AN ABSTRACT OF THE DISSERTATION OF

Katherine Anthony for the degree of Doctor of Philosophy in Public Health presented on November 10, 2016.

Title: Perceived Usefulness of Remote Health Monitoring among Healthcare Providers, Mexican-origin and non-Hispanic White Heart Failure Patients and Informal Caregivers

Abstract approved:

Carolyn A. Mendez-Luck

Few remote health monitoring (RHM) studies have included Mexican-origin Latinos, and even fewer have explored RHM acceptance and utility, reasons for RHM uptake success or failure, or how cultural values influence RHM use among this population. The primary purpose of this study was to determine the remote health monitoring (RHM) needs and goals of health care providers, older adult heart failure (HF) patients, and their informal caregivers with a focus on Mexican-origin Latino and non-Hispanic white patients and caregivers. Qualitative semi-structured interviews were used to determine the remote health monitoring needs and goals of participants. Content and thematic analysis of interview transcripts revealed that perceptions of RHM were influenced by attitude towards health management and, among caregivers, RHM emerged as a potential partner in care that could ease caregiver concerns. The findings from this study can be used to inform the development of appropriate remote health monitoring systems and interventions for both Mexican-origin and non-Hispanic white heart failure patients and their

caregivers to reduce both heart failure patient hospital readmissions and caregiver burden.

Perceived Usefulness of Remote Health Monitoring Among Healthcare Providers, Mexican-origin and non-Hispanic White Heart Failure Patients and Informal Caregivers

by
Katherine Anthony

A DISSERTATION

submitted to

Oregon State University

in partial fulfillment of
the requirements for the
degree of

Doctor of Philosophy

Presented November 10, 2016
Commencement June 2017

Doctor of Philosophy dissertation of Katherine Anthony presented on November 10, 2016

APPROVED:

Major Professor, representing Public Health

Co-Director of the School of Social and Behavioral Health Sciences

Dean of the Graduate School

I understand that my dissertation will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my dissertation to any reader upon request.

Katherine Anthony, Author

ACKNOWLEDGEMENTS

The author expresses sincere appreciation to her family, friends, and committee members for their support and encouragement during the writing of this dissertation. The author would also like to acknowledge the generous funders of this research: The Oregon State University Center for Healthy Aging Research, The National Science Foundation [Grant No. DGE 0965820], and the Intel Corporation.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

CHAPTER 1 INTRODUCTION

1.1 Overview of Context

The most recent American Heart Association (AHA) Heart Disease and Stroke Statistical Update estimates that 5.7 million Americans over the age of 20 have heart failure (HF) and projects that the prevalence of HF will increase 46% by 2030, resulting in over 8 million HF patients in the United States (Mozaffarian et al., 2015). HF is the leading principal diagnosis among Medicare beneficiaries and has been a major public health problem for older adults in the United States for decades (Brown, Haldeman, Croft, Giles, Mensah, 2004). HF incidence among older adults aged 65+ is currently 10 per 1,000 and the 1-year mortality rate is 29.6%, (Mozaffarian et al., 2015). At age 80, the prevalence of HF jumps to 80% (Hunt et al., 2009). Among older adults, prevalence of HF is growing faster than any other cardiovascular disease (Heidenreich et al., 2013). HF management outside of the hospital can be complex; nearly 25% of Medicare patients are readmitted to the hospital within 30 days and two thirds of readmissions are caused by potentially preventable factors (Desai, 2012). These readmission rates are particularly high among Latino older adults whose odds of having preventable post discharge complications are about 40% higher than those of non-Latino whites (Durstenfeld, Park, Katz, & Blecker, 2015). Reducing preventable Medicare HF patient hospital readmissions is a public health priority in the United States (Affordable Care Act, 2010).

The cause of HF among older adults, age 65+, is complex and includes physiological and behavioral risk factors (Chaudhry et al., 2013; Goldberg, 2010; Willacy, 2012; National Heart, Blood, and Lung Institute, 2014). The most recently published clinical guidelines from the American College of Physicians (ACP), American College of Cardiology Foundations, and the

AHA, for the treatment of HF suggest that for most older adults, a complex multipronged approach consisting of medications, dietary restrictions, regular exercise and weight management, implantation of assistive devices, and cardiac transplantation may all be necessary to control the disease (Goldberg, 2010; Yancy et al., 2013).

Improper HF self-care and disease management by patients is often responsible for rehospitalization within 30 days of original treatment, however hospitals take on fiscal burden in the form of financial penalties when patients are readmitted (Desai, 2012). The total direct cost of HF is currently estimated at $30.7 billion and, if current hospitalization trends increase at projected rates, this estimate will grow to $69.8 billion by 2030, with most of the increases in cost coming from adults 65+ years of age (Heidenreich et al., 2013). Given the high costs associated with HF hospitalizations and the financial penalties associated with high rates of 30 day readmissions, care providers have an incentive to improve outpatient HF care to reduce readmissions.

Recent technological advances have made it possible to include home-based health data collection, and communication technology in outpatient HF care protocols for older adults (Gaikwad & Warren, 2009). For example, weight monitoring, which is a usual part of HF care at home, can now be done on digital scales that are connected to wireless monitors that can transfer daily patient weight to remote patient monitoring data centers (Agboola, Jethwani, Khateeb, Moore, & Kvedar, 2015). Additionally, according to a recent American Association of Retired Persons (AARP) survey, seven in ten older adults saw benefit in using personal health monitoring devices, and 72% of participants indicated they would be willing to monitor their health at home to avoid clinic and hospital visits (AARP, 2011). However, this study also indicated that while participants were willing to participate in remote health monitoring (RHM), most (90%) were not actively using any RHM devices.

Hispanic older adults are even less likely to take advantage of technological advances related to health care in the home due to several factors (Ginossar & Nelson, 2010). Hispanic older adults are known to rely less on formal healthcare supports and more on informal, family based, care (Gallant, Spitze, & Grove, 2010; Shi & Singh, 2014). Among Mexican-origin Latinos, the largest subgroup of U.S. Latinos (64%) (Gonzalez-Barrera & Lopez, 2013), informal elder care is frequently assumed by a female family member of the older adult (Jolicoeur & Madden, 2002). Among Mexican-origin older adults that have informal caregivers, the caregivers are not always present when outpatient care instructions are given, yet they are responsible for the bulk of HF failure management among Mexican-origin older adults. Lack of including caregivers in outpatient care instruction appointments may have an impact on the later adoption of RHM, since family based informal care plays a large role in adherence to instructions provided by physicians and clinicians (Gallant, Spitze, & Grove, 2010).

Language barriers are another factor impacting computer usage and RHM among Mexican-origin adults (Ono & Zavodny, 2008). Most programs are provided in English although 66% of foreign-born Latinos only speak Spanish (Krogstad, Stepler, & Lopez, 2015). This has contributed to overall lower computer usage among Latino older adults. Recent studies show that younger, U.S. born Latinos are accessing and using technology at higher rates, however, according to a 2013 Pew Hispanic Center report on Latino technology adoption only 33% of all

Latinos age 65 and older are using computers (Lopez, Gonzalez-Barrera, & Patten, 2013) creating a situation in which traditional RHM approaches may be more difficult to implement. There is also a critical need to understand minority caregiver perspectives in regards to remote health monitoting (RHM) of HF so that RHM technologies can assist in lowering caregiver burden (Adler & Mehtra, 2014).

1.2 Research Significance and Implications

Remote health monitoring (RHM) among older adult heart failure (HF) patients may result in fewer hospital readmissions and better quality of life for patients (Black et al., 2014; Mabote, Wong, & Cleland, 2014; Madigan et al., 2013; Suh et al., 2011). RHM may also reduce physical caregiver burden due to its ability to assist in medical management of a complex health condition in the home. Additionally, RHM may reduce emotional burden by providing increased peace of mind to caregivers (Adler & Mehta, 2014). Reducing caregiver burden is important because burden experienced by informal caregivers is known to cause adverse psychological and physical health outcomes (Pinquart & Sorensen, 2003). However, despite the potential benefits of RHM, little is known regarding the perceived benefits and utility of RHM among informal caregivers and even less is known about these factors among Mexican-origin older adults and their caregivers.

1.3 Research Gap

Several remote health monitoring (RHM) technology studies have included Mexican-origin Latino participants (Copeland, Berg, Johnson, & Bauer, 2010; Czaja, Lee, Arana, Nair, & Sharit, 2014; Leeman-Castillo, Beaty, Raghunath, Steiner, & Bull, 2010; Price et al., 2013; Riegel, Carlson, Glaser, & Romero, 2006) but few have explored RHM acceptance and utility, reasons for RHM uptake success or failure, or how cultural values influence RHM use among this population.

1.4 Study Purpose

The primary purpose of this study is to determine the remote health monitoring (RHM) needs and goals of health care providers, older adult heart failure (HF) patients, and their informal caregivers. This study aims to identify the roles that culture, technological literacy, and environment play in RHM beliefs. The findings from this study will help inform the development of appropriate RHM systems and interventions for both Mexican-origin and non-Hispanic white HF patients and their caregivers to reduce both HF patient hospital readmissions and caregiver burden.

CHAPTER 2 LITERATURE REVIEW

2.1 Prevalence and Impact of Heart Failure

Heart failure (HF) imposes one of the highest disease burdens of any chronic conditions in the United States (Chen, Normand, Wang, & Krumholz, 2011). Risk of developing HF increases with advancing age (Ho, Pinsky, Kannel, & Levy, 1993), and it ranks as the most frequent cause of hospitalization and rehospitalization among Americans over the age of 65 (Hines, Barrett, Jiang & Steiner, 2014). The American Heart Association (AHA) estimates that 5.7 million Americans over the age of 20 have HF (Mozaffarian et al., 2015). HF incidence is slightly higher among U.S. adult males with annual rates of new HF events per 1000 population at 15.2 for those 65 to 74 years of age, 31.7 for those 75 to 84 years of age, and 65.2 for those ≥85 years of age. For white women in the same age groups, the rates are 8.2, 19.8, and 45.6, respectively (Mozaffarian et al., 2015). Racial and ethnic differences also exist for HF incidence. African Americans have the highest risk of developing HF, followed by Hispanic, white, and Chinese Americans. Higher risk among African Americans and Hispanics reflect differences in socioeconomic status and prevalence of diabetes mellitus and hypertension (Mozaffarian et al., 2015).

Literature regarding the prevalence of HF among U.S. Latinos and non-Hispanic whites indicates that when compared with non-Hispanic whites, Latinos with HF are more likely to be younger, underinsured, and to have higher rates of diabetes, dyslipidemia, metabolic syndrome, poorly controlled hypertension, and kidney disease (Alexander, Grumbach, Remy, Rowell, & Massie, 1999; Minutello, Chou, Hong, & Wong, 2006; Rosamond, Flegal, & Friday, 2008; Vivo, Krim, Cevik, & Witteles, 2009; Yeo, Li, & Amsterdam, 2007). In the past, Hispanics were found to have lower all-cause and cardiovascular mortality rates despite having higher rates of obesity and lower socio-economic status (SES) (Swenson et al., 2002). This previous research supported the “Hispanic Paradox,” where despite having lower SES, Hispanic health outcomes were similar to those of NHWs (Markides & Coriel, 1986). However, more recent findings show that Mexican-Americans are at greater risk of all-cause and cardiovascular mortality than non-Hispanic whites (Hunt et al., 2003). Hispanics have also been found to have a higher prevalence of abnormal left ventricle ejection fraction than non-Hispanic whites, which contributes to worse prognosis in HF (Minutello, Chou, Hong, & Wong, 2006; Vivo, Krim, Cevik, & Witteles, 2009; Yeo, Li, & Amsterdam, 2007). These conditions amplify the risk of HF for Latinos in the U.S. (Vivo, Krim, Cevik, & Witteles, 2009).

HF is associated with an increased risk of negative health outcomes including depression, myocardial infarction, pulmonary complications, lung infections, renal complications, and death (Maile, Engoren, Tremper, Jewell, & Kheterpal, 2014; Sherwood et al., 2011). In the U.S., nearly 300,000 deaths each year are attributed to HF, with 80% of those deaths occurring among adults aged 65 and over (Bui, Fonarow, & Horwich, 2011). Data from fee-for service Medicare beneficiaries indicates that inpatient hospital mortality from HF among fee-for-service Medicare recipients has seen a decline from 8.5% to 4.3% between 1993 and 2006, however approximately 1 in 4 HF patients is readmitted to the hospital within 30 days of discharge (Bueno et al., 2010; Joynt & Jha, 2011); this suggests tremendous opportunity for improvement.

HF is also one of the most resource-intensive conditions with costs in the United States estimated at $30.7 billion (Heidenreich et al., 2013). Informal care provision is not currently included in

HF costs estimates. A 2014 Centers for Disease Control and Prevention (CDC) study that utilized data from the 2010 Health and Retirement Survey investigated the costs of informal HF caregiving and found that the hours of unpaid informal care provided had a value of $3 billion (Joo, Fang, Losby, & Wang, 2014), indicating that current HF cost estimates are currently lower than the actual costs if informal caregiving was included.

2.2 Causes of Heart Failure

Understanding the causes of heart failure (HF) can help us identify areas of intervention to prevent HF from occurring and in management of HF in those with a current diagnosis. HF is caused by diseases that damage the heart such as coronary heart disease, high blood pressure/hypertension, type 2 diabetes mellitus, cariodtoxic substance use (drugs and alcohol), hyperlipidemia, tachycardia, and thyroid disorders (Goldberg, 2010; National Heart, Lung, and Blood Institute, 2014; Yancy et al., 2013). These conditions and the behaviors that contribute to them are normally treated to decrease the risk for HF.

HF is considered a progressive disorder that has 4 stages (A-D) on a clinical continuum (American Heart Association, 2015b; Goldberg & Jessup, 2006; Yancy et al., 2013). When a person presents with a disease that puts them at risk for HF, but they do not show any symptoms of impaired left ventricular function, they are placed in stage A in the clinical continuum (Yancy et al., 2013). The American College of Physicians, the American College of Cardiology Foundations, and the American Heart Association guidelines for treating HF strongly encourage that patients with risk factors for HF are aggressively treated to prevent future cardiovascular complications and progression to the later stages of HF development (Goldberg, 2010; Yancy et al., 2013). Coronary heart disease (CHD) is a major risk factor for HF and should be treated comprehensively with cholesterol-lowering drugs, aspirin, ACE inhibitors, and β-blockers to reduce the risk of future cardiovascular complications (Goldberg, 2010; Yancy et al., 2013). Untreated CHD causes a build up of plaque on the inside of coronary arteries which leads to a reduction in blood flow to heart muscles (National Heart, Lung, and Blood Institute, 2014). Hypertension, another risk factor for HF, is present in 75% of those presenting with HF and it is recommended that hypertensive patients follow treatment plans that call for lowering of systolic or diastolic blood pressure to reduce mortality and risk for HF (Goldberg, 2010; Yancy et al., 2013). Hypertension occurs when blood pressure, the force of the blood pushing against the walls to the arteries, stays above 140/90 mmHg for an extended period of time. If left untreated, hypertension results in a weakening of heart muscles and plaque buildup (National Heart, Lung, and Blood, Institute, 2014). A diagnosis of type 2 diabetes mellitus also puts individuals at higher risk for developing HF. Over time, poor glycemic control and high blood sugar levels damage and weaken heart muscles and blood vessels around the heart (National Heart, Lung, and Blood Institute, 2014). One in four adults over the age of 60 currently have a diagnosis of type 2 diabetes in the U.S. (American Diabetes Association, 2013) and it is best controlled with specific dietary changes, exercise, and medication or insulin if needed (American Diabetes Association, 2011).

If risk factors for HF are not properly managed or prevented from developing, cardiovascular diseases progress and can lead to later stages of HF development. In stage B, a patient presents with left ventricular dysfunction (LVD) but has never had symptoms of HF. LVD can be caused by coronary artery narrowing, ischemic heart disease, cardiomyopathy, hypertension, and other chronic conditions (Armstrong, 2000). LVD is characterized by low left ventricle ejection fraction caused by progressive structural remodeling within the left ventricle chamber (Goldberg & Jessup, 2006). Stage B HF presents two management challenges. First, if patients are asymptomatic, they may feel good and be unaware of their condition. Additionally, there are few specific therapies developed to treat LVD. Treatment for asymptomatic LVD is currently limited to medication, however these treatments appear to delay the onset of symptomatic HF and improve survival (Goldberg, 2010; Goldberg & Jessup, 2006).

Stage C is characterized by symptoms of HF associated with structural heart disease; left ventricle structural or functional abnormalities are present in this stage (Ammar et al., 2007). Patients in stage C develop dyspnea, fatigue, exercise intolerance, and fluid retention that leads to pulmonary congestion and edema. Many patients in stage C are incorrectly diagnosed with bronchitis, pneumonia, or asthma due to breathing difficulties and persistent coughs (Goldberg, 2010; National Heart, Lung, and Blood Institute, 2014). These symptoms are the result of fluid build up in the body which also causes weight gain and frequent urination (National Heart, Lung, and Blood Institute, 2014). Stage C includes systolic HF, also called HF with reduced ejection fraction (HFREF), and diastolic HF, also called HF with preserved ejection fraction (HFpEF), which occurs more often among elderly patients with hypertension (American Heart Association, 2015d; Goldberg, 2010). Ejection fraction is the percentage of blood the left ventricle pumps out of the heart with each heart contraction. In a non-diseased heart, ejection fraction has a normal range of 55% to 70%. In HFpEF the heart muscle contracts normally, but the ventricles do not relax properly (American Heart Association, 2015d). HFpEF is responsible for 50% of HF hospitalizations (Goldberg, 2010). In HFREF the ejection fraction is below 50% because the heart is not contracting effectively. HFREF causes less oxygen-rich blood to be pumped out into the body (American Heart Association, 2015d; Goldberg, 2010).

Stage D HF is the most advanced stage. Patients with stage D HF have true refractory HF and conventional heart therapies no longer reduce symptoms. Stage D HF patients have symptoms such as shortness of breath even when they are at rest (American Heart Association, 2015a; American Heart Association, 2015b; Goldberg, 2010).

2.3 Heart Failure Diagnosis

Tests used to diagnose suspected heart failure (HF) (stages C and D) are electrocardiography, echocardiography, stress testing, cardiac catheterization, and endomyocardial biopsy (Goldberg, 2010). Cardiographic HF testing can show history of heart attacks, whether heart muscle walls are enlarged including left ventricle thickening, presence of abnormal heart rhythms, and how well the heart is pumping. Stress testing determines how the heart responds to exercise, whether blood supply is reduced in arteries that supply the heart, and helps to determine the appropriate activity level for patients. Cardiac catheterization involves inserting a catheter into a blood vessel in the thigh or upper arm, positioning it in or near the heart, and injecting dye that is recorded by x-ray. The resulting images, angiograms, show blockages in the coronary arteries (American Heart Association, 2015c; Goldberg, 2010).

2.4 Treatment of Heart Failure

Every stage of heart failure (HF) has recommended treatment protocols. Patients that fall in stages A and B are involved in primary prevention and should strive to properly manage their risk factors for HF. In stage A, HF risk management may involve behavioral changes and medical management depending on the condition (Goldberg, 2010). Those in stage A should follow healthy diets low in sodium, added sugars, solid fats, and refined grains. Patients in stage A that smoke should quit smoking and avoid second hand smoke. Overweight and obese stage A patients should work with their health care team to design a weight loss plan. Participation in at least 60 minutes of moderate physical activity per week is also recommended for those in stage A (National Heart, Lung, and Blood Institute, 2014). Those in stages A and B may be prescribed medications for primary prevention of HF. Those with hyperlipidemia are generally prescribed hydroxymethlyglutaryl coenzyme A reductase inhibitors (statins). Patients with diabetes are given ACE inhibitors and those with high blood pressure are prescribed antihypertensive medications. Patients in stage B should begin preventative medical treatment for HF even though they may not observe any symptoms associated with their left ventricle dysfunction (Goldberg, 2010).

Once a patient enters stage C, treatment involves additional medication. ACE inhibitors, angiotensin-receptor blockers (ARBs), hydralazine and nitrates, β-blockers, aldosterone antagonists, diuretics, calcium-channel blockers, and anticoagulents are used in combinations specific to the requirements and responses of individual patients. Stage C HF treatment also involves maintaining physical activity levels at an appropriate level and diet management as described for stages A and B. Drinking too much fluid can worsen the symptoms of HF in stage C and fluid intake must be closely monitored (National Heart, Lung, and Blood Institute, 2014). Those in stage C may also qualify for an intracardiac device (ICD) or a cardiac resynchronization therapy (CRT) device, commonly referred to as a pacemaker, if they have a life expectancy of more than 6 months (Goldberg, 2010; National Heart, Lung, and Blood Institute, 2014). A CRT helps both sides of the heart contract at the same time while an ICD checks heart rate and uses electrical impulses to correct irregular heart rhythms (National Heart, Lung, and Blood Institute, 2014).

