
- Change in weight (3 lb or more weight gain in 1 day/ 5 lb weight gain in 1 week) Y/N
- Using more pillows to sleep/ sleeping upright in a recliner Y/N
- Shortness of breath Y/N
- Frequent urination at night Y/N
- New onset confusion Y/N
- Dizziness Y/N

Patient reports monitoring weight, blood pressure and heart rate on daily basis Y/N

Patient complying with low fat diet Y/N

Patient needs medication refills Y/N

Patient reports compliance with medication regime Y/N

Patient has follow-up appointments scheduled with \* and has next transitional care FU appointment on \*

Reviewed symptoms of heart failure exacerbation with patient Y/N

Reinforced the importance of contacting PCP, transitional care clinic or cardiology with initial presentation of symptoms of a heart failure exacerbation.

APPENDIX C:

SELF-CARE HEART FAILURE INDEX (SCHFI) SURVEY: ENGLISH

 **SELF-CARE HEART FAILURE INDEX (SCHFI)**

*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>Sometimes</b>	<b>Frequently</b>	<b>Always or daily</b>
1. Weigh yourself?	1	2	3	4
2. Check your ankles for swelling?	1	2	3	4
3. Try to avoid getting sick (e.g., flu shot, avoid ill people)?	1	2	3	4
4. Do some physical activity?	1	2	3	4
5. Keep doctor or nurse appointments?	1	2	3	4
6. Eat a low salt diet?	1	2	3	4
7. Exercise for 30 minutes?	1	2	3	4
8. Forget to take one of your medicines?	1	2	3	4
9. Ask for low salt items when eating out or visiting others?	1	2	3	4
10. Use a system (pill box, reminders) to help you remember your medicines?	1	2	3	4

**SECTION 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.*

0) No

1) Yes

11. If you had trouble breathing or ankle swelling in the past month...

(circle **one** number)

	<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

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>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
13. Reduce your fluid intake	1	2	3	4
14. Take an extra water pill	1	2	3	4
15. Call your doctor or nurse for guidance	1	2	3	4

16. Think of a remedy you tried the last time you had trouble breathing or ankle swelling.

(circle **one** number)

	<b>I did not try anything</b>	<b>Not Sure</b>	<b>Somewhat Sure</b>	<b>Sure</b>	<b>Very Sure</b>
How <u>sure</u> were you that the remedy helped or did not help?	0	1	2	3	4

### SECTION C:

In general, how confident are you that you can:

	<b>Not Confident</b>	<b>Somewhat Confident</b>	<b>Very Confident</b>	<b>Extremely Confident</b>
17. Keep yourself <u>free of heart failure symptoms</u> ?	1	2	3	4
18. <u>Follow the treatment advice</u> you have been given?	1	2	3	4
19. <u>Evaluate the importance</u> of your symptoms?	1	2	3	4
20. <u>Recognize changes</u> in your health if they occur?	1	2	3	4
21. <u>Do something</u> that will relieve your symptoms?	1	2	3	4
22. <u>Evaluate</u> how well a remedy works?	1	2	3	4

APPENDIX D:  
SELF-CARE HEART FAILURE INDEX (SCHFI) SURVEY: SPANISH

## SELF-CARE HEART FAILURE INDEX (SCHFI)

*Todas las respuestas son confidenciales.*

**Piense sobre cómo se ha sentido usted en el mes pasado o desde nuestra última charla mientras contesta a estas preguntas.**

### SECCIÓN A:

El listado siguiente son instrucciones comunes que se dan a las personas con insuficiencia cardíaca. ¿Con qué rutina usted hace lo siguiente?