The most advanced stage of HF, stage D, involves treatments recommended for stages A-C, but also involves additional tertiary medical management and surgical procedures. Patients in stage D should be hospitalized and additional medical specialists such as cardiologists and pulmonologists, if not already on the patient's care team, are consulted for specialized treatments. Patients in stage D HF are kept on sodium restriction, 2 grams or less per day, and salt-retaining medications are avoided. Fluid intake is strictly monitored to increase the effectiveness of diuretic therapy (Goldberg, 2010). If symptoms are severe, a mechanical heart pump, or left ventricular assist device, may be used to pump blood from the heart to the rest of the body while waiting for a heart transplant. Heart transplants are performed during stage D HF when previous medical treatment and less drastic surgeries have failed (National Heart, Lung, and Blood Institute, 2014).

HF is a heterogenous disease, presenting different combinations of symptoms across patients. Many HF patients suffer from other chronic conditions and diseases, making treatment protocols complex and the likelihood that one HF treatment protocol will be effective for all patients is low (Metra et al., 2010). In addition to the diseases mentioned earlier as risk factors for HF, renal dysfunction is also present in the majority of patients in stage D of HF. Co-morbidities significantly affect prognosis and available treatments for patients with acute HF (Metra et al., 2010). Unfortunately, the American Heart Association reports that treating clinicians frequently fail to correctly diagnose HF and often delay diagnostic testing. The American Heart Association and the American College of Cardiology Foundation note in their practice guidelines that the optimal therapy for HF remains a work in progress (Hunt et al., 2009).

2.5 Hospital Readmissions

HF has no cure and those suffering from HF must follow a treatment plan for the rest of their lives. Close to one million hospitalizations for HF occur annually, with a total of 6.5 million hospital days attributed to HF in the U.S. each year (Hunt et al., 2009). Not following the doctor recommended diet, drinking alcoholic beverages, and forgetting to take medications consistently can worsen HF and lead to hospital readmissions (National, Heart, Lung, and Blood Institute, 2014). Hospital readmission rates indicate that 50% of HF patients will be readmitted within 6 months after their initial hospitalization and 25%-35% will die within 12 months of hospitalization. These readmissions account for a substantial portion of the overall costs of caring for those with HF therefore it is important to ensure that patients understand how, and are properly able to, manage their condition once they leave the hospital (Hunt et al., 2009). Additionally, many patients are sent home from the hospital to early or without proper medications and discharge instructions (Fonarow, Yancy, & Heywood, 2005). This combination of factors may account for the U.S.'s high rate of HF hospital readmissions (Hunt et al., 2009).

2.6 Hospital Discharge

The hospital discharge process puts the task of heart failure (HF) care in the hands of the patient, their caregivers, and their primary care doctors and specialists. The immediate post-discharge period is an extremely vulnerable time for patients where increased congestion, deteriorating renal function, and additional abnormalities can contribute to readmission if patients do not follow home care instructions (Gheorghiade, Vaduganathan, Fonarow, & Bonow, 2013). Written discharge instructions and educational materials given to the patient and/or caregiver, should detail activity level, diet, discharge medications, follow-up appointments, weight monitoring, and what to do if symptoms worsen (Hunt et al., 2009). For older adults, comprehensive discharge planning and post-discharge support has been found to reduce hospital readmissions and improve health outcomes such as quality of life and survival (Hunt et al., 2009; Phillips et al., 2004; Roccaforte, Demers, Baldassarre, Teo, & Yusuf, 2005). Older adults that take part in post hospitalization disease management programs have been found to have reduced HF-related readmissions (31%) (Roccaforte et al., 2005).

2.7 Role of Informal Heart Failure Caregivers

Informal caregivers are often responsible for the medical management and care of older adult heart failure (HF) patients. Informal care from family members is important because it is known to affect self-care in HF, following treatment plans, morbidity, and mortality (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008). In 2006, the Heart Failure Society of America recommended that clinicians working with HF patients include informal caregivers in HF management interventions (Heart Failure Society of American, 2006), however few studies have specifically investigated HF caregiver experiences. Most studies of post-acute HF management have focused on the roles of physicians, discharge plans, and formal home health care (Martens & Mellor, 1997; Rich et al., 1995; West et al., 1997).

Informal HF caregivers have been described as older than other informal caregivers and less likely to access specialist palliative care services despite caring for family members with higher levels of unmet needs (Davidson, Abernethy, Newton, Clark, & Currow, 2013). Many informal HF caregivers continue to work, but some are forced to leave their jobs or work part time as some HF patients require 24-hour-a-day care from their informal caregivercaregiverss (Hwang, Fleischmann, Ayanian, Stotts, & Dracup, 2011). Informal HF caregivers provide support across all Activities of Daily Living (ADLs; Katz, 1983) and Instrumental Activities of Daily Living (IADLs; Lawton & Brody, 1969) including shopping, housekeeping, meal preparation, administering medication, and bathing (Li, Morrow-Howell, & Proctor, 2004). Bakas, Pressler, Johnson, Nauser, and Shaneyfelt (2006) investigated HF caregiver perceptions of control over their family members HF symptoms. The results show that 43% of caregivers felt a lack of control over symptoms and a third felt helpless in regards to symptom management.

Many factors impact informal caregiver perception of caregiving intensity and ability to provide adequate care for their family members. Inadequate social support for caregivers and patients has been found to be associated with worsening HF symptoms and social support has been reported to be lower among non-spousal caregivers (Hwang et al., 2011). In Hwang and colleauges'(2011) study of HF informal caregiving dyads (n=76), non-white caregivers felt more positive about their caregiving experiences than white caregivers, however caregivers of lower socio-economic status cared for family members that had worse HF related outcomes. This supports other research among informal caregivers of older adults that has found caregivers have varying experiences that are influenced by socio-economic circumstances and cultural orientation to caregiving (Aranda & Knight, 1997; Knight & Sayegh, 2010; Pinquart & Sorenson, 2005).

2.8 Mexican-origin Informal Caregivers

When compared to non-Hispanic whites, Hispanic heart failure (HF) patients are more likely to be discharged home and least likely to be discharged to a skilled nursing facility (Brown, Haldeman, Croft, Giles, & Mensah, 2005). Latino older adults are more likely than white older adults to receive care outside of a formal health care system and rely more heavily on informal care from family (Shi & Singh, 2014). Due to the higher burden of disease in older age, Latinos providing care to elderly relatives tend to be in more intensive caregiving situations than non-Latino caregivers (National Alliance for Caregiving & Evercare, 2008).

Latino HF caregivers may be especially vulnerable to the stresses and strains of caregiving due to the poor health of Latino elders and the increasing number of older adults in this group. The number of Latinos age 65 and older is expected to quintuple by 2050, making them the largest and second fastest aging sub-population in the United States (Federal Interagency Forum on Aging-Related Statistics, 2012). As this relatively young population ages in the coming decades, there will be an increased demand for informal elder caregiving in Latino populations, especially among Mexican-origin Latinos.

Mexican-origin Latinos make up the largest sub-group of U.S. Latinos (64%) and arrive at old age more disabled than do non-Hispanic whites due to poverty, physical labor, and substandard medical care throughout their lifetimes (Gonzalez-Barrera & Lopez, 2013; Markides, Eschbach, Ray, & Peek, 2007; Rote, Angel, & Markides, 2014). Additionally, when compared to non-Hispanic whites, cardiovascular diseases are increasing at higher rate among older Latinos (American Heart Association, 2014; Centers for Medicare and Medicaid Services, 2014). These conditions result in numerous adverse care recipient health outcomes, increase care intensity, and add complexity to intervention and prevention strategies (Ward & Schiller, 2013). The high presence of co-morbidities and functional disabilities among Latino older adults has an effect on the well-being of their caregivers (Aranda & Knight, 1997). These complexities impact the forms of support Latino caregivers must provide their elderly family members with HF, which can add to caregiver emotional drain and burden.

In a nationally representative study of Latino caregivers (n=1,007), the National Alliance on Caregiving and Evercare (2008) found that over half of Latino caregivers helped their family members with ADLs (Katz, 1983) such as transferring, feeding, and getting dressed; 43% helped with toileting, 40% helped with bathing and showering, and 24% managed incontinence and diapering their relative. These percentages were higher than non-Latino caregivers across all ADL domains. Latino caregivers also provided more IADLs (Lawton & Brody, 1969) assistance with housework, preparing meals, and giving medications, pills or injections than non-Latino caregivers (National Alliance on Caregiving & Evercare, 2008). These findings show that Latinos do indeed experience higher objective burden of care which may be related to higher levels of disability among care recipients but do not provide additional insight into possible emotional strains that caregivers maybe experiencing. The majority of Latino caregivers in this study reported little to no subjective (emotional) stress associated with caring for their elderly family members and were more likely than non-Latinos to report that caregiving was not stressful (National Alliance for Caregiving & Evercare, 2008).

2.9 Caregiver Burden

Racial and ethnic differences in caregiving outcomes such as physical health and burden have been attributed to baseline differences in caregiver health, as well as differences in stressors and resources (Pinquart & Sorenson, 2005). Cultural norms surrounding care provision also contribute to caregiver burden in differing ways for various ethnic groups. Western cultures traditionally place emphasis on individualism while ethnic minorities from non-Western cultures place greater emphasis on collectivism and the welfare of the family unit (Pinquart & Sorenson, 2005). However, past research has found inconclusive evidence for the protective nature of familism among minority caregivers with some caregivers benefiting from support of close family members and others anticipating familial support but not receiving it (Angel, Rote, Brown, Angel, & Markides, 2014; Mendez-Luck, Applewhite, Vicente, & Toyokawa, 2015; Pinquart & Sorenson, 2005). Some of these inconclusive findings may be a result of within-group differences that are not apparent when Latinos and other minorities are studied as a whole and not by specific country of origin (Pinquart & Sorenson, 2005).

Recent research has found that Mexican American (MA) women caring for elderly family members with high levels of impairments are especially vulnerable to burden and has pointed to the need for greater understanding of the effects of ADL and IADL supports on Latina caregiver mental health (Rote et al., 2014). Latina caregivers must often deal with extensive coordination of care, symptom management, and disability which may make them feel tired and overwhelmed leading to emotional drain (Lim & Zebrack, 2004). Using data from the Hispanic Established Populations for the Epidemiologic Study of the Elderly (HEPESE) 2010/2011, an analysis of MA caregivers investigated caregiver depressive symptoms in relation to care recipient functional, psychological, and cognitive impairments (Rote et al., 2014). The authors found that increased caregiver IADL support was associated with increases in caregiver depressive symptoms, whereas ADL needs were unrelated to depressive symptoms (Rote et al., 2014) indicating that perhaps major disabilities (ADL limitations) among care receivers cause less subjective burden in this population. However, in a study among Mexican-origin women caregivers investigating the relationship between care recipient illnesses, ADL/IADL support, and caregiver emotional drain, it was found that intensity of ADL/IADL support was related to whether that form of support was selected as causing emotional drain for the caregiver (Anthony, Geldhof, & Mendez-Luck, 2016). The study found that when MA women caregivers were asked to rate a form of support according to the difficultly of providing the support they were likely to rate those activities that were difficult to perform as also causing them emotional drain. These associations provided new perspective into characteristics of Latina caregiving that were unique from previous research. Previous studies reported that Latina caregivers did not report emotional burden associated with providing specific ADL/IADL supports (Evercare & National Alliance for Caregiving, 2008; Rote et al., 2014). Anthony, Geldhof, and Mendez-Luck (2016), in agreement with Knight and Sayegh's (2010) Updated Sociocultural Stress and Coping Model, integrated the Mexican cultural value of *respeto* and investigated the pathways of emotional burden using the terms "emotionally tiring" and "emotionally draining" to avoid addressing caregiving as a burden-inducing or burden-causing endeavor that would indicate a lack of *respeto*. Since the survey did not directly mention the term "burden" in relation to providing care to an elderly family member, it did not conflict with traditional cultural values and was therefore able to obtain responses directly associating difficulty of ADL/IADL activities with negative emotional outcomes. A wide range of ADL/IADL activities that show high objective burden in current caregiver research, from bathing the care recipient to administering medications and injections (Evercare & National Alliance for Caregiving, 2008; Sorensen & Pinquart, 2005) were associated with emotional drain among the caregivers in this study, indicating that intensity of support influences subjective burden and drain among MA women caregivers. The findings of this study are relevant for MA HF patients and their informal caregivers because HF patients have been found to have high levels of functional impairment which necessitate intensive ADL/IADL support (Gure, Kabeto, Blaum, & Langa, 2008).

Latinas may be at more risk for the negative effects of elder caregiving because caregiving for elderly relatives has traditionally been a role adopted by women. The responsibility to provide care typically falls to the eldest daughter in Latino families (Jolicoeur & Madden, 2002). These daughters take on the task of providing care for their elderly family members to fulfill role expectations and obligations by choice or out of a sense of duty (Jolicoeur & Madden, 2002), leading to unequal distribution of elder care by gender within families, where Latino men generally expect elder care to be provided by women (Mendez-Luck et al., 2008). Understanding relevant cultural values among Latinos can help us better understand how to investigate caregiver emotional strain and burden among Latina HF caregivers.

MA women's sense of duty may originate from the female *marianisma* role in Mexican culture, which emphasizes that women should embody feminine traits of submission, weakness, and reservation (Stevens, 1973). A *mariana* is expected to be self-sacrificing, putting the needs of her family above her own, even if it causes personal hardship (Mendez-Luck et al., 2008). Adopting the *mariana* role puts MA caregivers at risk for caregiver burden and emotional strain because they may be less willing to seek help when their caregiving duties become overwhelming.

Two additional cultural forces that are key to understanding how Latina caregivers conceptualize and experience caregiving— including how they report emotional drain and burden— are familism and *respeto*. Familism refers to placing value on the family as an institution, with family members having interdependence on one another rather than on formal institutions for support (Flores, Hinton, Barker, Franz, & Velasquez, 2009). Although familism in Latino culture typically refers to a broad network of social supports, the actual experiences of Latina caregivers suggest that having a single primary caregiver is most common (Evans, Coon, & Belyea, 2014; Neary & Mahoney, 2005). The cultural value and structure of familism may therefore explain part of Latinos' lower utilization of formal caregiving services compared to non-Latino whites.

Respeto, another Latino cultural value, is characterized by politeness and deference when interacting with others (Cardona, 2007). *Respeto* is especially important for younger generations interacting with older Latinos because older Latinos generally occupy a highly respected role within family support systems (Cox & Monk, 1996; Beyene, Becker, & Mayen, 2002). Respect for elders may also contribute to lower utilization of formal caregiving services because it would be disrespectful to the elder if the family did not provide care for him or her. Due to *respeto,* Latino caregivers may also be reluctant to answer traditional caregiving burden questions that portray their caregiving experiences negatively. Doing so would be disrespectful because it would indicate that providing care to a relative is a negative experience (Gallagher-Thompson, Solano, Coon & Arean, 2003).

Cultural values and meanings influence Latina caregivers' appraisals of their experiences; thus, our understanding of burden and stress among Latina caregivers may be incomplete when cultural values are not adequately included in caregiver burden measures and investigations (Calderon & Tennstedt, 1998; Evans et al., 2014; Mendez-Luck et al., 2008). Recent studies have found that common measures of caregiving burden may not sufficiently capture Latino experiences of emotional drain and stress, possibly because the questions are not phrased in ways that capture emotional burden and drain as described within the Spanish language and Latino culture (Crist et al., 2009; Mendez-Luck et al., 2008; Wells, Cagle, Marshall, & Hollen, 2009). There is a need to incorporate culturally relevant questions that focus on specific ADL and IADL supports and their roles in caregiver strain when studying Latino populations, especially among Latino HF caregivers whose caregiving experiences have been little explored.

A qualitative study of female caregivers in Mexico City explored the conceptualization of burden and strain in the context of everyday caregiving experiences with elderly relatives and indicated that, among Latina caregivers, burden was a multi-dimensional and situation dependent concept that resulted in feelings of emotional and physical heaviness (Mendez-Luck et al., 2008). The word burden does not have an exact translation in Spanish; some caregiver burden scales that are translated to Spanish from English utilize the term *carga* or *sobrecargado* (Martin-Carrasco et al., 2010), to replace the word burden. *Carga* and *sobrecargado* translate to load and overloaded in English. Caregivers in this study expressed their views of caregiver burden through discussions of when caregiving was *pesado*, a culturally relevant concept that translates to *heaviness* in English. While talking about the heaviness of caregiving, the women contextualized situations when emotional and physical strain were present in their caregiving experiences, similar to ways that caregiver emotional strain has been documented in studies among other racial and ethnic caregiver groups (Mendez-Luck et al., 2008). These results contrast with findings from Mexican American caregiver burden interview studies that report high objective burden scores with low subjective, or emotional, burden scores (Evercare & National Alliance for Caregiving, 2008) but support additional studies that report high levels of depression and stress among MA caregivers when compared to non caregivers (Hahn, Kim, & Chiriboga, 2011; Hernandez & Bigatti, 2010; Herrera et al., 2012) suggesting that the wording and phrasing of caregiver burden interview questions should be made culturally relevant to gain a true understanding of the stress, burden, and strain experienced by this population.

Language barriers also play a role in accessing proper caregiving information among Mexican-origin caregivers, with a recent National Alliance for Caregiving survey indicating that 78% of Mexican-origin caregivers feel that it is important that health information and services are provided in Spanish (National Alliance for Caregiving & Evercare, 2008).

2.10 Remote Health Monitoring (RHM)

Remote health monitoring (RHM) uses mobile communication technologies such as smart phones or tablets in the practice of medicine and involves use of health-related applications that convey health information over a mobile network between patients, physicians, and clinicians for the purpose of improving patient self-care and self-management of specific diseases (Malvey &

Slovensky, 2014). RHM utilizes two-way video, email, smart phones, wireless tools, sensors, and other forms of communication technology to remotely collect and send data to a home health agency or a remote diagnostic testing facility for interpretation. RHM can involve the collection of specific vital signs such as heart rate, blood pressure, or heart ECG (American Telemedicine Associaton, 2012). RHM was first targeted toward providing diagnostic and monitoring services to patients living in rural areas. These programs were primarily hospital based and utilized telephone landlines (Koehler et al., 2011; Malvey & Slovensky, 2014).

2.11 Remote Health Monitoring and Heart Failure

When compared to usual care, remote health monitoring (RHM) programs for stable heart failure (HF) patients have been found to reduce the odds of death and hospitalizations due to HF (Kotb, Cameron, Hsieh, & Wells, 2015). However, inconsistent evidence has been found in regards to RHM interventions for older adult HF patients post hospitalization. Some research indicates RHM has not reduced re-admissions when compared with usual care (Chaudhry et al., 2010; Pandor et al., 2013) and other studies indicate improved outcomes (Cleland, Louis, Rigby, Janssens, & Balk, 2005; Giordano et al., 2009; Inglis et al., 2011; Klersy, De Silvestri, Gabutti, Regoli, & Auricchio, 2009; Madigan et al., 2013). Given the increasing desire of older adults to use technology to monitor their health (AARP, 2011; Malvey & Slovensky, 2014) there is a need for further investigation of RHM among HF patients.

Several types of technology have been incorporated into RHM with HF patients. Structured telephone monitoring in which phone calls from nurses or doctors are used to monitor patient adherence to HF management is the most basic form of RHM and has been found to reduce hospital readmissions by 23% (Inglis, Clark, McAlister, Stewart, & Cleland, 2011). Other types of structured telephone monitoring can include having patients enter information in automated systems through telephones by leaving voice recordings or using the keypad to enter responses to automated questions (Bhimaraj, 2013). Equipment, such as electrocardiograms that measure heart rhythm, can also be connected through computerized gateways to phone lines and remotely transmit health information through internet servers to clinicians (Zhang, Goode, Cuddihy, Cleland, & the TEN-HMS Investigators, 2009). In the area of wireless RHM, Bluetooth devices have been used to communicate health information wirelessly through mobile phones to physicians and clinicians. Studies utilizing Bluetooth devices with HF patients have collected data on weight, blood pressure, heart rhythm, and self-rated health status (Bhimaraj, 2013). To gather more detailed patient information, RHM may also involve the use of wearable and implantable technology. Wearable technologies can monitor many health indicators including heart rate, respiratory rate and volume, activity duration and intensity, and body posture with the use of multi-sensor noninvasive external monitoring devices (Anand et al., 2012; Bhimaraj, 2013). Fully implantable devices can also be implanted in patients to remotely monitor ejection fraction and have been shown to reduce first time HF-hospitalizations. Implantable cardioverter defibrillators (ICD)/cardiac resynchronization therapy (CRT) are commonly used to treat HF and thoracic impedance can be remotely monitored with these devices (Shah et al., 2009).

2.12 Latino Remote Health Monitoring Technology Use

Latinos have historically had lower levels of technology use compared to non-Hispanic whites (Ono & Zavodny, 2008), but this trend is currently changing. Due to the increased availability of smart phones and mobile devices, Latinos are now just as likely to use the internet and cellular phones as non-Hispanic whites and blacks (Lopez, Gonzalez-Barrera, & Patten, 2013). While the digital divide may be shrinking among Latinos in general, there are still some subgroups that are being left behind. According to a recent Pew Hispanic Center study, only 14% of Latinos aged 65 and over use smart phones and only 35% of Latino adults in this age group own computers (Lopez, Gonzalez-Barrera, & Patten, 2013). Disparities in information technology access and use have been associated with lower income and education (Ginosarr & Nelson, 2010; Lopez, Gonzalez-Barrera, & Patten, 2013).

Cultural factors may influence perceptions of using remote health monitoring (RHM) technology among Latinos (Ginosarr & Nelson, 2010). Little research has been done investigating perceptions of RHM among Mexican-origin Latinos, however it is important to understand how RHM is perceived among Latino patients so that culturally tailored interventions can be developed in order to increase program adherence (George, Hamilton, & Baker, 2012). George and colleague’s (2012) study of RHM perceptions among urban Latino and African American adults found that Latinos perceived RHM positively because it would reduce waiting time, give immediate feedback regarding treatment, and would provide multiple medical opinions. Latinos also felt that the use of computers to provide medical diagnosis would decrease misdiagnosis because computers were more precise than humans. The researchers found that Latinos had a more trusting opinion of RHM and the medical system in general when compared to African American participants. Latinos in this this study perceived RHM as cutting edge and beneficial.

Studies involving use of RHM that have included Latinos have shown mixed results. A five year-long study by Trief and colleagues (2013) investigated the use of RHM home units to manage diabetes among African American, Hispanic, and white patients over the age of 55 with type 2 diabetes. The RHM units consisted of computers with web-enabled cameras for video visits, capability to upload blood pressure and blood glucose measurements, and provide access to diabetes education and patient specific data. Participants video conferenced with nurse case managers once a month and set goals for health management based on the data they provided. The intervention was supervised by endocrinologists who made recommendations for changes in medical management to primary care providers. The researchers found that the RHM intervention group was more adherent to their diabetes self-care than the usual care group, however Hispanics and African Americans were less adherent to good diabetes self-care than white participants. These differences were thought to be attributed to inadequate cultural tailoring of the intervention. The researchers shared that while they did translate the intervention to Spanish and used Hispanic American and African American nurses to deliver the intervention, more should have been done to tailor the intervention to the appropriate ethnic group (Trief et al., 2013).

In another diabetes focused intervention that utilized RHM among Hispanics, Lorig, Ritter, Villa, and Piette (2008) investigated whether adding a reinforcing phone call component to a diabetes self-care intervention would help participants maintain diabetes management improvements better than those just receiving the intervention without the phone call component after 18 months. The researchers found no difference in diabetes self-management between the two treatment groups at the end of 18 months indicating that the reinforcing phone call did not significantly contribute to better self-care. At the conclusion of the study it was thought that more a personalized form of reinforcement may have produced better results than the RHM phone calls (Lorig, Ritter, Villa, & Piette, 2008).

A recent survey conducted by Cedars-Sinai Medical Center, in Los Angeles, CA, investigated the receptivity of Hispanic women aged 18 and older to receiving medical information electronically (Dang, Estrada, Bresee, & Phillips, 2013). They found that the majority of Hispanic women did not use the internet (58%) or email (64%), but that 70% did have mobile phones. Of those that used mobile phones, 65% used text messaging daily and 45% of those women were interested in receiving medical examination reminders by text message (Dang, Estrada, Bresee, & Phillips, 2013). These results indicate that text messaging may be an inexpensive way to promote healthcare among Hispanic women.

The CarePartner Program, an international study of RHM among Hispanics in the U.S., Honduras, and Mexico, investigated the usage of interactive phone calls to improve diabetes and hypertension management (Piette et al., 2013). During the calls, patients reported information about their health status and self-care using their keypads and received tailored self-management advice. Both the diabetes and hypertension phone calls focused on symptoms, diet, medication use, and home physiologic monitoring (i.e., glucose self-monitoring and home blood pressure monitoring). Based on patients' reported data, alerts were automatically sent via email to clinicians. An informal caregiver of each participant was also encouraged to participate. The caregiver received structured feedback via a phone call or email based on the patient's reports. Phone calls and emails to caregivers focused on changes in the patient's health status, and what they could do to support the patient's self-care (Piette et al., 2013). Results showed that patients whose informal caregiver participated had better program participation rates than those who participated alone. It was also found that all patients reported that the information provided in the calls was helpful and, despite patients' limited educational attainment, 98% reported that the automated calls were easy to use. Patients reported that the program was helpful in managing their chronic disease, with 86% of all patients reporting that the programs helped them "a great deal." Additionally, 77% of all patients reported that their diet improved "a great deal" as a result of the intervention, 80% reported that their symptom monitoring improved "a great deal," and 80% reported that their medication adherence improved "a great deal." Call completion rates were lowest among those whose health at baseline was reported as fair or poor. The results of this study indicate that RHM can be successfully implemented in a Hispanic population and that informal caregiver involvement may improve adherence and outcomes. The barriers to participation among those who were in poorer health should be further investigated (Piette et al., 2013).

2.13 Studies of Remote Health Monitoring of Heart Failure and Inclusion of Latinos

There are few remote health monitoring (RHM) studies that focus on Mexican-origin Latinos with heart failure (HF) even though HF prevalence and hospital readmissions have been found to be higher among Mexican-American Hispanics than among non-Hispanic whites (Alexander, Grumbach, Remy, Rowell, & Massie, 1999; Bahrami et al, 2008; Brown, Haldeman, Croft, Giles, & Mensah, 2005; Rodriguez, Joynt, López, Saldaña, & Jha, 2011; Roger et al., 2004; Vivo, Krim, Cevik, & Witteles, 2009). Many RHM studies of older adult HF patients in the U.S. have focused on non-Hispanic white and African American participants or do not provide information on participant ethnicity (Gellis et al., 2012; Hughes & Granger, 2014; Madigan et al., 2013; Maisel et al., 2013).

A randomized controlled trial (RCT) testing the effect of telephone case management, one of the most basic forms of RHM, to decrease hospitalizations and improve health related quality of life and depression among Mexican-origin HF patients found no significant difference between the intervention group and the control group (Riegel, Carlson, Glaser, & Romero, 2006). The intervention was originally designed in English and then translated to Spanish and delivered by nurses who received training in Mexican cultural values of *personalismo* or personalized caring, trust, and inclusion of the family (Riegel, Carlson, Glaser, & Romero, 2006). The results of this study indicated that while this form of telephone case management had been successful among non-Hispanic whites and other ethnically diverse groups (Riegel et al., 2002), a different, culturally relevant approach may be needed to achieve success with Mexican-origin HF patients.

Chaudry et al. (2010) conducted a randomized control trial of RHM among HF patients aged 51-73 utilizing daily telephone calls administered by an established medical telemonitoring company, Tel-Assurance. Participants (n = 1,653) were 49.3% White, 39% Black, 11.7% other, and 2.7% Hispanic. Patients enrolled in the intervention group made daily toll-free calls to the RHM system and entered responses to a series of questions about general health and HF symptoms. Information collected from the system was downloaded daily to a secure website and reviewed by study staff every weekday. Patients with abnormal responses were flagged by the system and study staff was required to contact the participant and document their management of symptoms. Study results indicated that the intervention did not reduce hospital readmissions among HF patients. Reasons for the failure of this intervention were thought to include lack of formal HF education targeted at patients, lack of a medication management component, and lack of a peer support component. In some instances, an intervention that included more contact between patients and clinicians may have been more effective (Chaudry et al, 2010).

Suh et al. (2011) developed a multidisciplinary RHM intervention with medical oversight called the Weight and Activity with Blood Pressure Monitoring System (WANDA) for use with HF patients. Study participants were 68% male, 40% White, 13% Black, 32% Latino, 15% Asian/Pacific Islander, and had a mean participant age of 68.7. The purpose of WANDA was to improve physician monitoring of patients' daily progress, improvephysicians' ability to make decisions through an automated data analysis of patient data, and to provide a customizable monitoring platform to meet patient needs that fit easily into their daily lives. WANDA monitored patient weight, blood pressure, physical activity, and the Heart Failure Somatic Awareness Scale (HFSAS). Abnormal trends in patient data were flagged to alert physicians. Patients were given the RHM technology (Bluetooth weight scales, blood pressure monitors, and physical activity monitors) and answered daily questions that were provided to them through WANDA. Data was uploaded onto a secure system that was able to aggregate and interpret data for each patient by ID number from multiple devices and then made it available to physicians. Results have shown that WANDA enabled HF patients to reduce 5.6% of weight and blood pressure values that were out of acceptable range, suggesting that it is a potentially effective platform for aiding HF patients (Suh et al., 2011).

2.14 Concerns with Remote Health Monitoring

To date, studies of remote health monitoring (RHM) of heart failure (HF) patients have shown mixed results and have only recently begun including Latinos as participants (Chaudry et al, 2010; Riegel, Carlson, Glaser, & Romero, 2006; Suh et al., 2011). Lack of culturally relevant intervention tailoring has been referred to when RHM studies that include Latino patients are unsuccessful (Trief et al., 2013). There is a need for those developing RHM interventions for Mexican-origin Latinos to better understand the relevance and utility of RHM as it relates to home based informal care and self-care from a Mexican oriented cultural perspective. Having a better understanding of Mexican-origin patient and caregiver perspectives regarding RHM will aid in the development of RHM interventions that are better tailored to their needs and may result in better adherence to interventions and lower hospital readmissions.

2.15 Theoretical Perspectives

This study draws from several theoretical perspectives from human computer interaction, health behavior and promotion, and psychology. Remote health monitoring (RHM) interventions for older adults are often designed by interdisciplinary teams from the health sciences, computer sciences, and gerontology and provide a unique opportunity for theoretical frameworks from multiple disciplines to intersect (Plaza, Martin, Martin, & Medrano, 2011). The first theoretical perspective in this study involves the Technology Acceptance Model. The Technology Acceptance Model (TAM) was designed by Davis (1986) to explain computer usage behavior and has been applied to understanding RHM technology use (Scheibe, Reichelt, Bellman, & Kirch, 2015). The TAM was developed as an adaptation of the Theory of Reasoned Action (TRA) (Davis, Bagozzi, & Warshaw, 1989). The TAM uses the TRA to help determine causal linkages between perceived usefulness (PU) and perceived ease of use (PEOU) and users' attitudes, intentions, and actual technology adoption behavior (Davis, Bagozzi, & Warshaw, 1989).

Perceived usefulness and perceived ease of use are the two main constructs included in the TAM. From a RHM perspective, perceived usefulness (PU) can be described as the extent to which a person believes a technology will help them manage their condition better (Davis, 1989). Perceived ease of use (PEOU) is another key tenet of the TAM. Even if a potential user believes that a given health technology is useful, they may simultaneously think that the technology is too hard to use and that the benefits of usage are outweighed by the effort of using the particular technology. Perceived ease of use (PEOU) refers to the degree to which a person believes using a particular system would be free from effort (Davis, 1989). Perceived usefulness and perceived ease of use are both incorporated into this study's theoretical framework. See Table 2.1 for selected definitions of the TAM applied to this study.

Table 2.1

Selected definitions of Technology Acceptance Model components applied to understanding RHM for HF management.

Component	Definition
Perceived Ease of Use (PEU)	The extent to which a person believes that using RHM will be free of effort
Perceived Usefulness (PU)	The extent to which a person believes that using RHM will enhance his or her ability to manage HF
Intention to Use (IU)	A function of PEU and PU which refers to person's evaluation of whether or not they would use RHM to manage HF

The second theoretical perspective is the Theory of Planned Behavior (TPB) (Azjen, 1991), which has been validated in studies that have investigated behavioral intentions to use health interventions and RHM (Azjen, 1991; Deng, Mo, & Liu, 2014; Holden, 2010; Vissman et al., 2011). The TBP is also based on the Theory of Reasoned Action (TRA) (Ajzen & Fishbein, 1975; Ajzen & Fishbein, 1980), however it differs from the TRA in its additions of perceived behavioral control (PBC) (Ajzen, 1991). PBC refers to a person's perception of the ease or difficulty of performing a behavior of interest. PBC can vary across situations and actions and is closely linked to Bandura's (1982) concept of self-efficacy. PBC is concerned with beliefs about presence of control factors that may facilitate or inhibit performance of the behavior (Glanz, Rimer, Viswanath, 2008). In the TPB, attitudes, perceived norms, and PBC are used to predict whether the behavior will be performed (Ajzen, 1991). This study incorporates the indirect measures of behavioral belief (attitude), normative belief (perceived norm), and control belief (PBC) of the TPB into its conceptual framework. Brief definitions of the TPB components as applied to this study are presented in Table 2.2.

Table 2.2

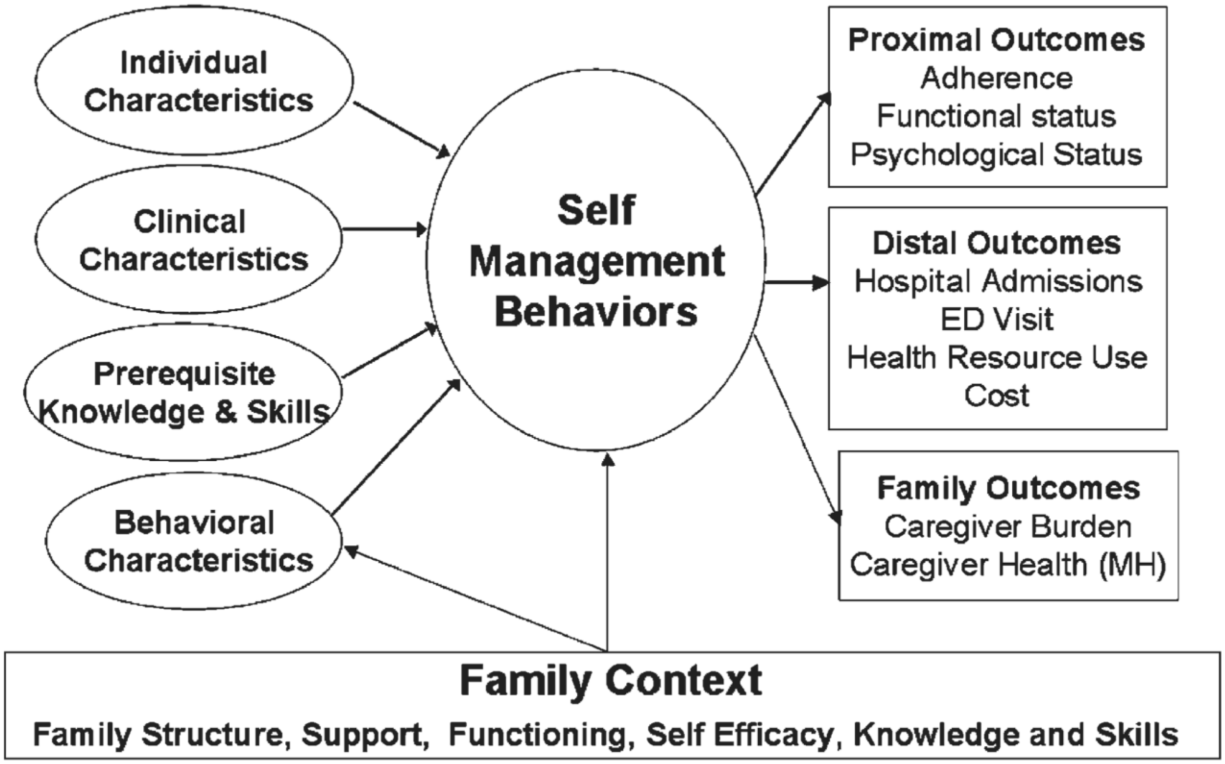
Selected definitions of Theory of Planned Behavior components applied to understanding RHM beliefs and utility.

Component	Definition
Behavioral Beliefs	Belief that RHM of heart failure (HF) leads to certain consequences (both positive and/or negative) Beliefs that RHM leads to certain consequences (both positive and/or negative)
Normative Beliefs	Beliefs identifying specific external pressures from important others who encourage or discourage HF management Beliefs identifying specific external pressures from important others who encourage or discourage all technology use in general and RHM Individual subjective norms about how the behavior fits with one's self-identity and moral values
Control Beliefs	Beliefs identifying the facilitators for, or impediments to adhering to HF management instructions, including self-efficacy Beliefs identifying the facilitators for, or impediments to adhering to potential RHM of HF, including self-efficacy

An additional framework incorporated into this study is Dunbar, Clark, Quinn, Gary, & Kaslow's (2008) conceptual model describing family influences on heart failure (HF) self-care and outcomes that incorporated informal family based care, individual patient characteristics, behavioral characteristics and long term and short term outcomes for both patients and informal caregivers. This conceptual model, see Figure 2.1, was put forth as a framework for studying HF self-care and informal caregiver contributions to care within the home environment. It is useful for aidingin understanding relationships and activities surrounding HF self-care as well as for use in HF intervention development (Dunbar et al., 2008). The proposed study expands on this framework by adding additional variables from the TPB, the TAM, and the Updated Sociocultural Stress and Coping Model described in the next paragrah.

Figure 2.1

Framework for Heart Failure Self Management with family variables.



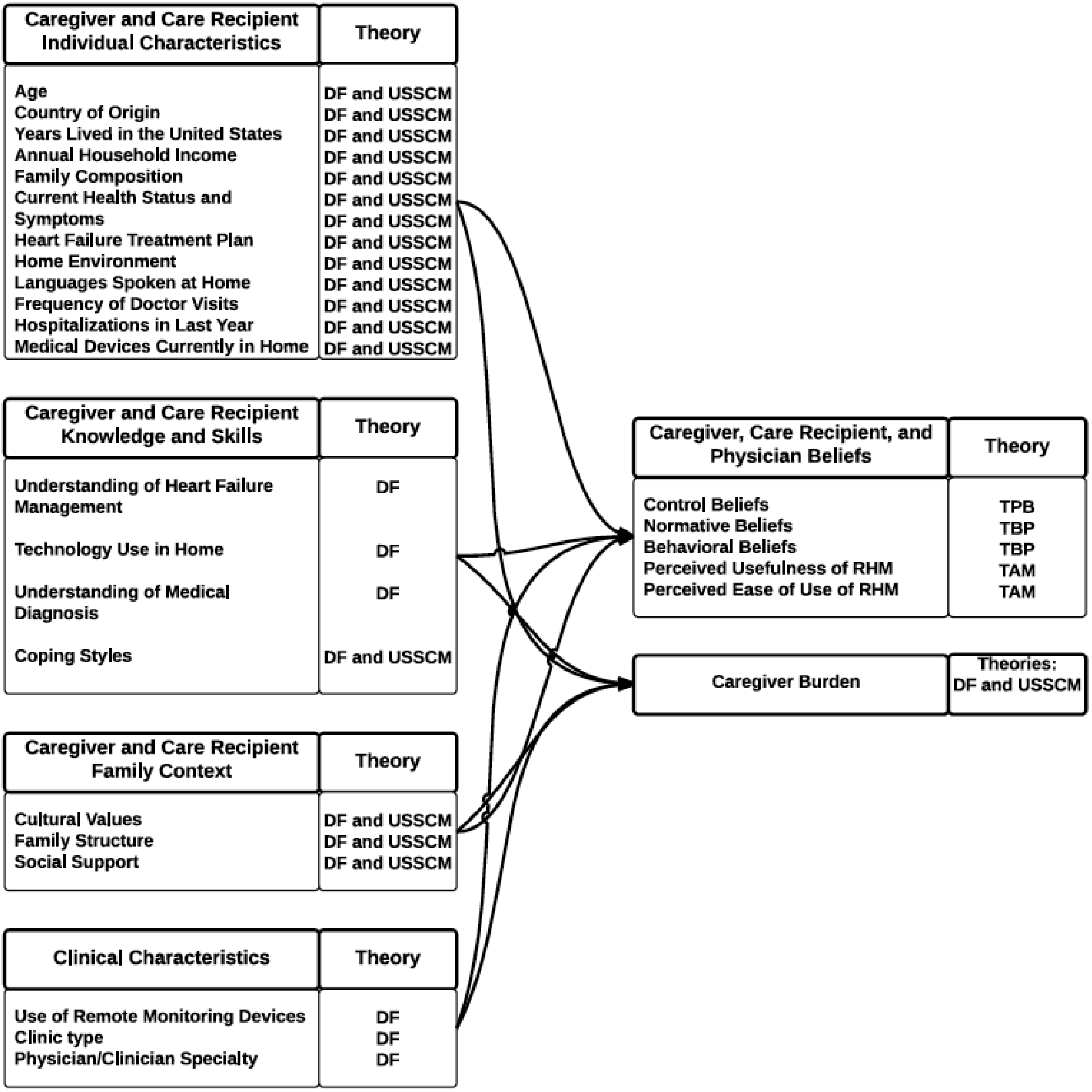
Dunbar et al. (2008) Framework for heart failure self-management and family variables. MH: mental health; ED: emergency department.