	Nunca o rara vez	2	3	4	Siempre o diariamente
1. ¿Pesarse usted mismo?	1	2	3	4	5
2. ¿Comprobar si los tobillos están hinchados?	1	2	3	4	5
3. ¿Tratar de evitar la enfermedad (ej. vacunarse contra la gripe, o evitar a las personas enfermas)?	1	2	3	4	5
4. ¿Hacer algo de actividad física? (ej. limpiar el polvo, andar, jardinería, tareas domésticas...)	1	2	3	4	5
5. ¿Acudir a las visitas del médico o de la enfermera/o?	1	2	3	4	5
6. ¿Comer una dieta baja en sal?	1	2	3	4	5
7. ¿Hacer 30 minutos de ejercicio físico?	1	2	3	4	5
8. ¿Olvidar tomar uno de sus medicamentos?	1	2	3	4	5
9. Pedir alimentos bajos en sal cuando sale a comer fuera o visita a otras personas?	1	2	3	4	5
10. ¿Usa un sistema (caja para pastillas, recordatorios) para ayudarle a recordar su medicación?	1	2	3	4	5

### SECCIÓN B:

*Muchos pacientes tiene síntomas debido a su insuficiencia cardíaca. Problemas respiratorios y los tobillos hinchados son síntomas comunes de la insuficiencia cardíaca.*

*En el pasado mes, ¿ha tenido problemas respiratorios o los tobillos hinchados? Marque una opción*

0) No

1) Si

11. Si usted ha tenido problemas respiratorios o los tobillos hinchados en el mes pasado...  
(marque **un** número)

	No he tenido eso	No he reconocido eso	No rápidamente			Muy rápidamente	
¿Cómo de rápido lo reconoció como un síntoma de insuficiencia cardíaca?	N/A	0	1	2	3	4	5

El listado siguiente son medidas que la gente con insuficiencia cardíaca utiliza. Si usted tiene problemas respiratorios o los tobillos hinchados, ¿qué probabilidad hay de que usted intente una de estas medidas?

(marque **un** número por cada medida)

	No es probable			Muy probable	
12. Disminuir la sal en su dieta	1	2	3	4	5
13. Disminuir la ingesta de líquidos	1	2	3	4	5
14. Toma un pastilla diurética extra	1	2	3	4	5
15. Llamar a su médico o enfermera/o para pedir ayuda	1	2	3	4	5

16. Piense en una medida que trató de hacer la última vez que tuvo problemas respiratorios o los tobillos hinchados.

(marque **un** número)

	No intenté nada	No estaba seguro			Muy seguro	
¿Cómo de <u>seguro/a</u> estaba que la acción ayudaba o no ayudaba?	0	1	2	3	4	5

### SECCIÓN C:

En general, cuánta confianza tiene respeto a que usted puede:

	Sin confianza				Extremadamente confiado
17. ¿Mantenerse <u>sin síntomas de insuficiencia cardíaca</u> ?	1	2	3	4	5
18. ¿Seguir las <u>recomendaciones de tratamiento</u> que le han dado?	1	2	3	4	5
19. ¿Evaluar la <u>importancia</u> de sus síntomas?	1	2	3	4	5
20. ¿Reconocer <u>cambios</u> en su salud si éstos ocurren?	1	2	3	4	5
21. ¿Hacer <u>algo</u> que alivie sus síntomas?	1	2	3	4	5
22. ¿Evaluar cómo de bien funciona un remedio?	1	2	3	4	5

APPENDIX E:  
PARTICIPANT RECRUITMENT SCRIPT AND CONSENT FORM: ENGLISH

## **Heart Failure Transitional Care Project The University of Arizona**

You are invited to participate in a Heart Failure Transitional Care Project. The purpose of this quality improvement project is to gain a better understanding of the impact of a transitional care program on heart failure symptom recognition and self-management.

### **You are eligible to participate in this project if:**

1. You are at least 18 years of age
2. You are able to speak and read English or Spanish fluently
3. You have a diagnosis of heart failure

### **As a project participant you will be asked to:**

1. Complete a demographics questionnaire
2. Complete a brief heart failure questionnaire that will take about 10 minutes upon check-in for your initial transitional care appointment
3. Complete the same heart failure questionnaire once you have completed the transitional care program (usually 1-4 weeks from your initial visit - you will turn it in at your last visit)

Your participation in this project is entirely voluntary. You are able to withdraw from this project at any time without adverse effects. Personal information collected as well as your questionnaire scores will remain confidential. Measures will be taken to protect your confidentiality. If you decide not to participate in this project, there will be no impact on the quality of care you receive. Although there is no compensation for your participation, a summary of the results will be available by your request. There is no cost for participating in this project. There are no risks associated with participating in this project.

The results of this project will give us a better understanding of the impact of this transitional care program on heart failure patient's symptom recognition (i.e. recognition of weight gain, cough, shortness of breath, leg swelling, etc.) and adherence to self-management (low salt diet, fluid restriction, monitoring of weight, etc.) The results may lead to program improvement measures.

An Institutional Review Board, responsible for human subjects' research at the University of Arizona reviewed this quality improvement project and found it acceptable, according to federal state and regulations and University policies designed to protect the rights and welfare of project participants. For questions about your rights as a project participant or to discuss other issues or complaints related to the project with someone who is not part of the project team, you can contact the Human Subjects Protection Program at 520-626- 6721 or online at <http://rgw.arizona.edu/compliance/human-subjects-protection-program>

If you have any questions about the project or your participation, you can email [carolynmhull@email.arizona.edu](mailto:carolynmhull@email.arizona.edu). By completing and submitting the surveys you are providing your informed consent.

**Thank you for your interest and participation in the Heart Failure Transitional Care Project.**

APPENDIX F:  
PARTICIPANT RECRUITMENT SCRIPT AND CONSENT FORM: SPANISH

Participante Reclutamiento Guión y Carta de Estudio -Spanish versión  
**Heart Failure Transitional Care Project**  
**The University of Arizona**

Les invitamos a participar en un proyecto de cuidado transitorio de la insuficiencia cardíaca. El propósito de este proyecto es obtener una mejor comprensión del impacto de un programa de cuidado transitorio en reconocimiento de síntomas de insuficiencia cardíaca y la autogestión.

**Usted es elegible para participar en este proyecto si:**

1. Usted es por lo menos 18 años de edad
2. Son capaces de hablar y leer con fluidez Inglés o español
3. Usted tiene un diagnóstico de la insuficiencia cardíaca

**Como participante del estudio se le pedirá que:**

1. Completar un cuestionario de datos demográficos
2. Completar un cuestionario breve de insuficiencia cardíaca que llevará unos 5-10 minutos a la llegada a su cita de atención transitoria inicial
3. Completan el mismo cuestionario de insuficiencia cardíaca y girar en su visita de seguimiento de transición (generalmente de 1 a 4 semanas desde su última visita).

Su participación en este proyecto es totalmente voluntario. Son capaces de retirarse de este proyecto en cualquier momento sin efectos adversos. Información personal recopilada, así como sus resultados cuestionario permanecerá confidenciales. Si decide no participar en este proyecto, no habrá ningún impacto en la calidad de la atención que reciba. Aunque no existe ninguna compensación por su participación, un resumen de los resultados estarán disponible por su petición. No hay ningún costo por su participación en este proyecto. No existen riesgos asociados con participar en este proyecto.

Los resultados de este proyecto nos dará una mejor comprensión del impacto de este programa de cuidado transitorio en reconocimiento del síntoma (es decir, el reconocimiento de aumento de peso, tos, dificultad para respirar, hinchazón en las piernas, etc.) y la adherencia a autogestión del paciente de la insuficiencia cardíaca (dieta baja en sal, restricción de líquidos, control de peso, etc.) Los resultados pueden conducir a medidas de mejora del programa.

Una Junta de revisión institucional, responsable de investigación de sujetos humanos en la Universidad de Arizona revisó este proyecto de investigación y encontró que era aceptable, según estado y regulaciones federales y políticas de la Universidad diseñadas para proteger los derechos y el bienestar de los participantes en la investigación. Para preguntas acerca de sus derechos como participante en la investigación del proyecto o para discutir otras cuestiones relacionadas con el estudio o quejas con alguien que no es parte del equipo de investigación, puede comunicarse con el programa de protección de sujetos humanos en 520-626-6721 o en línea en <http://rgw.arizona.edu/compliance/human-subjects-protection-program>

Si usted tiene alguna pregunta sobre el estudio o su participación, puede correo electrónico carolynmhull@email.arizona.edu. Al completar y enviar esta encuesta, va a proporcionar su consentimiento informado.