A theory of caregiver stress and burden that is incorporated into this study's theoretical framework which can be applied to informal HF caregivers is Knight and Sayegh's (2010) Updated Sociocultural Stress and Coping Model. Knight and Sayegh's model, originally proposed by Aranda and Knight (1997), posits that caregiver stress is a consequence of a process that involves interrelated conditions and stressors with an emphasis on the importance of cultural values when measuring stress and burden among minority caregivers. This model specifically focuses on obligation values, family solidarity, and support values of familism as key cultural components of caregiving. The value of this model is that the many characteristics of the caregiver, the care recipient, and the caregiving situation are interwoven throughout the stress process. This synthesis provides a holistic view of the caregiver's life and the context in which the care is being provided. This multidimensionality may resonate among Latinos and influence their reasons for caregiving and interpretation of caregiving burden. This study incorporates the background and context, primary stressors, secondary role strains, cultural values, coping style, and social support aspects of the Updated Sociocultural Stress and Coping Model in the conceptual model described in the following section.

2.16 Conceptual Model

This project proposes that cultural values influence heart failure (HF) patient and caregiver acceptance of remote health monitoring (RHM) and the perceived utility of RHM and that there are additional factors involved in beliefs regarding RHM use to prevent hospital readmission. The conceptual model for this project is shown below.

Figure 2.3 Project Conceptual Model



Note: DF: Dunbar et al. (2008) Framework; USSCM: Knight & Sayegh (2010) Updated Sociocultural Stress and Coping Model; TPB: Azjen (1991) Theory of Planned Behavior; TAM: Davis (1986) Technology Acceptance Model.

2.17 Specific Aims

The objectives of the study were to 1) determine the remote health monitoring (RHM) needs and goals of healthcare providers, older adult Mexican-origin and non-Hispanic white heart failure (HF) patients, and their informal caregivers and 2) identify the roles that culture, technological literacy, and social environment play in RHM technology beliefs. These objectives were accomplished through three specific aims listed below:

- ***Specific aim #1:*** Compare the RHM goals and beliefs of clinicians to those of Mexican-origin and non-Hispanic white HF patients and their caregivers.
- ***Specific aim #2:*** Investigate the influence of the culture and social environment on the perceived utility of RHM technology among Mexican-origin and non-Hispanic white patients and caregivers.
- ***Specific aim #3:*** Investigate ways that Mexican-origin and non-Hispanic white caregivers of older adults with HF perceive that RHM technology may alleviate caregiver burden.

These specific aims were accomplished by conducting qualitative semi-structured interviews with cardiologists, HF patients, and informal HF caregivers in the greater Portland and Willamette Valley areas of Oregon and in Los Angeles, California. Results from this study identify and provide insight on beliefs regarding RHM among HF patients, their caregivers, and cardiologists which can be utilized to develop future interventions among the study population.

CHAPTER 3 METHODS

3.1 Overview of Methodology

This study utilized a qualitative methods research design. Qualitative semi-structured belief elicitation interviews (Azjen, 1991; Francis et al., 2004) with open-ended questions were used for this project to elicit salient behavioral beliefs, normative beliefs, and control beliefs regarding remote health monitoring (RHM) and heart failure (HF) care at home. This method allowed the inclusion of questions that elicited discussions around topics included in the conceptual model. Iinductive qualitative methods were chosen for this research due to their ability to allow examination of relationships within systems and cultures with a focus on understanding social settings and beliefs. The goal of this study was to generate hypotheses, not to prove or disprove them (Janesick, 2000).

3.2 Semi-Structured Interview Guide Development

I created three separate interview guides, one for each participant group. Preliminary semi-structured belief elicitation interview guides (Azjen, 1991; Francis et al., 2004) incorporated questions based on the project's conceptual model and specific aims (see Appendix A-C). Interview guides were pilot-tested and modified as needed. Caregiver and patient interview guides for Spanish speaking participants were translated into Spanish by a native Spanish speaker and back translated into English to establish equivalence with the original interview guide (Francis et al., 2004). Interview questions were written so that, during analysis, comparisons could be made between the three different groups of participants. To address Aim 3, questions about the difficulties, challenges, and struggles caregivers experienced were used to encompass the concept of caregiver burden. These questions were used to represent burden instead of direct questions using the term “burden” to maintain cultural relevance among participants. Consistent with a grounded theory approach (Charmaz, 2006), interview guides changed as new topics emerged during the course of the study. At the end of each interview, interview transcripts and notes were analyzed and questions were added to the interview guide as new topics and discussion points emerged from previous interviews. Examples of questions and topical areas that were added addressed how participants struggled with managing HF, diet, and what might provide them more peace of mind when managing HF.

3.3 Data Collection

Population of Interest

This research included older adult Mexican-origin and non-Hispanic white heart failure (HF) patients age 50+ and informal HF caregivers, age 18+, as well as clinicians. Patients and caregivers were recruited independently of each other. Caregivers were not required to have their care recipient participate in the study, and patients were not required to have their caregiver participate. However, if a caregiver responded to study recruitment and their care recipient wanted to participate, or a care recipient responded and their caregiver wanted to participate, caregiving dyads were allowed to enroll. There was no requirement that clinician participants be actively involved in treating the enrolled patient participants. Inclusion criteria for informal caregivers included being of Mexican-origin or non-Hispanic white, being at least 18 years of age, and providing care to an older adult (age 50+) family member with a diagnosis of HF. Providing care was defined as assisting the older adult in one or more ADL/IADL on a weekly basis. Inclusion criteria for patients/care receivers were being at least 50 years old and having a self-reported diagnosis of HF, receiving help with one or more ADL/IADLs from a family member, and being of Mexican-origin or non-Hispanic white. Access to personal health records was not necessary for this study. Inclusion criteria for healthcare providers included meeting one or all of the following requirements: treating HF patients in an outpatient setting, treating HF patients in a hospital setting, and/or working as a case manager for a HF patient.

Recruitment

Recruitment took place after IRB approval from November 2015 to May 2016. Non-probability purposive sampling was used to recruit 13 non-Hispanic white HF caregivers, 15 non-Hispanic white HF patients, 16 Mexican-origin HF caregivers, 14 Mexican-origin HF patients, and 12 cardiologists. Purposive sampling is recommended by Bernard (2012) for use in hard-to-find-population studies such as those involving Mexican-origin caregivers and patients. Purposive sampling uses researcher judgment to find recruitment sites that reflect the population they are interested in studying (Bernard, 2012). The researcher and three bilingual research assistants used a combination of recruitment techniques to recruit participants. The study was advertised in senior center newsletters and fliers were posted at senior centers and activity centers that provide services for older adults, health clinics that serve the Latino community, and at Mexican markets. Recruitment flyers were also handed out at health fairs and church bible study meetings. Parish nurses were given flyers to hand out to potential participants and the lead researcher also attended county wide community services meetings to provide flyers and discuss the study. We recruited participants from two registries, the Layton Aging & Alzheimer's Disease Center (LAADC) registry at Oregon Health and Science University (OHSU) and the Oregon State University (OSU) Center for Healthy Aging Research (CHAR) LIFE Registry. Participants were also recruited by word of mouth and by email.

Recruitment emails were sent to members of the OSU CHAR Life Registry. Those interested in learning more about the study then replied to the email and a screening telephone call was scheduled. Letters announcing the study were mailed to qualifying members of the OHSU LAADC registry. The LAADC prescreened their registry database based on this study's inclusion criteria to determine which registry members would receive a study announcement letter and the LAADC mailed the letter. The LAADC provided the study team the names and phone numbers of registry members that were mailed a letter. We waited a week from the mailing date of the study announcement letter to call potential participants who received the letters.

In all recruitment efforts, when contacting potential participants by phone, the study team used the IRB approved phone call consent to screen script to obtain consent to screen potential participants for the study. During the phone call, if a potential participant qualified for the study and wished to participate in the study, an appointment was then made with the participant to obtain signed inform consent and conduct the interview. Some participants consented to screen for the study in person. When this was the case, the in person consent to screen script was followed. If the person qualified for the study and wished to participate a later appointment was made to obtain signed informed consent and to conduct the interview.

Recruitment flyers were created in both English and Spanish and a cell phone line was obtained to answer all Spanish language calls that inquired about the study. A bilingual research assistant answered and returned calls on this phone line. The Spanish language study phone line was payed for by the Intel Corporation. The lead researcher, Katherine Anthony, was also a graduate technical intern at the Intel Corporation. As part of the internship, Intel Corporation funded some of this study's efforts. Recruitment flyers informed participants of the $50.00 participation inventive. Participation incentives were funded through a Life Scholars grant from the OSU CHAR and by Intel Corporation.

Recruitment of participants was more difficult in Oregon than the study team had originally anticipated. One study funder, Intel Corporation, provided funding to use a professional recruitment firm. A firm was contacted and hired to recruit participants, but had difficulty finding people who met study inclusion criteria. The firm recruited one Mexican-origin patient participant for the study. When it was determined that the private recruitment firm was unable to locate an adequate number of potential participants the study team decided to discontinue the use of the firm and continue our community based recruitment efforts until we reached our recruitment goal. At this point we expanded our recruitment efforts to include the city of Los Angeles, CA. Los Angeles, CA was chosen as additional area for study recruitment because Latinos represent 49% of the city's population (Unites States Census Bureau, 2016), the lead researcher's committee chair had a trained research assistant that could assist with the study in that location, and previous recruitment efforts for prior studies targeted at recruiting Latino participants in this area had been successful. A trained bilingual research assistant and a trained bilingual community member volunteer led recruitment efforts, as described above, in the Los Angeles area with the oversight of the lead researcher. 8 Mexican-origin participants and 1 non-Hispanic white participant were screened and enrolled in the study from the Los Angeles area.

We accepted 5 participants into the study that were exceptions to our screening criteria. Three patient participants had caregivers that were not legal relatives, two were the girlfriends of care recipients and the other care recipient was being cared for by a lifelong friend. In all three instances the patient considered the caregiver to be a member of their family and was therefore included in the study. Additionally, two MA caregivers were not legal relatives of their care recipient, one was the girlfriend of the care recipient and the other was a lifelong friend of her care recipient. In both instances the caregiver considered the care recipient to be a member of their family and was therefore included in the study.

Healthcare provider participants (n=12) were recruited, using purposive sampling, from the OHSU Knight Cardiovascular Institute, with which Intel Corporation has an established research relationship; Samaritan Hospital in Corvallis, OR; and Providence Heart and Vascular Institute in Portland, OR. All clinician participants were cardiologists. The researcher was introduced to one cardiologist from OHSU in person on the Intel campus. This cardiologist consented to participate in the study and an interview time was scheduled. After the completion of this interview, the cardiologist then referred the researcher to several other cardiologists at OHSU who also participated in the study. The researcher also knew a community contact that worked at Samaritan Hospital in Corvallis. This community member introduced the researcher to a key member of the Samaritan Hospital cardiology department who consented to participate in the study. This cardiologist then referred other cardiologist participants to the researcher through email. The researcher also emailed cardiologists at Providence Heart and Vascular Institute in Portland with study recruitment information. One participant from Providence responded, consented to participate, and was interviewed. An additional clinician participant was referred to the study by a community member who learned of the study from the researcher’s committee chair through casual conversation.

We stopped recruitment efforts prior to reaching the original proposed study goal of 90 participants, because participant discussions during the study revealed mostly similar concepts and beliefs within the different participant groups.

Procedure

All patient and caregiver participants provided signed informed consent to participate in the study before study interviews began (see Consent Forms, Appendix D). Clinician participants provided verbal informed consent prior to the beginning of each interview. Participants were interviewed in their home or in another agreed upon location appropriate for conducting an audio-recorded interview. Most patient and caregiver interviews occurred at participants’ homes and most clinician interviews occurred at the cardiologists’ places of work. When interviews did not occur at the home or place of work, the lead researcher arragned for them to occur in public meeting places such as public libraries and university library meeting or study rooms with doors that closed to ensure confidentiality. Three interviews took place at a rural senior center that allowed the researcher to conduct interviews in unused multi-purpose rooms. Most cardiologist interviews took place during normal working hours, although one took place on the weekend. Patient and caregiver interviews were scheduled at times that were convienient for participants and meeting times ranged from mid day on a week day to evenings and weekend afternoons. Audio recorded telephone interviews were conducted with three participants who were unable to meet in person. Interviews were conducted in English or Spanish, based on the preference of the participant. Spanish language interviews were conducted by a bilingual, Spanish speaking, research assistant. All English language interviews were conducted by the lead researcher. The lead researcher attended all Spanish language interviews that took place in Oregon. Interview notes were taken at all interviews and notes that were taken at Spanish language interviews were discussed by the bilingual research assistant and the lead researcher.

Semi-structured interviews for healthcare providers included questions designed to elicit discussion of remote health monitoring (RHM) technology use from a clinical perspective. Probing techniques were used to follow new lines of dialogue as they emerged in the course of the interviews. Interviews with clinicians lasted 30 minutes on average and ranged from 25 minutes to 50 minutes. One cardiologist volunteered to be interviewed twice, once at the beginning of they study and then again towards the end, but others were only interviewed once. Patient and caregiver interviews used open ended questions designed to elicit beliefs about remote health technology from a practical, home based use, perspective. Patients and caregivers were interviewed one time and interviews lasted about 60 minutes. Photos and diagrams of RHM devices were used to support discussions during some interview questions (See Appendices B and C). At the conclusion of the interview, caregiver and patient participants were given a $50 participation incentive as compensation for their time. Clinician participants were given a $350 participation incentive as compensation for their time. However, due to contractual arrangements between Intel and OHSU, clinicians at OHSU were not given a participation incentive.

3.4 Data Analysis

Interview notes were typed and saved as Microsoft Word documents and upload to Atlas.ti, a qualitative analysis software program, for analysis and to supply contextual information and clarification regarding the interview such as interruptions, emotional situations, or explanations for interviews that ended early. Interview audio recordings were sent to a professional transcription service. Transcripts were reviewed for accuracy by reading them while listening to interview audio files. Spanish language audio recordings were first transcribed in Spanish and then translated to English. Transcripts were then uploaded into Atlas.ti. All data collected during the course of the study was deidentified and kept in a secure, password protected, computer file. Handwritten and paper documents were kept in a locked filing cabinet in Carolyn Mendez-Luck's lab at Oregon State University.

Interview transcripts were first read in their entirety and then structurally coded (Saldana, 2013) by interview question as part of the content analysis process. Content coding of cardiologist interviews was completed first, followed by the MA patients, MA caregivers, NHW patients, and then the NHW caregivers. The same codes were used for MA and NHW participants to allow for cross group comparisons. Excel spreadsheets were created for each participant group to organize participants' responses to interview questions. Once participant responses to all questions were entered into the excel spreadsheet, similar responses within each participant group were consolidated together. Next participant reponses were summarized as a whole for each group, then compared across groups to explore similarities and differences. The comparisons among caregivers and care recipients in the analysis were not made at the caregiving dyad level but were made cross-culturally between caregivers and patients. For example, dyad concordance was not explored; however, results among Mexican-origin caregivers and non-Hispanic white caregivers were compared and contrasted. The results of this analysis are presented under the “Sample Characteristics” and “Content Analysis” sections of the results.

A second round of coding was completed by freely coding passages based on topics and concepts that emerged during participant discussions. Free coding of the transcripts took place in the same order as the content coding. These codes were further arranged into major catagories within Atlas.ti and added to the excel spreadsheets that contained the content analysis. The thematic analysis was conducted after the second round of coding was completed. For the thematic analysis, all coded portions of all the transcripts, both the structural codes and the free codes, and the transcripts in their entirety were examined for commonalities, differences, and relationships between and across participant discussions to establish themes that emerged around the specific aims of the study. Excel spreadsheets were used to group and organize transcript passages around emerging themes. The results of this analysis are presented under the “Thematic Analysis” sections of the results.

Thematic and content analysis results for each study aim were then mapped back to the study’s theoretical frameworks included in the conceptual model. This was done to examine how study findings aligned with the conceptual model and to determine if new insights uncovered by the study could improve the conceptual model. The results of this analysis are presented in the “Conclusion” section of the results for each aim.

3.5 Human Subject Research Protocol

Because this project involved human subjects, IRB approval from the Oregon State University was obtained before study recruitment and data collection began. (See IRB approvals Appendix E.)

CHAPTER 4 RESULTS

4.1 Sample Characteristics

Full sample. A total of 70 participants (29 patients, 29 caregivers, and 12 cardiologists) were enrolled in the study and completed semi-structured interviews. Many participants were part of a caregiving dyad, meaning both the caregiver and the care recipient chose to participate in the study. A total of 19 dyads (13 Mexican American (MA) caregiver/patient pairs; 6 non-Hispanic white (NHW) caregiver/patient pairs) participated in the study. All physician participants (n = 12) were cardiologists, and are henceforth referred to as "cardiologists." More detail about participant groups is provided below and in tables 4.1, 4.2, and 4.3.

Patient characteristics. Table 4.1 describes the demographic characteristics of the patient participants, which were gathered at the beginning of each interview. Patients resided in both urban and rural Oregon (n = 24) and in Los Angeles, California (n = 5) and shared that they were born in the United States (n = 18), Mexico (n = 10), and Europe (n = 1). Patients' living situations varied and ranged from rural homes homes that housed multiple generations of family members, small homes in the country, small modest mobile homes in suburban areas, housing complexes for those aged 65 and over, to townhouses and apartments in the city. Most patients were retired and spent their time with family members and participated in leisurely activities such as daily walks and visits with friends. Some patients also volunteered their time with church groups and some still maintained contact with their former places of work in a consultative or mentoring role.

While a few patients only managed HF, 23 patients managed other chronic diseases in addition to HF and explained that their family members helped them manage those diseases. In general, most patients managed HF and 2 other chronic conditions. Blood pressure issues, which are common among HF patients, were discussed by 7 patients and 11 patients also managed type 2 diabetes. Some had been managing type 2 diabetes for many years. Additionally, since the average age of the patients was around 76, many patients also managed chronic diseases that are common among older adults such as arthritis and chronic aches and pains.

Caregiver characteristics. Table 4.2 describes the demographic characteristics of the caregiver participants, which were gathered at the beginning of each interview. Caregivers lived in either Los Angeles, CA (n=4) or rural, urban, and suburban areas of Oregon (n=25) and shared that they were born in the United States (n= 18) and Mexico (n=11). Caregivers' living situations varied and ranged from rural homes homes that housed multiple generations of family members, small homes in the country, small modest mobile homes in suburban areas, housing complexes for those aged 65 and over, to townhouses. About half were retired or not working and several had children they took care of at home. Some caregivers were able to work from home so that they could be near their family member

While some caregivers only provided support with managing their family member's heart condition, most caregivers had helped their family member manage other conditions such as type 2 diabetes for many years prior to their HF diagnosis. Most caregivers helped their family member manage 2 illnesses in addition to HF. Caregivers also discussed their own health status and how often they went to the doctor for their own health. Most caregivers tended to say they were in excellent to normal physical and mental health, with only four describing their own health as poor and one MA caregiver that described his health as bad. Most caregivers mentioned that they went to regular check-ups with their primary care doctors one to two times per year, however three caregivers shared they had not gone to the doctor in the past 12 months and eight caregivers had been to see a doctor more than five times in the last 12 months.

Cardiologist characteristics. Table 4.3 describes the demographic characteristics of cardiologist participants, which were gathered at the beginning of each interview. Cardiologists (n = 12; 10 men and 2 women) included cardiology fellows, general cardiologists, HF and heart transplant specialists, research directors, and professors of medicine. Cardiologists had been in practice between 4-23 years and represented urban, suburban, and rural hospitals and clinics. All cardiologists shared that they were actively providing care in both hospitals and outpatient clinics in the state of Oregon. Cardiologists worked in several types of settings, a regional medical center located in a rural area (n = 7), a medical school in an urban area (n = 4), and a cardiovascular center that was part of a medical group network in a suburban area (n = 1). Cardiologists described their patients as mostly non-Hispanic white and mostly insured since the passage of the Affordable Care Act. They shared that their patients' ages ranged from children under the age of 18, to adults between the ages of 35-85.