**Gracias por su interés y participación en el Proyecto del cuidado de transición de Insuficiencia Cardíaca.**

APPENDIX G:  
DEMOGRAPHICS QUESTIONNAIRE: ENGLISH

ID #: \_\_\_\_\_

### Demographics Questionnaire

1. What is your age?
  - 18-34 years old
  - 35-44 years old
  - 45-54 years old
  - 55-64 years old
  - 65-74 years old
  - 75 years or older
  
2. What is your ethnicity of origin?
  - White
  - Hispanic or Latino
  - Black or African American
  - Native American or American Indian
  - Asian / Pacific Islander
  - Other
  
3. What is your gender?
  - Male
  - Female
  
4. What is the highest level of education you completed?
  - No schooling completed
  - 8th grade
  - Some high school, no diploma
  - High school graduate, diploma or the equivalent (for example: GED)
  - Some college credit, no degree
  - Trade/technical/vocational training
  - Associate degree
  - Bachelor's degree
  - Graduate school
  
5. How far did you travel for this appointment (miles)?
  - 5 miles
  - 10 miles
  - 20 miles
  - More than 20 miles

6. Method of transportation to today's visit?
  - Bike
  - Walking
  - Car
  - Taxi
  - Bus
  
7. What is your marital status?
  - Single, never married
  - Married or domestic partnership
  - Widowed
  - Divorced
  - Separated
  
8. Living arrangements
  - With family
  - With spouse
  - With friends
  - Alone
  
9. What is your total household income?
  - Less than \$10000/ year
  - \$10000-\$20000/year
  - \$20000-40000/year
  - \$40000-\$60000/year
  - More than \$60000/year
  
10. What other health conditions do you have?
  - Coronary artery disease
  - Diabetes mellitus
  - Hypertension/ high blood pressure
  - COPD
  - Chronic kidney disease
  
11. Approximate time since heart failure diagnosis?
  - Less than 6 months
  - 1-2 years
  - 2-5 years
  - 5-7 years
  - More than 7 years

APPENDIX H:  
DEMOGRAPHICS QUESTIONNAIRE: SPANISH

ID #: \_\_\_\_\_

### Cuestionario de Datos Demográficos

1. ¿Cuál es su edad?
  - 18-34 años
  - 35-44 años
  - 45-54 años de edad
  - 55-64 años de edad
  - 65-74 años de edad
  - 75 años o más
  
2. ¿Cuál es su etnia de origen?
  - Blanco
  - Hispano o Latino
  - Negro o afroamericano
  - Americanos nativos o indios americanos
  - Isleño asiático / pacífico
  - Otros
  
3. ¿Cuál es tu género?
  - Hombre
  - Mujer
  
4. ¿Cuál es el nivel de educación completado?
  - No escolarización completado
  - 8° grado
  - Algo de preparatoria, sin diploma
  - Alta escuela graduado, diploma o equivalente (por ejemplo: GED)
  - Algunos créditos universitarios, sin título
  - Formación comercial/técnico/profesional
  - Grado asociado
  - Título de licenciatura
  - Escuela de postgrado
  
5. ¿Cuál es su código postal? \_\_\_\_\_
  
6. ¿Hasta dónde viajaste para esta cita (millas)?
  - 5 millas
  - 10 millas
  - 20 millas
  - mas de 20 millas

7. ¿ método de transporte para la visita de hoy?
  - La bicicleta
  - Caminar
  - Coche
  - Taxi
  - Bus
  
8. ¿Cuál es su estado civil?
  - Solo, nunca casado
  - Asociación casado o doméstico
  - Viudo / a
  - Divorciado
  - Separados
  
9. Vivir:
  - Con la familia
  - Con su cónyuge
  - Con amigos
  - Solo
  
10. ¿Cuál es su ingreso total?
  - Menos de \$10000 por año
  - \$10000 a\$ 20000/año
  - \$20000-40000 al año
  - \$40000 a\$ 60000/año
  - Más de \$60000 por año
  
11. ¿Qué otras condiciones de salud tienen?
  - Enfermedad arterial coronaria
  - Diabetes mellitus
  - Hipertensión / presión arterial alta
  - EPOC
  - Enfermedad renal crónica
  
12. ¿tiempo desde el diagnóstico de insuficiencia cardíaca aproximado?
  - Menos de 6 meses
  - 1-2 años • 2-5 años
  - 5-7 años
  - Más de 7 años

APPENDIX I:

THE UNIVERSITY OF ARIZONA INTERNAL REVIEW BOARD APPROVAL – HUMAN  
SUBJECTS REVIEW NOT REQUIRED



**Research**  
Office for Research & Discovery

Human Subjects  
Protection Program

1618 E. Helen St.  
P.O.Box 245137  
Tucson, AZ 85724-5137  
Tel: (520) 626-6721  
<http://rgw.arizona.edu/compliance/home>

<b>Date:</b>	August 30, 2016
<b>Principal Investigator:</b>	Carolyn Muller Hull
<b>Protocol Number:</b>	1608765014
<b>Protocol Title:</b>	ASSESSING THE IMPACT OF A TRANSITIONAL CARE PROGRAM ON SYMPTOM RECOGNITION & SELF-CARE IN HEART FAILURE PATIENTS
<b>Determination:</b>	Human Subjects Review not Required

The project listed above does not require oversight by the University of Arizona because the project does not meet the definition of 'research' and/or 'human subject'.

- **Not Research as defined by 45 CFR 46.102(d):** As presented, the activities described above do not meet the definition of research as cited in the regulations issued by the U.S. Department of Health and Human Services which state that "research means a systematic investigation, including research development, testing and evaluation, designed to contribute to generalizable knowledge".
- **Not Human Subjects Research as defined by 45 CFR 46.102(f):** As presented, the activities described above do not meet the definition of research involving human subjects as cited in the regulations issued by the U.S. Department of Health and Human Services which state that "human subject means a living individual about whom an investigator (whether professional or student) conducting research obtains data through intervention *or* interaction with the individual, or identifiable private information".

Note: Modifications to projects not requiring human subjects review that change the nature of the project should be submitted to the Human Subjects Protection Program (HSPP) for a new determination (e.g. addition of research with children, specimen collection, participant observation, prospective collection of data when the study was previously retrospective in nature, and broadening the scope or nature of the research question). Please contact the HSPP to consult on whether the proposed changes need further review.

The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).

APPENDIX J:  
PERMISSION LETTER FROM SITE TO PROCEED WITH PROJECT



## YUMA REGIONAL MEDICAL CENTER

April 28, 2016

University of Arizona Institutional Review Board  
c/o Office of Human Subjects  
1618 E Helen St  
Tucson, AZ 85721

To Whom It May Concern:

Please accept this letter of support for the project inquiry, "Assessing the Impact of a Transitional Care Program on Symptom Recognition & Self-Care in Heart Failure Patients," to be conducted by Ms. Carolyn Hull, UA-DNP Graduate Student. Yuma Regional Medical Center is granting this letter of support in order for Ms. Hull to submit her project to the University of Arizona IRB so that her project may be considered for conduction at Yuma Regional Medical Center's Transitional Care Services ambulatory clinic. Once the University of Arizona IRB has deemed the project exempt or non-exempt, Ms. Hull will provide the IRB letter to Yuma Regional Medical Center, and we will submit the project to our IRB for approval if necessary.

Yuma Regional Medical Center acknowledges the following project procedure:

Ms. Hull will recruit patients by providing information about the project inquiry during their initial transitional care clinic encounter. If interested, patients will complete the Self-Care Heart Failure Index (SCHFI) survey and demographics questionnaire prior to their initial visit. The SCHFI survey will be completed again by participating patients prior to their transitional care discharge date. Her goal is to include up to 30 patients and to complete the project inquiry within a three month time frame (with an anticipated completion date of October, 2016).

Ms. Hull has agreed to provide to Yuma Regional Medical Center's Institutional Research Department a copy of the University of Arizona IRB-approved, stamped consent document before she recruits participants in the clinic, and she will also provide a copy of any aggregate results.

Please let me know if you have any questions or need additional information.

Sincerely,

Ricci Sanchez, MBA  
Vice President of Clinical Service Lines and Ambulatory Care  
Yuma Regional Medical Center  
2400 S. Avenue A  
Yuma, AZ 85364  
(928) 336-7015  
[risanchez@yumaregional.org](mailto:risanchez@yumaregional.org)

**YOUR HEALTH | YOUR HOSPITAL**

2400 S. Avenue A | Yuma, AZ 85364 | 928 344-2000

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