Table 4.1 Sample Characteristics by Race/Ethnicity: Heart Failure Patients (N=29)

	Mexican American Participants				Non-Hispanic White Participants			
Characteristic	*n*	%	*M*	Range	*n*	%	*M*	Range
Mean patient age (in years)	14	-	69.6	50-86	15	-	83.3	60-95
Mean years of patient education	14	-	5.5	0-14	15	-	15.3	12-19
Mean years since heart failure diagnosis	14	-	13.1	-	15	-	4.5	-
Mean years receiving care from a family member	14	-	17.80	<1 – 55	15	-	6	1.5 – 21
Median monthly income (US dollars)	14	-	1,047	0-2,383	15	-	3,500	1,308 – 6,000
Number of persons in household	14	-	3	2-7	15	-	1.5	1 – 3
Marital Status								
Married	10	71.4	-	-	5	33.3	-	-
Widowed/Widower	4	28.6	-	-	8	53.3	-	-
Divorced	0	-	-	-	2	13.3	-	-
Patient/Caregiver live together	14	100	-	-	5	33.3	-	-
Patient is Caregiver’s								
Husband	4	28.6	-	-	3	20.0	-	-
Wife	2	14.3	-	-	1	6.7	-	-
Mother	3	21.4	-	-	8	53.3	-	-
Father	3	21.4	-	-	1	6.7	-	-
Other Relative	2	14.3	-	-	2	13.3	-	-

Table 4.2 Sample Characteristics by Race/Ethnicity: Heart Failure Caregivers

	Mexican American Participants				Non-Hispanic White Participants			
Characteristic	*n*	%	*M*	range	*n*	%	*M*	range
Mean caregiver age (in years)	16	-	52.5	33-76	13	-	63	27-86
Mean years of caregiver education	16	-	10.8	0-16	13	-	16	9-18
Mean years providing care to family member	16	-	14.3	1-37	13	-	9.5	1-42
Median monthly income	16	-	$1,916	0-5,000	13	-	4,000	0-10,000
Number of persons in household	16	-	3.9	2-8	13	-	2.2	1-4
Marital Status								
Married	12	75	-	-	8	62	-	-
Single	1	6	-	-	3	23	-	-
Divorced	2	13	-	-	1	7.7	-	-
Widowed/Widower	1	6	-	-	1	7.7	-	-
Patient and Caregiver live together	16	88	-	-	7	54	-	-
Patient is Caregiver’s								
Husband	4	25	-	-	5	38.5	-	-
Wife	1	6	-	-	1	7.6	-	-
Parent	8	50	-	-	5	38.5	-	-
Sibling	1	6	-	-	0	0	-	-
Other Relative	2	13	-	-	2	15.4	-	-

Table 4.3 Sample Characteristics: Cardiologists

Characteristics	*n*	%	*M*	Range
Male	10	83	-	-
Female	2	17	-	-
Years in practice	12	-	10	4-23
Practice type				
Regional Medical Center	7	58.3	-	-
Medical Group	1	8.3	-	-
Medical Research Institution	4	33.3	-	-
Patient Ages (in years)	-	-	-	0-85

4.3 Aim 1 Results

The first aim of this study was to compare the remote health monitoring (RHM) goals and beliefs of cardiologists to those of Mexican-origin (MA) and non-Hispanic white (NHW) heart failure (HF) patients and their caregivers. Content and thematic analysis results for Aim 1 are presented below.

4.4 Content analysis

Conceptualizations of RHM. In their discussions, all participants explained what they believed RHM could do and what it could be used for. Participant discussions of RHM varied depending on whether the participant was a cardiologist, patient, or caregiver. Some conceptualizations of RHM differed between the NHW and MA groups as well. Conceptualizations of RHM ranged from using devices such as blood pressure cuffs and scales at home and writing down measurements to systems that involved transmission of patient data to doctors without much effort from patients.

How cardiologists conceptualized RHM. Cardiologists described that RHM was a type of system that involved collecting vitals and patient symptoms in the home. RHM communicated that information on vitals and symptoms back to the clinical staff who then made treatment decisions based on data that was received. Cardiologists conceptualized RHM in ways that did and did not involve technology. Cardiologists that explained RHM in ways that did not involve technology described it as, "*a means of managing heart failure outside of a clinic setting, outside of direct contact*," "*keeping logs of weights and blood pressures and medication usage*," and "*The monitoring that happens in their home. So, their scale and they're writing it down*." Some cardiologists also considered phone calls with patients a form of RHM and shared that phone calls were often the best way to communicate with patients and keep track of their health in between visits. Other cardiologists talked about health technology when they discussed RHM. Dr. Jones, a cardiologist, professor, and director of HF transplants at a medical school, described RHM as:

> In the heart failure world, a lot of it has been based on sensor technology, that being a scale, a blood pressure cuff, heart rate, sensor technology as it relates to implantable devices for monitoring abnormal heart rhythms in implantable devices…the device that gives you computed pulmonary artery diastolic pressure…an implantable pulmonary artery sensor. There is left atrial, interatrial septum transfusers to give direct left atrial pressure in monitoring. And then there's a variety of tools that the patient can interact with to let us know how they're feeling…So it's sort of measuring vital signs at home and measuring patient symptoms at home as best we can. But we've been trying to distill it down to non-symptom based and discrete measures such as the PA pressure or the pulmonary capillary wedge pressure with the cardioMEMS device. But certainly there's more to it than that.

Several other cardiologists also mentioned the types of technology that Dr. Jones described above when they discussed how they conceptualized RHM. Dr. Jones explained how cardiologists that used RHM were trying to move beyond just measuring symptoms of HF exacerbation and mearue the root causes and indicators that caused the symptoms.

How patients conceptualized RHM. Patient conceptualizations of RHM had similarities and differences to those shared by cardiologists. Patients, in general, conceptualized RHM as something that was beneficial to their health. However, among MA patients, RHM was not necessarily perceived to be a specific device or a system. MA patients' conceptualizations of RHM included technologies that were common in their everyday lives like the internet and cellphones as well as devices such blood glucose monitors and blood pressure cuffs. Several MA patients shared that they considered the internet a form of RHM technology because they could use it to search for health information. MA patient Maria, age 64 and an avid smartphone user, started having problems with her heart 25 years ago and shared her thoughts on RHM technology, explaining, "*It's good because you will know right away. If I need to…I can email her [the doctor] or text…I can text the nurse…so I get my answer. They send me an email or whatever."* Maria's example shows how the cell phone itself was considered a form of technology that could benefit health when she communicated with her MD by text.

When NHW patients shared what first came to their mind when they thought of RHM, most discussed the value of pacemakers for HF patients and their discussions focused more on medical devices. NHW patient Michelle, age 72, had managed her condition for the past two years with the help of husband Harold. Michelle discussed the RHM system her pacemaker was connected to, which is what she thought of when she described what RHM meant to her:

> At St. Jude Medical, this thing…it's reporting something, supposedly, at 2:00 in the morning, and that's very wonderful. For a long time, I didn't believe there was somebody who was there, but my doctor said there was such a person, and he's been doing it for years. That's kind of interesting. My father died because his battery on his pacemaker ran out before he went to the hospital, and that was ridiculous. They say, "That's not going to happen to you because we can tell how much battery life you have."

Like many other NHW patients, Michelle thought of pacemakers when she first thought about RHM for managing her condition. Michelle's conceptualization and experience of RHM was similar to the one shared by cardiologists because she discussed the topic soley in terms of the medical device she used.

How caregivers conceptualized RHM. Caregiver conceptualizations of RHM revealed that they thought RHM was "*very practical*" and it allowed them to help their family member more. All caregivers tended to discuss specific health indicators that could be monitored in RHM through the use of devices such as blood pressure cuffs and blood glucose monitors, but did not necessarily include providing the information to the cardiologist or other clinicians. NHW caregiver, Harold, age 86, helped his wife Michelle manage her condition for the past two years. Here he shared what first came to his mind when he thought about RHM for HF:

> Well, the big thing is this thing in the bedroom that monitors her heart every time she's sleeping and records the heartbeat, the spacing, which is an EKG, and it's recorded in the doctor's office, and they either monitor that, or, independently, if something's wrong with that, I guess they have a program that would alert somebody. If something was wrong, they'd call 911 or something like that. All that is through the phone line and everything. That's amazing. And also what they do is implant these leads, for example, in her heart. That technology is incredible, what they do – and they can adjust those leads to pull them out or push them a little bit more, just in the office with simple technology. I think if she had this problem 20 years ago, she might not be here now, but the technology is so improved, medically.

Harold's wife used an implanted pacemaker that was a form of RHM and he conceptualized RHM in a way that was similar to some of the cardiologists because he focused on soley describing medical devices in his conceptualization of RHM.

Overall participants conceptualized RHM as something that was beneficial for both patients and caregivers. RHM was described as involving health technologies and additional technologies available to participants in their everyday lives such as cell phones and the internet. For some cardiologists, RHM did not need to involve technology and could be done by writing down patient weight on a piece of paper. There were some differences in how MA and NHW patients described RHM. NHW patients tended to describe RHM in specifically in terms of medical devices, while MA patients also included easily accessed forms of commication such as text messaging in their conceptualizations of RHM.

Advantages of RHM for HF. All cardiologists, caregivers, and most patients, described benefits and advantages to RHM technology for use in managing HF. Many cardiologists described benefits that tied to better management of the condition and how RHM could assist with better recording and archiving of patient vitals and health indicators. Patient discussions on the advantages of RHM also highlighted the additional information they would have about their health condition, how RHM could provide them with peace of mind, and how RHM might assist with mobility issues. Caregivers shared that RHM had the potential to assist them in having a sense of greater control over their family member's health and that it could help patients adhere to healthier behaviors.

Caridologists' thoughts on advantages of RHM for HF. Most cardiologists shared that a benefit to RHM is that patients would use the data collected in technology based RHM programs to better manage their condition. They shared that patients who were frequently admitted to the hospital would most likely appreciate RHM and the information it could provide them in order to stay out of the hospital. Cardiologists described how RHM would assist them in doing their job better and help to prevent hospital readmissions. Dr. Juarez, who worked in a rural hospital and medical center, shared:

> Advantages would be that we would have an accurate, consistent record for everybody and we would have access to it all the time. And should they come in for an emergency or should something happen then we could see their trends and if they're gaining weight or if their pressure's going low, or if their heart rate's going high, we could have data beforehand and hopefully we would have preemptive data to prevent hospitalizations.

Dr. Juarez described the system as advantageous because it would not only provide information that would be helpful to patients, it would also provide longitudinal data for clinicians to use in medical decision making and management of HF.

Patients' thoughts on advantages of RHM for HF. Patient discussions that focused on the advantages of RHM for HF fell into three main domains: RHM could provide important information to patients, RHM could contribute to peace of mind, and RHM could assist patients with balance and mobility issues.

RHM provides information. Patients agreed that in situations where they could be provided with information on their health status on a regular basis, having knowledge of their health status would be helpful to them in many ways. Both MA and NHW patients, explained that having this information would help when it came time to discuss medication management with their doctors. Other MA and NHW patients thought that the data collected by health monitoring devices in their homes would be helpful to their doctors when determining if their condition was changing. MA patient, Carmen, thought her cardiologist would "*put it in my file…He would keep a record of how I do on one month and the next. He would see if I'm improving or worsening.*" Patients shared that longitudinal data collection on their condition would help doctors in determining their health status and treatment plans.

RHM provides peace of mind. Patients thought health monitoring technology may also provide them with peace of mind about the status of their health. MA patient, Maria, who had open heart surgery and a pacemaker implanted, worried about her health when she was not feeling well and shared how knowing her health status in between doctor appointments would benefit her:

> It would help me tremendously because…I don't have to wait until I go to the doctor, to my next appointment, if I wasn't feeling well, you know, sometimes you don't feel [well], you know, and then it concerns me because what all the things I had done.

Not having to wait until a regularly scheduled appointment to find out if her symptoms were within a normal range, would ease Maria's mind. Many other patients felt that having the information from the devices monitoring their health would increase their knowledge about their personal health condition and ease their minds. One MA patient, Roberto, described, "*I would be relaxed because they would have the results of what's going on with me, and what I have.*"

Patients also discussed the ways personal emergency response systems (PERS; e.g., Life Alert buttons) contributed to their peace of mind and their caregiver's peace of mind. Both NHW and MA patients shared that cell phones could be just as good at providing peace of mind as personal emergency response systems if you carried them around everywhere with you. NHW patient, Donna, age 86, who had been getting help from her niece for the past 15 years, explained:

> My one niece about five years ago wanted me to get one of those necklaces, and I said, "I don't want one of those." But now after that fall, they told me be sure and keep your cell phone on you. Have your phone on you all the time in case you fall, you won't be able to get up. So since I had that fall, I said they're probably right. I hadn't thought about that. So now I take it, put it in my pocket and have it on me. Because I never had it on me before. So now I actually use it. And if I'm working in the yard, I'll put it on my pocket because then if something happened, who knows – I might have a stroke out there. I don't know. But at least I'd get help, I think. I'd never thought about it before until this fall, and then I realized that if you fall, you can't get help. So I should have something on me. So now if I go for a walk, I'll take it, which I never did before, take it with a walk because most of the time I'm alone. Or if I'm working in the yard, now I just change my habits. Good thing.

For Donna, and other patients, having a PERS or a cell phone provided a tool to use in an emergency, which they considered to be a technology that was part of RHM.

RHM can help with balance and mobility. NHW patients shared that technology could address and provide benefit to them if it could assist with balance and mobility. NHW patients considered walkers and chairlifts assistive health technology and a part of RHM. They shared that having them in their homes was important for their health. NHW patient, George, shared his views on having assistive technology for mobility and said, "*Yeah, the walker is particularly – well, you fall once and break you're – you break something, you – I don't want to fall again*. George also found benefit in the chair lift his caregiver installed to help him get up to his bedroom on the second floor of his home.

MA and NHW patients discussed many similar benefits and advantages they perceived to be related to RHM use in managing HF such as how it can provide valuable information and contribute to their peace of mind. One difference between MA and NHW patient discussions was that NHW patients also considered assistive technologies such as walkers and chairlifts to be a potential part of RHM for HF and they discussed the advantages of these devices for assisting with balance and mobility.

Caregiver thoughts on advantages of RHM for HF. Caregivers discussed many of the same topics that patients and cardiologists shared on the advantages of RHM but also saw additional advantages in the use of RHM such as how it gave them a sense of more control over the health of their family member and how it could possibly persuade family members to engage in healthier behaviors. MA caregiver, Gabriela, age 74, shared her views on the RHM technology she used as a caregiver for her husband:

> I see it as very practical. For example, it's very practical that I can check. I have the device to check the blood sugar. I have the machine to check the blood pressure. I know the symptoms more than him [the care recipient]; how I can manage it, what is happening with him so that I can control it. If it's an emergency I can take him to the hospital.

For Gabriela, RHM included devices that provided information that helped her better control and manage her husband's condition. To caregivers like Gabriela, an advantage that RHM provided was a personal sense of greater control over HF and its management. Another advantage caregivers shared that RHM provided was how it could be helpful in changing their family member's bad habits. NHW caregiver, Joyce, age 68, explained that she often told her husband what he needed to do to manage his health, but he was not consistent in following through. Here she described why she thought an RHM system that included an activity tracker would be good for him:

> I really think that would be helpful to him because he goes for a walk periodically, but he really doesn't do exercise, per se. He'll do yard work or something, and it's erratic…and for somebody with lung problems and heart problems, knowing that, you would think that he would do something more, but he thinks the medication just takes care of it and he can eat all the red meat and all the high cholesterol things because he's on cholesterol medication, it's taking care of it.

For caregivers similar to Joyce, who had a hard time getting their family member to comply with doctor recommendations, RHM provided an opportunity to have something else take on the task of reminding the family member to make healthy choices. Joyce also shared that she thought her husband would be more likely to take advice that came as part of the RHM system than he was to take the advice that she gave him.

Overall, participants shared that there were many advantages to RHM use. Cardiologists felt RHM could assist in preventing hospital admissions and provide longitudinal data collection of patient vitals and symptoms that would assist medical decision making. Patients thought RHM was beneficial because it would provide them with more information about their condition, it would provide them peace of mind, and it could help with mobility and balance issues. Caregivers discussed the benefits that patients and cardiologists shared, but also thought RHM provided caregivers more of a sense of control in managing their family member's health and it could also encourage family members to adhere to healthier behaviors.

Unsure about RHM for HF. Some participants shared that they were unsure about using RHM data and wondered if RHM would provide any benefit in HF managment. These participants discussed concerns about the reliability, accuracy, and validity of RHM devices and the data they produced. Several patients, caregivers, and cardiologists described similar situations in which RHM devices failed to meet their expectations.

Patient, caregiver, and cardiologist reasons for being unsure about RHM for HF.

Several caregivers, patients, and cardiologists shared unsatisfactory experiences with RHM related to implantable devices that had sent remote signals to clincians. Caregivers described instances where the implantable device had triggered an alert, but their family member did not find out that anything odd had happened until several days later when a technican called their home. Joyce talked about her frustration with the RHM system that monitored her husband's defibrillator and shared, "*They [technicians] call us three days later or not at all, and the doctor didn't seem to even know that they called three days later, or that they even called at all*." Other caregivers that had experiences similar to Joyce's shared similar stories and frustrations. These caregivers wondered if new RHM systems would work efficiently. Similarly, several cardiologists did not fully trust RHM. Dr. Pham, a general cardiologist, shared his concerns about the data he had received from pacemakers:

> We have a lot of the pacemakers, these days, they are able to somehow test the impedance between the leads and they are able to tell if they are maybe filling up with fluid or whatnot. I have not found that as useful and I feel like those numbers kind of go up and down without a lot of specificity to actually having fluid overload or not. So, sometimes when I see those things and I call patients, their weights are stable and they feel fine. I don't know why, all of the sudden their impedance has gone up or something. So, I don't find that a very good way, but people have tried things like that and I guess the pacemaker field is sort of leading, but I have not found that as useful. I think, to me, the weights are always the best and that seems to be, for the majority of my patients, where we first start seeing a change and maybe even before they have symptoms.

Additionally, cardiologists that had experience using RHM that required patients to write down their health data, explained that the process had flaws. One cardiologist shared that he did not know if the logs were filled in right before the appointment or if they were actually representative of daily measurements. In both the hand written and technology based examples from cardiologists, the doctors shared reasons to have doubts about the validity of the data they were receiving.

MA patient, Teresa, age 65, shared that technology needed to work properly to give you peace of mind. She explained that in her past experiences using call buttons for nurses in hospitals, "*you push the button and they come, but when you push the button and they don't come, it feels bad.*" Teresa's previous experiences with health technology did not always provide her peace of mind because the technology didn't produce the results it was supposed to. Teresa thought there was benefit to RHM for HF, however, she wanted to make it clear that the devices needed to function reliably.

In general, those that were unsure about RHM shared previous experiences in which RHM devices and systems did not function as the participant expected. These previous experiences influenced their current opinions on how well new RHM systems for HF might work.

Barriers associated with RHM for HF. Some patients, caregivers, and cardiologists discussed potential barriers to using RHM to manage HF. Barriers that patients discussed were related to not understanding the technology they might be asked to use. Caregivers anticipated barriers similar to the ones that patients had and discussed that RHM technology needed to be easy to use in order for their family members to properly use it. Cardiologists discussed more barriers to adopting RHM than patients and caregivers, and shared that they had doubts about patients using RHM at home.

Patient barriers to RHM. Barriers for patients were commonly related to their knowledge around using new technologies or physical limitations that made it difficult to use certain forms of technology. Commonly mentioned barriers to RHM use that related to perceptions of self-efficacy among patients included, "*I don't understand them* [new technologies] *due to lack of education*," "*I am just very illiterate when it comes to computers,*" "*I do certain things, but if I have a problem I don't know what to do*," and "*I do not text because I don't see well enough to do it*." Other patients discussed having difficulties hearing communications on cell phones as well. MA patient, Javier, age 66, explained a barrier he had experienced using RHM due to not being an English speaker:

> [The doctor] gave me a heart monitor for three days and I didn't even know how to work it…I didn't know because we have to write it down, or he does. In the hospital they told me in English. So no, since I don't know much about writing, I don't understand much about the devices like those. I need a teacher to give me the pulse thing. I need someone to be here for a week to teach me, right? So I don't know about those devices. I don't know how to use them. I know how to use the car and go to the doctor if I don't feel well but not those devices.

Other MA patients also shared that not being able to speak Spanish with their clinicians presented barriers when it came to following instructions at home.

Caregiver barriers to RHM. Barriers to RHM use that caregivers anticipated had more to do with the ease of using RHM devices. Here MA caregiver, Valeria, age 43, explained an issue that she had encountered with an RHM device that her 77-year-old mother needed to be able to use:

> Well, my mother was measuring the sugar level but it practically never worked. We went to the clinic and they gave her a new one, like it's too complicated and especially because elderly people forget things. So they explained to her what to do, but as I couldn't accompany her that day because I had an interview at the time of her appointment, when she came home she had forgotten what they had explained to her. We went again on another occasion and they taught us but it was difficult to use. So, it would be preferable it the devices could be more practical, or faster, less complicated.

Caregivers like Valeria shared that they wanted RHM devices to be simple and easy for older adults to use or else the devices themselves might create a barrier to participating in RHM.

Cardiologist barriers to RHM. Cardiologists discussed many barriers that centered around how the patient would or would not engage with the RHM system once the patient brought it home and the use of RHM in their own practice. The first barrier discussed by cardiologists was that they anticipated that some patients would not engage with RHM devices due to challenges that patients might encounter when trying to use RHM. Some of these perceived patient challenges were lack of internet connectivity and affordability of internet connections in the home, patient comfort with using computers, and general lack of health and technological literacy. The second barrier to RHM use cardiologists mentioned was lack of motivation to use the devices. Cardiologists described scenarios where some patients would bring the equipment home and never turn it on. Another reason for lack of motivation to use the devices that was shared by cardiologists was that patients might not have the time to follow through with RHM since they are already busy managing many other aspects of their lives. These cardiologists shared previous experiences with patients that lacked follow through, for example, many patients could log on to their web based patient portals to see test results, however cardiologists explained most patients did not set up the accounts in order to take advantage of this service. A third barrier to RHM use that cardiologists shared was that patients might forget to use the devices in general, not using them when they felt fine and then when they felt bad they would be too sick to use them. The last barrier that cardiologists discussed was related to patients using the data RHM could provide. A few cardiologists shared they were skeptical about patients using the data they collected with RHM and did not think that patients would be especially interested in the data. These cardiologists explained that patients would be more interested in how they felt each day than in what the data said and that older adults would not be as interested in using the RHM data.

Cardiologists also described barriers to use of RHM in their own practices. They shared that managing the data generated with RHM devices might increase workload for them or for those that work in their offices. Cardiologists thought this problem could be addressed by having staff that is specifically trained in how to interpret the data so that cardiologists do not become overwhelmed as explained by Dr. Hardy, who worked at rural hospital and cardiology clinic:

> It will be really physician dependent in…how each physician wishes to spend their time…What I mean by that is I speculate all this data trending, all this information, there's going to be a whole plethora of information, and it's what you do with it. And so depending on the frequency, how often you're getting that data, and how receptive that physician is about notifying the patient and keeping track of everybody. It could get overwhelming…Creating a network or a particular group of individuals who primarily focus on data gathering, interpretation of that data, and being able to weed out more critical value or red flags, versus others that are, you know, being able to just identify what heart failure – pre heart failure exacerbation will be.

Another area that cardiologists thought might present a barrier within their practice was around patient privacy. One cardiologist explained that caregivers and patients might feel that RHM is intrusive and shared:

> I think there's a potential for intrusiveness for patients and caregivers depending upon the kind of monitoring. So it depends where this remote sensory technology evolves in the future, but I think that there is a potential for people to feel that their privacy is not being respected.

Overall, barriers to RHM use shared by patient participants involved lack of education around and/or familiarity with technology, low perceived self-efficacy in relationship to certain forms of technology, and language barriers that made understanding instructions presented only in English difficult to understand. Caregivers shared that the devices needed to be easy to understand or older patients might not be able to use them. Cardiologist discussions revealed that they anticipated a variety of barriers to RHM use among their patients which included lack of motivation to engage in RHM to wanting to engage with RHM but not being able to afford an internet connection in the home.

RHM Goals. All participants discussed that the main goals of using RHM for HF were to have more knowledge about the patients' health status, better manage the condition, and prevent emergencies. Each group of participants had specific goals in mind for what they wanted to do with the data that RHM would provide to them. Cardiologists wanted to have knowledge of a wide variety of health indicators to identify patients that are at risk for symptom exacerbation early enough to prevent hospital admissions and readmissions. Patients wanted the information for self-management of HF and to provide it to their caregivers and family members. Similar to patients, caregivers wanted to use the information provided by RHM to better understand and manage their family member's condition, but they also saw value in how RHM could help them be prepared for emergencies.

Cardiologist goals. Dr. Hardy, a general cardiologist in a rural medical center and hospital, explained that the goal of using RHMwas that it would allow for, "*potentially identifying triggers for heart failure exacerbations, so catching it earlier than later, hopefully resulting in a prevention – preventing hospitalization*." Cardiologists also explained the importance of receiving RHM data in a form that was actionable, so they could follow through and prevent HF emergencies. Dr. Jones explained his goal for how RHM data should be used in HF management:

> I mean, you can get data. The question is what do you do with it? And what's the system that you put in place to make that data actionable? If you just look at a bunch of data and say yeah, it looks okay, that's not a really good treatment algorithm. Just like the devices have very stringent algorithms, we should have as stringent [disease] management algorithms that are just very concrete.

Cardiologists that shared Dr. Jones' point of view thought a successful RHM system should include more than just trending data in the electronic health record and wanted to be able to identify common factors in the data that might be contributing to good versus bad outcomes in each patient. Some cardiologists wanted to take these RHM insights one step further and shared that RHM data should initiate conversations with patients that could teach patients about how their condition changed from day to day and the potential triggers of these changes.

Patient goals. HF patients shared that their goals for using RHM were to keep better track of and get a better understanding of their health indicators. They also felt RHM could help them manage their diet. MA patient, Diana, age 77, had been managing her heart condition for the past 8 years and was interested in having some type of RHM technology that she could use to see how clogged her arteries were because:

> …the doctor said my arteries are all clogged and I don't believe it because he said I couldn't go out anywhere on my own because in one of those coming and goings I could fall dead. And that was a few years ago…And here I am, thank God, I'm still here. I would like to have… a device like that…

Diana was not sure if she wanted to believe what her doctor had been telling her about her heart and she wanted to be able to see for herself if what the doctor reported was true. She felt that some type of RHM technology might have been able to help her verify if her doctor was right and give her a clear understanding of her health status. Some patients shared that their goal was to follow their doctor's health monitoring instructions, keep track of their weight and blood pressure, and then contact the doctor when their vitals were outside of their normal ranges. Many of these patients also shared that they would provide this information to their caregivers. Other patients said that their goal was to use RHM to help them eat healthier. These patients discussed that they would use RHM to monitor their condition and that the system would use the health indicator information to provide a daily food plan so they would know what to eat each day to best help their condition. They explained that RHM that did this would help them follow the correct diet.

Caregiver goals. Caregivers had a variety of goals for RHM use from using the data to educate their family member to using it to better understand the health status of their care recipient. MA caregiver, Adriana, and her family, lived with her father in order to keep a better eye on his health. Adriana's father did not have a blood pressure monitor and she described an instance in which she could have used one to show him the effects of not taking his medications:

> I am a medical assistant so I do have a stethoscope. And my daughter was playing with it and he got a hold of it so he's like, I've never heard my heart rate before…So he put it on and he's like, oh my god, that's impressive. That's a really strong heart. I'm like, let me hear it. I'm like, that is very high. That is impressive in a different way, like, that's dangerous. That is not being impressive like your hearts strong. And he's like, oh. I'm like, why is your heart beating so fast? And he's like, oh, I forgot to take my meds. I'm like, well, you shouldn't be proud of that…no, it's not because it's strong. It's because it's racing very rapidly. So yeah, he forgets to take it…if I could keep a blood pressure cuff here to check his blood pressure and have him see the effects of him not taking that medication, maybe have a visual for him to see the effects. You know, it's not good that your heart is racing so hard or so fast. It's not something to be proud of. It doesn't mean that your heart is strong. It means that your heart is over working.

According to Adriana, monitoring and tracking of blood pressure at home with RHM would have helped her explain the connection between taking medications and the impact on the heart to her father. Other caregivers that described their goals for using RHM data shared they would "*provide it to the doctor*" and also use it to determine what activities or meals might be altering the care recipient's condition. These caregivers described how they would adjust foods and medications based on the data they received. One MA caregiver mentioned that her goal for RHM data was to have it on hand during emergencies because she could have quickly sharedshared it with 911 operators, "*I can call and then check her appearance, if she's* *diaphoretic or dry skin, because they'll ask me to have all the consulting in seconds and I won't lose time*." From this caregiver's perspective, having this information at hand would save vital seconds during an emergency.

In general, participants' goals for RHM use involved having a better understanding of the patient's health status. For cardiologists, this meant being able to prevent hospital admissions and also being able to use RHM to help educate patients and their caregivers on the disease. Patient goals for RHM use mostly focused on using the data to learn more about their condition. The goals that caregivers shared included using RHM to inform physicians about the patient's condition and also using the information to help with preparing meals. Much like cardiologists, some caregivers also focused on using RHM to educate the patient.

4.5 Aim 1 Thematic Analysis Results

When exploring what cardiologists, patients, and caregivers shared about their RHM beliefs and goals, one major theme emerged across all groups. This theme, HF is a challenging condition to manage, emerged in different ways when participants shared their goals and beliefs around RHM. HF was challenging to manage for different reasons depending on the role of the participant. Patients described challenges that occurred with diet and medications. Caregivers described challenges in managing their family member's condition when their family member told them everything was fine, but the caregiver knew something was wrong. Cardiologists shared many challenges they encountered helping patients who did not grasp the seriousness of their complex condition or follow through with self-care instructions. See Table 4.4 for an overview of this theme.

Table 4.4 Theme: Heart failure is challenging to manage

Participant Group	Challenges with HF Management
Patients	Medication management and following recommended diet
Caregivers	Blood pressure and blood sugar regulation/management, needing to constantly be aware of family member, and family member is not honest about symptoms
Cardiologists	One management plan will not work for all patients, HF is a degenerative disease, and family members of HF patient must also follow recommended diet

Patients discussed the challenges they had managing their condition such as remembering to take their medications and following the diet their physician recommended. Rosa, age 75, had been managing her disease with the help of her husband for the past 50 years. Rosa was challenged by remembering to take her HF medications on time throughout the day and shared:

> It’s not that easy for me. I tend to get lazy sometimes and that’s – I’ve got to be truthful, that’s it, you know? I get so busy doing around the house that I forget. That’s where I forget my pills, saying “OK, I’m going to” and then at night-time I’m taking them all because my husband’s after me.

Rosa became busy going about her day and often forgot to take her pills until the evening. When she did this, she ended up taking them all at once, not following the recommendations of her physician. Remembering to take medications and take medications on time was a challenge for many patients and something they often relied on their caregivers to remind them to do. Another challenge that patients mentioned was understanding when the appropriate time to take a medication was. Some medications were meant to be taken only when patients were feeling certain symptoms. Patients were challenged by knowing the appropriate situations to use these medications. Twila, age 92, was also managing COPD in addition to HF. She found it challenging to know when she was supposed to use her inhaler because she had not been properly instructed on when to use it:

> Inhalers. And the one, I had it for several years and never used it, and it probably was when I had the pneumonia. They said, "You use this –," and it always said this is the emergency – emergency inhaler. I think it's called Proair. "This is your emergency inhaler." And I thought, "Well, I haven't had an emergency so I'm not going to use it. I could've been using it all the time. Yes, it's great for an emergency, but it's also great to use any time you need it. Now, I haven't used it today. If I were going to go downstairs and get my mail and walk around a bit, I would use it to get me more air.

Twila was managing two complex chronic conditions and shared that determining when to use her inhaler was challenging for her at the beginning because the times to use it were not properly explained to her. Other patients also shared that they had been given pills to take in emergency situations but were challenged by determining if their situation was an emergency or not.

Many patients discussed challenges around following the HF diet to better manage their condition. Javier, age 66, had been managing his heart condition since he was a young man. Javier had worked for many years as a farmer, and shared that he understood the nutritional value of eating correctly, however with his current fixed income he found it challenging to eat the diet his physician prescribed for him:

> Well it's not easy, it's not. It's not easy for me to eat like the doctor wants me to or how I think I should…I live economically and don't get to truly nourish myself how my body requires it…We have to buy vegetables, one of those mushrooms, that's like three dollars a pound or something…food is not easy…even if the doctor tells me to only eat 2 tortillas a day, I eat 4. Some for breakfast and another two for dinner…. Sometimes, well maybe a radish with some lettuce, but not all of the vegetables as if my plate were just vegetables. It's all expensive.

The challenges of following the HF diet came up in other patient discussions as well. Some patients felt the HF diet their physician recommended was challenging to follow because it was bland and repititous. Maryanne, age 89, shared:

> I'm always struggling with staying on a low-fat diet, and basically not eating too much, other than chicken and fish. Sometimes I feel like I'm either going to grow scales or feathers. I thought, oh dear. You know, you've got to do something different. Let's find a new fish that you can bake or a new fish that you can cook. The diet is challenging.

Other patients followed recommendations for both diabetic and HF diets and found it to be exceptionally challenging. One patient explained that if one of her favorite restricted foods, chocolate, was brought into the house it would drive her crazy so her family was not allowed to bring it to the house.

Caregivers discussed that there were many challenges they faced when helping their family member manage their condition and that these challenges often caused them to worry. Caregivers found it difficult to manage their family member's "*blood pressure*" and "*blood sugar*," and described that changes in blood pressure and blood sugar could be sudden and they needed to constantly be aware of these indicators. Sofia age 49, explained how she was constantly thinking about her husband, Manuel, age 50. She shared that she was challenged in managing her husband's condition because she felt he was not honest with her about how he was feeling and explained, "*he* [Manuel] *avoids telling me when he feels bad because he doesn´t want to cause any worries to us.*" This caused problems and issues because:

> …we [his family] are all there and since he´s not well it affects us all. I think he doesn´t understand that, he just sees himself and he doesn´t think it affects us just the fact of watching him be sick, because it worries all. And I think that if he starts to take care of himself, if he starts being careful of what he eats and to assist in his medic [medical care] to see how he´s doing that would help us all. That way we can be certain that he´s taking care of himself and take away some of the worries that we have.

Because Manuel had not taken ownership of his medical care, Sofia felt that she must be extra vigilant in observing Manuel to determine if he was unwell. Sofia felt that it affected not only her, but other family members who saw him in ill health. Sofia shared that it was a challenging situation for the entire family and felt that if he would take more ownership of his care by keeping track of his blood sugar and blood pressure and taking his medications on his own that providing care to Manuel might not be so challenging. Sara, age 37, also shared that her father, Jorge, did not always tell her when he was feeling unwell so she was constantly attentive saying, "*For me, every time I see him quiet or tired, it is there when I think…What's happening with him? And I get worried*." Caregivers seemed to discuss more challenges in managing their family member's condition when they perceived that their family member was not feeling well and the family member said they felt fine or when health indicators such as blood pressure or blood sugar did not stay within normal ranges.

Cardiologists described HF as a challenging condition to manage because patients needed to follow a strict protocol which included medications, exercise, and proper diet in order to control their disease. Cardiologists described HF and its management as complex and dependent on the needs of each individual patient, the stage of their disease, and the various co-morbidities the patient might be managing. One challenge cardiologists discussed was that there was no one exact HF management plan that would work for every patient. Cardiologists had many patients on many different plans that had to be specifically tailored. Another challenge they faced was that patients did not follow these management plans closely. Dr. Blackwell, a general cardiologist who worked in a rural medical center and hospital, gave a detailed explanation of how he approached the HF management protocol and how he assisted his patients with managing their condition based on their response to treatment plans:

> Well, there are multiple different types of heart failures so if we know which type of heart failure they have then we can kinda discuss that. Beyond that they have dietary restrictions and then they need to focus on medication compliance and know what to look out for and what kinda behaviors will force them to come back to the hospital. So, things like their diuretic regimen, if they are prone to retain water because of their diet, whether it's a lot of fluid and a lot of salt intake or sodium intake, then maybe we would need a higher dosage of diuretic…these medications can also change the amount of electrolytes that they have so they would need to know that we could be replacing electrolytes as well and so one of the first things they need to do is take responsibility for the diagnosis and weigh themselves every day. So, keeping a record of their daily weights and checking to see if their weight has increased over 3 lbs. within one day or 5 lbs. within a week. That would be the time that they would wanna call the clinic and we'll discuss the next step. The next step would normally be increase their diuretic. Possibly more fluid restriction along with rechecking their labs to make sure that their electrolytes stay in the correct range. They should also look out for signs that they could– other than their weight, that they could be having more heart failure symptoms. Those could be activities that they used to be able to do, now are causing them to be short of breath. Or not being able to lie down or breathe when they're lying down I should say. They can…have a feeling of chest pressure. They could also be experiencing swollen lower extremities. So, we would kinda discuss those kinda symptoms. A lot of them they've already had and so when they eventually get on the correct regimen those kinda things will go away. And we'll see where there baseline weight is. Initially we would normally wanna titrate their medications to a goal…Most people, it seems like, can't make it to their goal…the heart failure patient is different than your normal patient.

Dr. Blackwell's process of tailoring HF management protocols to his patients was similar to most other cardiologists. Even though all the cardiologists explained they tried hard to work with patients to manage the disease, HF was described as a progressive disease that could be difficult to manage even for those who closely followed all care instructions. Dr. Lee, who treated advanced HF patients and transplant patients, described her views on managing the disease:

> …They [patients] have a chronic progressive disease that's hard to manage for some people, particularly the patients I see, no matter how much they weigh

> themselves, no matter how little salt they take, no matter how they watch their fluid. Their disease is bad and it is hard to manage because of the disease itself.

Dr. Lee had seen many patients fail to manage their condition even though they tried their best to follow the HF management plan she provided them. Dr. Lee wanted to be clear that in these cases, it was not really a failure on the patient's part to manage the disease, but the nature of the disease itself. Dr. Solomon, an interventional and general cardiologist at a rural medical center and hospital, shared how he saw challenges for both the patient and their family members when it came to following the appropriate diet. He explained that he told caregivers that in order for the patient to stay out of the hospital, everyone around the patient would also need to change their diet, which could be challenging for family members trying to help the HF patient manage the condition:

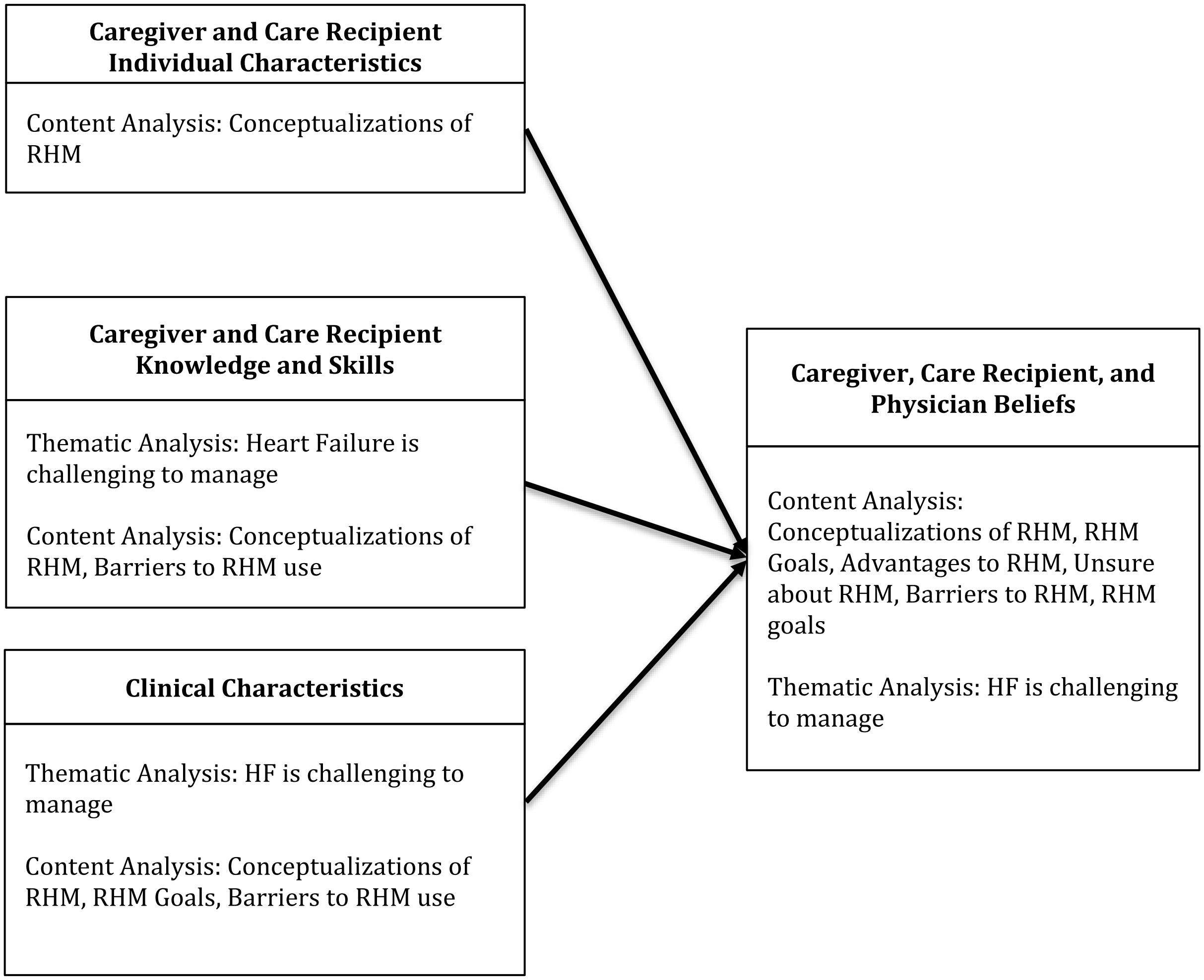
> The biggest thing is no matter what they do, if there's anybody else in the household, spouse or kids, if they're not following the program with them, it's not going to work. So if you have somebody that eats hamburgers and McDonald's all day long, the patient is not gonna do well in that environment, just like smoking….I'd say 90 percent of the patients I see, the spouse is with them, or a caregiver is with them. And so I…try to tell them…that a big portion of your eating is not just what you and you want, but it's environmental. So whoever you're with, you're around, the setting that you go out and eat in will dictate a lot of your food. So it's tough, but trying to tell them, okay, for this person not to go back in the hospital all the time, everybody around them has to help out with that by changing their diet a little bit.

Dr. Solomon shared that it is challenging for the patient to change their eating habits in general and it would be harder for them to do it if those around them did not also change their habits.

Overall, HF was challenging to manage for participants for a wide range of reasons. Physicians found it challenging to persuade their patients to follow complex care plans, patients found it challenging to eat recommended diets and remember to take their medications, and caregivers found it difficult to control their family member’s health indicators, such as blood pressure, and also found it challenging to manage the disease when their family members told them they felt fine when it was not true.

Aim 1 Summary. The first aim of this study was to compare the remote health monitoring (RHM) goals and beliefs of cardiologists to those of Mexican-origin (MA) and non-Hispanic white (NHW) heart failure (HF) patients and their caregivers. Through their discussions of RHM for HF participants shared how challenging it can be to manage the disease. They also shared how they thought RHM could assist them in meeting this challenge. A few participants shared their doubts about whether RHM would work well, especially cardiologists, but the majority saw many advantages to using it in HF management. Figure 4.1 shows where the results of Aim 1 fit in the conceptual model.

Figure 4.1 How Aim 1 fits into conceptual model



4.4 Aim 2 Results

The second aim of this study was to investigate the influence of culture and social environment on the perceived usefulness of remote health monitoring (RHM) technology among Mexican-origin and non-Hispanic white patients and caregivers. Thematic analysis of the influence of culture and social environment across all HF patient and caregiver interviews revealed that participants' views on the usefulness of RHM were influenced by an overarching theme, attitude towards health management. Variation existed in health management attitudes and they emerged in participant discussions across a spectrum. At one end there were participants who had a family centered attitude towards health management, and on the other end were those that had individualistic attitudes. These two attitudes towards health management emerged when participants discussed how they managed HF, how they wanted to use RHM in the management of HF, and their experiences with technology in general. Those patients who had individualistic attitudes towards health management often discussed how they were independent and tried their best to manage their condition on their own. Patients who had a family centered attitude towards health management often deferred to their caregivers in all aspects of their care. Caregiver participants also followed these two management styles. Caregivers that had an individualistic attitude towards health management discussed that they would make suggestions to their care recipient on what needed to be done, or help the family member in instances when help was requested. Caregivers who had a family centered attitude towards health management described that they worked as a team with their family member to manage their condition. Some caregivers that had family centered attitudes toward health management took on all responsibility for managing their family member's health. These two attitudes towards health management influenced the types of technology caregivers and patients perceived to be most useful in RHM. Table 4.5 summarizes this theme.

Table 4.5 Summary of Aim 2

Group	Attitude towards health management	Technology perceived as useful in RHM
MA caregivers and patients	Family centered: patients deferred to caregiver for all or most aspects of HF management	RHM technology needed to facilitate and incorporate social interactions
NHW caregivers and patients	Individualistic: less reliant on caregivers for HF management instructions, patients asked for help when they wanted it	PERS were seen as extremely helpful

Individualistic attitude towards health management and perceived usefulness of RHM. NHW caregivers and patients tended to have individualistic attitdues towards health management. This individualistic attitude came out when NHW patients referred to how they did things for themselves and when NHW caregivers discussed how they wanted to let the family member request help when it was desired. Commonalities among those that had an individualistic attitude included more problems with technology use in the home, less reliance on caregivers for HF management instructions, similarities in preferred forms of RHM data communication, and more use of personal emergency response systems (PERS).

Problems with technology in the home. NHW patients and caregivers discussed having more problems with technology in their homes than those who took a more family centered approach. The problems they shared ranged from internet connectivity issues, not understanding how to retrieve information stored in smartphones, not being able to hear conversations while using cellular phones, and not being able to see cellular phone, tablet, and computer screens very well. They also discussed running into difficulties with technology when their operating systems needed to be updated. NHW HF patient Maryanne, age 89, discussed how having gout gave her problems on small touch screens:

> I have gout, I'm not nearly as dexterous as I used to be. So I have trouble typing – that's really the reason I don't text, is I have trouble typing because my fingers don't move the way they should. It's like having five sticks instead of things that really – hinges that really work.

Maryanne also shared that the type size on smartphones was too small for her to read, but shared, "*I use a magnifying glass and see what it says. You have to adapt to these things, my dear.*" Maryanne found ways to adapt to using technology when she had difficulties rather than asking for help from someone else. Others shared that some of their difficulties with technology resulted from a lack of skills with new devices and shared that they "*need to know a lot more about technology*" and "*it's a lot to learn*." Some of these participants shared that they would just stop using certain types of technology that they couldn't figure out how to use while others shared that they knew where to get help. These participants sought help from family members as well as professionals such as the "*Geek squad*," "*Verizon*," or took a visit to the "*Apple Store*" or the "*Genius Bar*."

Less reliant on caregivers for HF management instructions. Many NHW patients shared that they did not rely on their caregivers for instructions on how to manage their condition at home. These patients discussed getting adequate instructions from their doctors or nurses at their doctor's appointments. These patients also generally described the instructions as easy to follow. Anna, age 81, was cared for by her son, but lived alone. Anna shared, "*my primary care doctor is really good about explaining things and so is the pulmonary doctor*." Anna did not rely on anyone else to help her understand home care instructions. Shirley, age 92, lived alone and was also cared for by her son. She explained, "*I think the doctor or his nurse told me, and I just do it myself. I know how to do it.*" Shirley made it clear that she did not need to rely on anyone else to explain her HF management instructions. Tom, age 72, lived with his wife who was also his caregiver. Tom shared that he followed the doctor's instructions and explained:

> My general doctor…he's got the most practical approach. He knows me the best. The practical approach. The cardiologist, when I go to see him, they sit at their laptop and talk to you and interview you. And I guess he's inputting things in or out of it and he gives me a couple things. But I will say that I do what he tells me to do.

Tom went on to explain that if he had questions when he got home as he was managing his self-care that he felt he could call the doctor's office himself and get help:

> I would call the doctor's office. Actually at The Portland Clinic, it's very good. They have a new thing, I think, just this last year that's very good. There is a, let's see, she's more than an RN. I don't know quite what her qualifications are, but she's very good and also very good with people, and she synchronizes your connection between doctors and stuff, and if you have any questions about anything, she has a phone number you can call and call her anytime for any questions you have, and it's really a very good thing that they offer now.

Tom took advantage of the nurse help line when he needed extra help and did not rely on anyone to make those calls for him. Another patient, George, age 91, who lived down the street from his daughter who was his caregiver, explained that he followed his doctor's instructions and they were easy for him to follow. George shared, "*they not only give me written instructions, but they talk too and it's not very complicated. I – nothing that I have to worry about very much*."

Preferences for RHM data and communications. NHW patients and caregivers had similar preferences for the ways in which they would like to receive RHM data. In situations where the health monitoring device sent information to the patient's clinical care team, a majority preferred to find out about the trends in their health information digitally through an email, by visiting a website, or through a text message. Several thought that a phone call with information about the data being collected would be acceptable as well. Two patients wanted to be told the information in person by their doctor and one of those patients said that after the first time hearing it in person they would be fine with receiving the information over the phone for future updates. Michelle, age 72, who lived with her husband who was also her caregiver, used her clinic's patient portal to stay in touch with her doctors and obtain test results. Michelle thought that it would be good to have the RHM health data sent to her in two different ways and shared:

> Well, right now, we're registered on the website for the clinic. They tell you you have a message. They tell me by e-mail that you have a message, assuming that your e-mail works. So I'd say I don't know that that would be the case. So I'd actually like two things because I think they could call and say there's something the matter and make sure that they know that you have received that phone call. The other message is by the e-mail or the clinic site, and then you would get that message. I'm not that sure that the computers will work all the time. Sometimes it doesn't.

Michelle wanted to be sent the data two different ways in case her computer or the doctor's computer did not always work properly, but she was the exception. Most participants that had individualistic health management attitudes were fine with just one form of a digital update.

Usefullness of PERS. NHW patients and caregivers frequently discussed having previous experience with personal emergency response systems (PERS) and discussed how they were useful. Some NHW patients that didn't have PERS and did not live with their caregiver had special cell phones that had buttons on them that they could press which would call emergency contacts. Some NHW caregivers that did not live with the family member they took care of explained how valuable having a PERS was. Heather, age 47, took care of her grandmother who lived in a senior living community. Heather explained that other members of her family had previously tried to live with her grandmother to keep a closer eye on her, but her grandmother wanted to keep her independence and did not enjoy that arrangement. Heather described the instance that prompted her to get a PERS for her grandmother:

> – because she accidentally fell when she went into the bathroom. She had her clothes on and was going to go to potty and she ended up – for some reason she left her laundry clothes in the shower area and she fell and she ended up – she had her clean clothes in the laundry basket kind of in the bathroom area next to the toilet. She got up; she pulled up her pants and then she fell into the laundry basket and the shower. She stayed there for a couple of hours until she could finally reach her cellphone to call us and she couldn't get up and she had no handle where she could – she was all awkward in the basket and I felt for her.
>
> And so she finally had her cellphone on the counter and finally managed to get her cane over there to – but it took her a long time. And she called us. But it was too far to reach the cord in the bathroom where she could pull the 24 hour nurse that lives on the property to be alerted because she couldn't quite reach the cord. Because there's a cord in the bathroom and there's a cord in the living room and in the kitchen, but she couldn't reach it.
>
> And I thought oh gosh, that's terrible because she sat there for an hour and a half until she could finally work her way to get to the phone to pull it and she called us first before she reached to pull the pull cord to reach the 24 hour nurse. I thought oh god, this is – so we had to get over there and be careful picking her up. And she was all hunkered over and she was sitting in a laundry basket in the shower and I felt for her. I said, "Oh gosh." At least she didn't break anything and that was a relief. But I thought right then and there it would be important to get a little something, a ringer when she couldn't reach her phone or the cord to wear

> something because or at least an extra device that they could put together on the property to call the nurse.

Heather viewed the PERS as a tool that could be used to allow her grandmother to continue to live on her own and alert the family in case of emergencies. Many other NHW participants with an individualistic attitude towards health management shared this view of PERS. David, age 53, was afraid that his mother, age 86, might fall and have trouble since she lived alone and also had a history of falls. Here he described the PERS device he bought for her, "*That little unit she has, you buy the unit, it's basically just a pager, or a cell phone on her neck, with a button, a speed dial button. But she has to be awake to call it*." David valued the assistance the device provided but wanted it to be able to go one step further and detect if his mother had fallen and alert him without her having to press the button. That way if something happened and she was unconscious and could not press the button he would get an alert. Another participant, Elizabeth, age 55, who took care of her mother who lived alone, really valued the PERS her mother used and explained:

> The Life Line was great because all she had to do was push the button, and then they would contact me. We did that in the middle of the night a couple times where – once she fell. I was out of town. It was an instant connection. I always knew…if she ever needed anything, it would be right there with her.

Many NHW participants discussed how PERS had been helpful.

Inconsistency in health management attitude and actual help received. Among patients with individualistic health attitudes there was an inconsistency with how patients described managing their health and the amount of help they actually received. When first describing how they managed their care, many of the patients with individualistic health management attitudes did not mention the support they received from their caregivers, even though having a family caregiver was a requirement for participation in the study. When further pressed about how their family member assisted them, these patients did acknowledge there were things that their caregivers helped them with. Their view of their own health management did not include the whole other support system that they had in their family caregiver.

Family centered health management and perceived usefulness of RHM. MA caregivers and patients all had family centered health management attitudes. Family centered attitudes towards health management emerged when MA patients referred to how they relied on their caregivers and other family members to manage their disease, when MA caregivers discussed how they assisted their family member in many aspects of care, and how MA caregivers were involved in most discussions about patient care. Commonalities in the discussions of these participants included care recipients deferring care management to caregivers, patient barriers to accessing healthcare, little to no difficulties with technology use in the home, and a desire to use RHM technology in their home to also help others around them.

Patients deferred care management to caregivers. MA patients described how they tended to defer to their caregiver for most aspects of managing their condition. These MA patients discussed how they strongly relied on their caregiver when determining what to do in order to manage their condition. Some patients described why they relied on their family member to help them overcome barriers to care and others seemed to defer to them naturally without discussing a specific reason for doing so. They explained they experienced difficulties communicating with physicians who did not speak Spanish and that they did not read English. Therefore, these patients had to rely on their caregiver or another family member, such as a son or daughter, to translate instructions for them and had to bring them along to doctor’s appointments. Those patients that had a family member attend doctor’s appointments with them thought that following the doctor's recommendations for self-care was easy. A 70-year-old MA patient, Jorge, explained that the instructions were very easy to follow because his caregiver told him exactly what to do. Other patients relied on their caregivers for motivation. A 77-year-old MA patient, Carlos, shared that the instructions were not hard to follow, but sometimes he just didn't want to do what he was told to do and he needed his caregiver to get him back on track. Jorge, who lived with his wife and extended family, was cared for by his daughter. Here, he explains why he had few worries about managing his heart condition:

> She [caregiver] is always checking on me, she prepares the meals, she gives me my medication. She asks me whether I have taken my medication…I don't worry about anything because they [his wife and his daughter] are always checking in on me.

Other MA patients also shared that they put their trust and reliance in their caregiver, by saying things such as, "*She's [caregiver] the one at home, the one who helps me, if I need something she'll be there. She takes care of my health*."

MA caregivers shared how they were very involved in their family member's care and that it had a direct impact on their family member's health. They also explained the level of care in terms of different family roles and dynamics to better describe the level and impact of the care. MA caregiver, Gabriela, age 70, had been taking care of her husband Roberto for over 25 years, and compared the care she provided to her husband to be similar to caring for a child. Gabriela explained that her husband's health status was not static:

> …[it's] between normal and bad. Yes, in the middle of both. It's normal because I can control it with the medication, the insulin, take a rest, going somewhere, and like that. If I leave him [Roberto] a day without –It would be bad. I can't leave him alone for a moment. If he's outside I need to be looking at him, that's why I have my curtains like this, I see him and I go out …I'm aware of him. He's like little baby. And I compare the care of – because I took care of old people, the attention of an old person and a kid, I compare both and it's the same thing, the same attention. The kid fell, he stood up, he slipped, he can't take a shower by

> himself, you have to change him and have his food and not – you know what taking care of a kid is.

Gabriela referred to the care of her husband as similar to taking care of child, which provided a contextual description of his state within her family centered health management view. She was constantly observing Roberto and was able to keep him in good health because she knew, much like a mother and her child, when it was time for him to take medications or rest. She compared the level of support that she provided him to be similar to that of a mother and a child and described a relationship between the amount of support she provided him and his level of function. Gabriela explained that as Roberto’s caregiver she made an impact on his current health status which could vary depending on how attentive she was as a caregiver. Other caregivers that tended to be family centered in how they managed health also explained how they were always keeping an eye on their family member, much like a mother would do with her child.

Few difficulties with technology in the home. Those that had a family centered attitude towards health management also seemed to manage technology in a family centered way. Many MA participants explained that technology did not present them with many difficulties, but shared that when they did have issues with technology not working correctly in their home they would ask a family member to help with the issues. MA participants shared that they relied on younger family members to teach them how to use smart phones. Some MA patients mentioned that they did not have any problems with technology mostly because they used simple forms of technology such as TV and cable or smart phones and computers with the help of other family members. None of these participants mentioned asking for help with technology outside of their family.

Engaging and educating others with RHM. MA participants also wanted all family members and friends to be able use RHM technology in their homes. When discussing how they would use RHM devices given to them by their physicians, most MA patients wanted their caregiver and other family members to know how to operate the technology. MA patients and caregivers were generally fine with other people seeing the devices when they came over to their home and they discussed how they would explain to visitors what they used the devices for saying, "*I would give them information so they can use it*" and "*I'd give it to the people I can, for example my sister, "Do this." Or my nephew. To educate them, so they can know and they take care of themselves.*" Another caregiver shared, "*if someone has the same disease then they´ll know how to use it, and [I will] let them know how it works…teaching them, and maybe they say…where did you get it? I need one*." Educating others on how to use health monitoring devices was mentioned by several MA patients and caregivers.

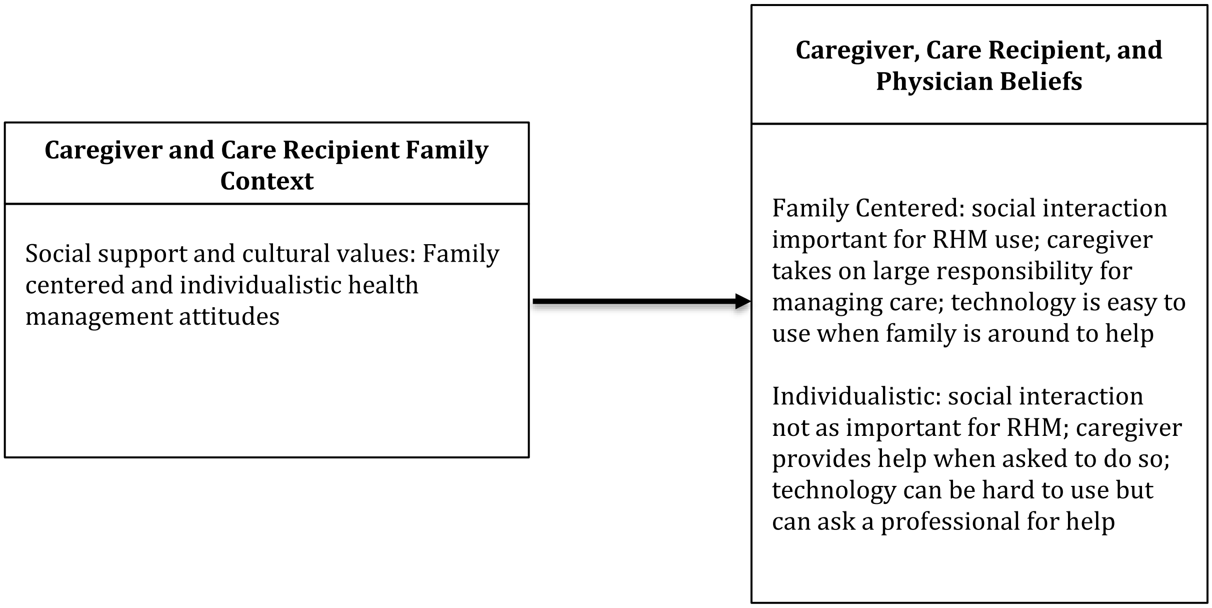
RHM included social interaction. MA participants discussed a desire to include social interactions with RHM use. One participant, 57 year old Carmen, shared that she felt younger people were communicating less due to being distracted by technology, "*I think that communication is coming to an end…before my children would come and sit down and talk. Now, they're on the phone.*" Retaining social interaction when using RHM was important to patients and caregivers like Carmen. Another way that the importance of social interaction emerged was when these participants discussed receiving RHM data. Family centered participants had varying thoughts on the best way to receive data and information back from health monitoring devices. In cases where the health monitoring device sent information to the patient's clinical care team, a majority of the MA patients preferred to find out about the trends in their health information in person at their next doctor's appointment and shared that a phone call with information about the data being collected would be just as helpful if they were not scheduled to go into the office. MA caregivers preferred getting phone calls from their family member's doctors or, similar to MA patients, hearing the information in person at their care recipient's appointments. Some MA caregivers also thought video conferencing with clinicians, text messages, and emails were good ways to receive updates on their family member's health. Alejandra, age 33, provided care to both her mother, age 62, and her father, age 66, both of whom did not speak English. Alejandra shared what that she thought the best way to receive information about her parent's health:

> A text message and then a phone number where I could follow up if I have questions. And it would be amazing if there's a place I can call after hours, because I think that's really hard as a caregiver, to be expected to be taking all this time off of work to coordinate somebody else's care – it's really hard.

Alejandra made it clear that sharing health information was not a one-way communication and that she needed to be able to talk to someone to better understand the implications of the information she would be receiving. Most MA caregivers were not opposed to getting text messages from clinicians, but they preferred to be able to talk with someone instead. The majority of MA participants preferred to keep a level of social interaction with their clinical team involved in the health monitoring process.

Aim 2 Summary. The second aim of this study was to investigate the influence of culture and social environment on the perceived usefulness of remote health monitoring (RHM) technology among Mexican-origin and non-Hispanic white patients and caregivers. There were clearly two distinct health management attitudes among participants. NHW participants tended to have an individualistic attitude and MA participants tended to have a family centered attitude and these different attitudes influenced perceptions of RHM and its potential uses. NHW participants tended to discuss the benefits of PERS more than MA participants. In contrast, MA participants more commonly discussed wanting RHM technology to incorporate and facilitate social interactions between patients, caregivers, and clinicians. Figure 4.2 shows where the results of Aim 2 fit in the conceptual model.

Figure 4.2 How Aim 2 fits into the conceptual model.



4.5 Aim 3 Results

The third aim of this study was to investigate ways that Mexican-origin (MA) and non-Hispanic white (NHW) caregivers of older adults with heart failure (HF) perceived that remote health monitoring (RHM) technology could alleviate caregiver burden. Discussions revealed that both MA and NHW caregivers envisioned RHM as a partner in care that could provide assistance in easing their worries, challenges, struggles, and burdens in many ways. Content and thematic analysis results are presented below.

4.6 Aim 3 Content Analysis Results

RHM technology to ease caregiver concerns. Participants shared many ideas about the ways they could use RHM technology to alleviate some of the worries, challenges, and burdens they experienced as HF caregivers. Three common stressful situations that caregivers discussed as times where RHM could help them better manage their worries and challenges were when they had to be away from the home, when they felt they did not have the proper knowledge or tools to help their family member, and when measuring vitals and health indicators for caregivers. Caregivers often worried about leaving their family member home alone and thought RHM technology could assist them when they were not able to be right next to their family member but still wanted to know how their family member was doing. Times when they could not stay with their family members included when caregivers went to work, when they left the home to run errands, and when the care recipient stayed overnight in the hospital. Another way that caregivers thought RHM technology could take away some of the burdens of care was if it came with special tools that were specific to the needs of caregivers and not just to the patients. Tools that caregivers wanted RHM to provide in addition to those provided for patients provided real-time feedback on things that caregivers could do to assist their family members and educational explanations about the meaning of the data that was being collected by RHM devices. Finally, caregivers thought RHM could eliminate some of the tasks that took up time in their day such as checking blood pressure or heart rate.

RHM can alleviate worry when caregivers are not at home. Caregivers explained that they worried when they had to leave the house and several caregivers chose not to leave the house or participate in activities because they were fearful something might happen when they were away from their family member. Many of these caregivers shared a desire to know their family member's health status and what their family member was up to when they were not able to be at home with their family member. Some caregivers wanted to know how their family member was doing in general and others wanted to know and monitor specific measurements such as "*blood pressure*, *vitals,* and *physical activity"* when they were away from the home. These caregivers shared that they would need some type of a mobile device such as a wrist band or cell phone with an app to receive this information when they were out and about. MA caregiver Daniel, age 61, was interested in having his wife wear a health monitoring bracelet and described this alert system:

> …a bracelet that could alert me…while I´m working…it would give me an alert with a light or something…red for emergency, green, yellow…If it´s an emergency she won´t be able to call, so to have something that she could press to send a signal.

The alert system that Daniel described had wrist bands for both himself and his wife and she could communicate her status to him through the wristband. This system would alleviate his worries about whether or not his wife would be able to get to a phone when there was a problem with her health and he was not home to help her. MA caregiver Sofia, age 49, wanted to be able to know her husband's blood pressure and vitals when she was away from the home and shared, "*That I can see what he sees, because he doesn´t like to get us worried so he doesn´t tell us how he really feels, so this way I could know even if he doesn´t tell me."* If such a system was in place, Sofia would know her husband's health status when she left the home as well as when she was at home with him during the times he would not tell her how he was feeling. This type of system could potentially alleviate some of the worry Sofia had when she left the home for work. Another MA caregiver, Natalia, age 34, who provided care to her mother, described wanting a similar system to the one described by Sofia but had an additional goal for its use:

> If they invented an app where it connected to patients' health monitoring…I would use it. That way I know – and if she doesn't get on her phone and she doesn't check, well, I can tell her, well, this is happening…what were you doing?

Natalia wanted to use the information that such a system provided in the ways that Sofia shared using it but also to facilitate discussions with her mother about what initiated the changes in her signs and symptoms to prevent the unwanted changes from occurring again. The system that Natalia described would alleviate her worries but also have an educational component for her family member.

MA caregiver Martina, age 62, provided care to her 80-year-old sister. Her sister was frail and supposed to be on bed rest, but Martina would often return home after being gone for a short amount of time to find that her sister had gotten out of bed, which made her worry about leaving the house. Martina shared:

> Well, I like to know if it's going to be all right with her, staying by herself, or not for maybe an hour, two hours, or something like that…I would want to know whether she's going to stay in bed or not…monitor something that she's gotten up...Then I'll call her going, "Get in bed." [LAUGHTER] That would be really helpful. Like, "Get in bed. I'm seeing you."

Martina wanted a way to know if her sister was moving around the house and then wanted a quick way to remind her to get back in bed. Martina shared that if she had something like that in place she would not worry so much about leaving the house.

NHW caregiver Brenda, age 65, provided care to her father, age 91, that lived down the street from her. Brenda shared that it would be helpful to know how her father was doing in the night when he was asleep. She explained that having this information would help her sleep through the night since she would not constantly be worried about her father. Here she explains how she would set it up:

> Like when he was here sleeping, if you had a monitor that monitored his heart rate or his blood pressure, something like that, if you had a remote way to access that at home, I could be two miles away and know that he's okay. Then, it would have an alarm so I knew that I needed to come over here. If somebody else wasn't here, I could be at home sleeping in my own bed…it would ease my comfort… something like that would be very handy.

RHM as a resource and tool for caregivers. Caregivers shared that they thought RHM should come with tools that were specific to caregivers to make it easier for them to manage their family member's condition. NHW caregiver Melissa, age 49, took care of both of her parents. Melissa, like many other caregivers, explained that she understood a bit about HF but was not always certain that she correctly interpreted the readings she was taking for her mom. She wanted an RHM system to explain the implications of health indicator readings, such as blood pressure and blood oxygen, so she would not have to worry about whether or not she was interpreting the readings correctly. She explained it simply as, "*when you see this number combined with this number, it means this*." Having RHM provide this type of feedback would ease Melissa's concerns. Other caregivers wanted RHM to help them with different aspects of the care they provided such as diet. Caregivers who struggled with knowing the appropriate food to cook for their family member thought that RHM could provide heart healthy recipes and meal suggestions to caregivers based on the health data that was being collected.

Understanding health indicators and how medications affected their family members was another area that caregivers struggled with. An additional tool that caregivers wanted was something to help them organize medications by time of day, dosage, and the health indicator readings at times when the medication was given. Caregivers explained that keeping track of medications, weight, and blood pressure readings and trying to make inferences about the ways they were connected was difficult for them and that RHM might have something in it that could help with this. MA caregiver Francisco, a former community health worker, age 44, took care of his father who suffered from kidney failure and HF. He described how it was important for him to monitor both conditions when caring for his father. Francisco explained that when he started providing care to his father he did not really understand the intricacies of managing his father's complex conditions. Francisco spent hours doing research to understand how the conditions effected each other:

> Monitoring the heart and monitoring the chemistry as well which has a lot to do with the kidneys…The chemistry is extensive…the kidneys regularize all of the chemicals…I know a lot about the heart, the lungs…but the kidneys are a different study. The person that works [at the library] is the one that is giving me the complete information so that I can have an idea about how to question the doctors and what questions to ask them. And that's what I'm doing…study more like…what is the chemical function that the kidneys do to alleviate the stress of the heart a little bit. Because it's two organs that work together, without the kidneys the heart is unstable, without the heart the kidneys as well. And within that process, there are clogged arteries, there are lungs with liquid so you become familiar with the anatomy and that's where I'm at right now. So I'm monitoring everything, everything in that aspect.

Most caregivers were helping a family member manage more than one condition which made keeping track of multiple health indicators complex and it required a lot of background knowledge as Francisco explained. Understanding the relationship between his father's conditions was important to his survival, but it also required Francisco to spend hours becoming more educated on managing complex chronic conditions. Francisco explained that other caregivers still came to him for help with this type of health management and that they were scared because they did not understand the best way to manage these complex conditions. Francisco shared that RHM needed to provide educational support to caregivers that assisted in managing multiple chronic conditions to ease their concerns that came from not fully understanding the diseases and the best ways to manage them.

Another NHW caregiver, Heather, age 47, took care of her 86-year-old grandmother who did not live with her. Heather thought that it was time consuming for caregivers to take health indicator measurements throughout the day when there were devices that could completely eliminate the need for that. Here she discussed a new device she had recently heard about in the news. Heather shared how it would make things a lot less confusing for her:

> I did like the tattoo idea. I thought those were inventive because you just – they use some sort of – just like glued it on and then it monitors it for one to three months or something. And it wires it right to the doctor. You don't even have to bypass it through your computer or plug anything in or do a daily log. It just heads right over there and I guess it's supposed to be – I thought that was kind of neat because you didn't have to deal with computing anything or logging in three or four times day or writing anything down or interact to it. It's just all done for you.

Heather liked the idea of something the doctor just stuck on the patient, like a tattoo or a sticker, that could collect health indicator data without the patient or the caregiver actively being involved in collecting the data. Heather shared that she thought it would be really helpful in making things less complicated for caregivers.

Caregiver discussions revealed the challenges they encountered as they shared their worries, concerns, and sources of stress as HF caregivers. As they talked about these challenges they encountered, they also discussed how RHM could potentially ease their concerns. First they discussed how having RHM that could give them insight into what their family member was doing when they were not able to be home with them would be beneficial. Having information like this had the potential to make caregivers feel more comfortable leaving the home and reduce worry because they would know to come back home if something went wrong. Caregivers also shared they were uncertain that they were interpreting device readings correctly and they worried if they were providing the appropriate care based on the readings. These caregivers discussed that RHM that included educational information on the meaning of the device readings with suggestions on how to proceed in administering care would alleviate some of their confusion and worries about their efficacy as caregivers. Caregivers also shared how RHM could do some of their tasks, such as measuring blood pressure, for them and might lessen the amount of time they needed to devote to measuring these health indicators themselves.

4.7 Aim 3 Thematic Analysis Results

When exploring what caregivers shared about their struggles, challenges, and difficulties managing HF and how they thought RHM might help alleviate some of their burdens, a major theme emerged. This theme, RHM as a partner in care, emerged as caregivers discussed how it would ease their minds to know that something else would be able to double check what they were doing and provide feedback. Caregivers explained that RHM would alert them to emergencies they could not see coming, much like a second set of eyes on their family member. Three main areas where RHM represented a partner in care were in relation to educating caregivers about the best care to provide given the patients' health indicators, having a second way to gauge whether caregivers were interpreting signs and symptoms correctly, and through the alerts that RHM could provide if a health indicator was outside of normal ranges. Highlights from this theme are presented in table 4.6.

Table 4.6 Aim 3 Thematic Analysis: RHM as a partner in care

Groups	How RHM is a partner in care	Perceived benefits
MA and NHW caregivers	Provides educational support	More knowledge leads to better management which leads to fewer emergencies and less stress
	Second set of “eyes” on patient	Aides in symptom interpretation which reduces caregiver worry about patient
	Detects and alerts to emergencies	Reduces the need have constant vigilance and caregiver can relax more, therefore stress is reduced

RHM could educate caregivers. Caregivers viewed RHM as something that could provide educational support based on real-time symptoms, symptoms in general, and the condition in general, much like an expert care partner such as a doctor or cardiology nurse. NHW caregiver Sara, age 37, who cared for her 72-year-old father, explained that RHM that provided health indicator readings such as blood pressure that combined it with a detailed explanation of what it meant and what could be done to improve the situation would ease her stress. Sara explained:

> I think we would all be more relaxed if there would be a person who could teach us. I know it´s hard because these are doctors' things [systems of keeping track of patients], but if they could tell us this [what could be done] could help you. A device to control blood pressure for example that tells you how he´s doing.

Sara shared that it would be great to have a person who could explain what the readings meant, but if a device could do the same thing it would be helpful as well and reduce her stress. MA caregiver Josephina, age 76, was a retired nurse. She shared another way RHM combined with education would help caregivers:

> Like a video or something where we could access an app for…heart failure, the symptoms, what you can expect, what could happen, and when to call the doctor, in the case this occurs, when you have to call the doctor…– "When this is happening I have to call, I have to –" Because many of us know…diabetes, but it's different when you have heart failure, the weight is very important, if you drastically are gaining weight, that's not good, that's against to what you have. The other thing is the pulse oximeter, if it's decreasing is because everything is congesting in the lungs and you don't have enough oxygen. So they can check it and see it's part of their lives, "I need to be careful with this."

Josephina discussed that many caregivers have a better understanding of diabetes than of HF because they have been have providing diabetes care for many years. Josephina talked about how RHM with an educational component could address this lack of HF education and translate into better management of HF. Josephina shared that RHM could educate caregivers as well as patients and that a better understanding of the condition would lead to better HF management and result in fewer emergencies which would reduce stress in the long run.

RHM could provide valuable insights to aid in symptom interpretation. Caregivers explained how RHM was like a partner because it would give them insight into symptoms that family members said they were feeling and help them gauge and interpret those signs and symptoms correctly. NHW caregiver Erin, age 27, sometimes interpreted her grandmother's health complaints to mean that something else was wrong and explained:

> It [RHM] would definitely help me. The blood sugar and the pulse, it would definitely help me realize kind of what she was feeling so that I knew. When she's feeling really bad I would know whether it was emotional or a health concern. Because me and my mom, we really thought that a lot of it was emotional. I don't think we realized the extent. And so I think that would help. And then also, obviously, it would help just when I need to call the emergency room or when I need to get her food or her insulin or something like that.

Erin wanted a way to double check on what her grandmother was saying was wrong with. Erin had originally misinterpreted some of her grandmother's complaints in the beginning of her disease. Having the information and extra help that RHM would provide would give caregivers like Erin peace of mind, because they would have greater insight into the things their family members were experiencing. Another NHW caregiver, Donna, age 68, took care of her husband, age 80, further explained the help these insights from RHM would provide. Donna shared, "*it would be peace of mind, I would think because that's what I think some of these things are. It's a peace of mind, and it's just another way of gauging*." RHM was described as something that would provide insights that would help caregivers provide better care, letting them know if their family member "*was calm* ["tranquilo"], *or that he* [care recipient] *was sicker*" and this would provide "*a feeling of control, having control over the situation*." Having RHM would reduce caregiver's worries about their own knowledge about HF symptoms as one MA caregiver who took care of his wife shared, "*It could help me see what´s her health state and what can I do to help her*" and, as Sofia shared, "*I could know what´s going on with him*." Another caregiver, who did not really always believe what her family member said about how she was feeling, shared, "*having the actual facts would be really helpful*" and she thought RHM would be able to provide the facts.

RHM could alert caregivers to emergencies. RHM was also described as a partner that could alert caregivers to emergency situations, much like another person in the home would. Personal emergency response systems (PERS) were described as providing peace of mind to caregivers even if their family member had never activated it. Martina explained how having RHM that included something like a PERS would help her feel like there was a second caregiver checking in that could detect emergencies:

> Yeah, somebody's double-checking and would know it. Like those things they say monitor, that when you fall or whatever, you don't have nobody, so it's an alert or something. They would know it over there or something. I don't know how they do it. So they would know over there. So they say, "OK, we'll send you ambulance right now.

Gloria, age 51, who took care of her mother, age 73, woke herself up multiple times in the night to check on her mother. Not getting enough sleep took a toll on Gloria. She described an RHM emergency alert that would allow her to sleep better through the night:

> An intercom. Like an intercom or a certain – not an alarm clock, but a button that she can push and it would wake me up in the room. And, if she needs something, I could come out here.

With this type of system in place, Gloria would only have to wake up if there was an emergency and she would be able to sleep better through the night. This form of RHM would assist Gloria and other caregivers that woke up multiple times in the night to check on their family member. Another caregiver, Gabriela, age 74, who had been taking care of her husband, age 70, for 25 years, described how she would like to leave the house more, but her husband was not very mobile. She did not want to leave him at home without someone to look after him. She shared that an RHM system with something similar to a PERS would allow her to leave the house, would alert her to emergencies, and get her husband the help he needed if she was not there. Gabriela explained this type of RHM would allow her a little respite to do things that she needed to do for her own self-care, health, and enjoyment. She shared:

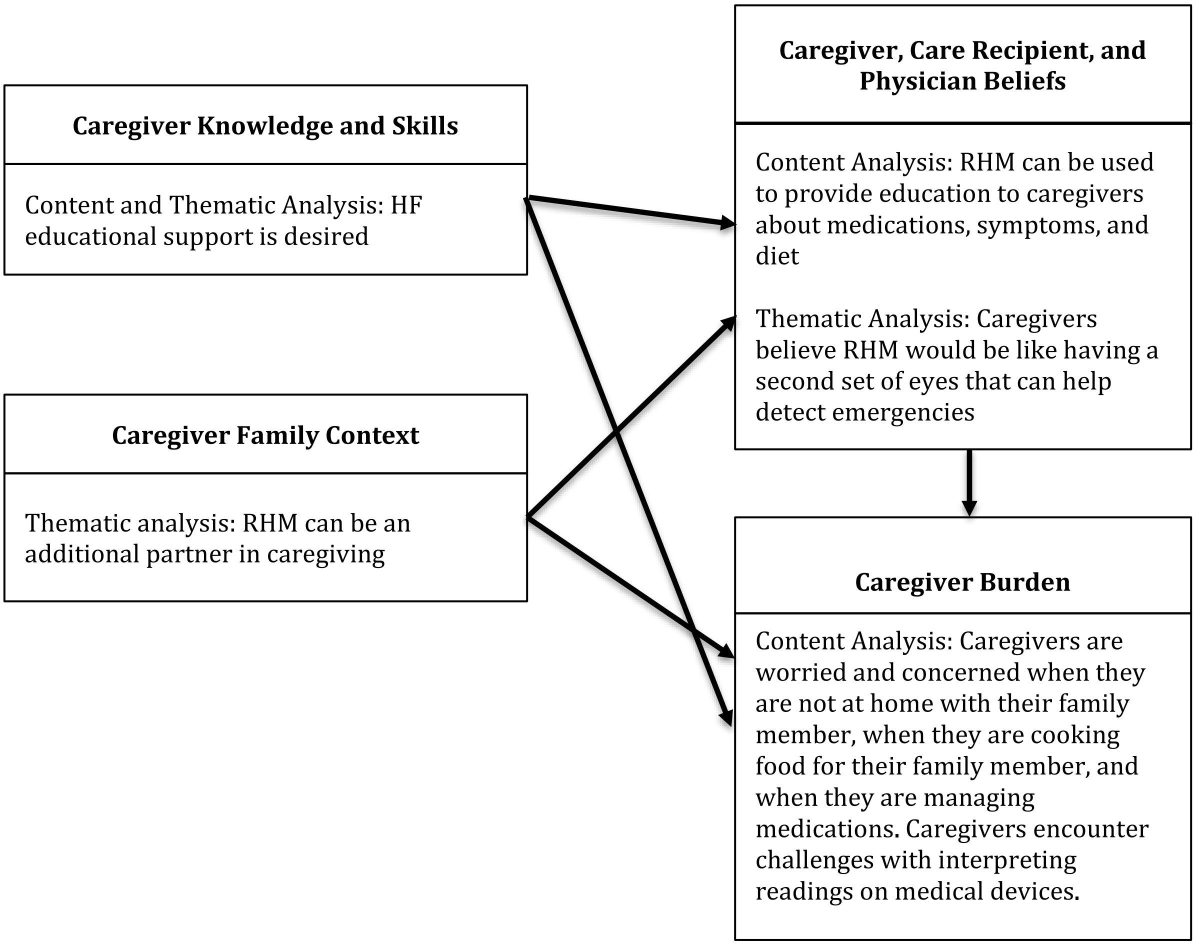
> So I could leave even for a day. Go to the beach, go out with a friend. He doesn't want to go…it's very difficult to walk with him…And if there's an emergency, what to do; call me or something like that, bring him to the emergency room, call the emergency room, or something. Help him, to be aware…that the things turn out well.

RHM, for Gabriela and other caregivers in situations similar to hers, was a care partner that would get help for her husband in an emergency when she was not at home. This would provide Gabriela a sense of security and allow her to leave the house to do things that she enjoyed, which she shared she did not do because she worried about who would watch her husband.

All Caregivers thought of RHM as a partner in care that could alleviate caregiver burden through its potential to provide educational support to caregivers, by providing a second way for caregivers to gauge whether they were interpreting patient signs and symptoms correctly, and by providing alerts when their family member's health indicators were outside of normal ranges.

Aim 3 Summary. The third aim of this study was to investigate ways that Mexican-origin (MA) and non-Hispanic white (NHW) caregivers of older adults with heart failure (HF) perceived that remote health monitoring (RHM) technology could alleviate caregiver burden. Caregivers shared that there were three main areas in which RHM would be helpful for reducing their worries, stresses, and challenges as HF caregivers. RHM represented a partner in care to caregivers that could help educate them on their family member's condition, could assist them in knowing how their family member was doing when they had to be away from the home, and help them better understand the symptoms their family members experienced. Figure 4.3 shows how Aim 3 relates to the conceptual model.

Figure 4.3 How Aim 3 fits into the conceptual model



CHAPTER 5 DISCUSSION

5.1 Overview of main findings

This study aimed to investigate RHM beliefs and goals, the influence of culture and social environment on RHM use, and perceptions of how RHM could be used to alleviate caregiver burden among cardiologists, MA and NHW heart failure (HF) patients and their family caregivers while guided by a conceptual framework. Based on the currently available literature, this is the first study to investigate perceived usefulness of RHM among Mexican American HF patients and caregivers. The first major finding from this study was that RHM uses and goals for HF management were conceptualized differently by different participant groups. Cardiologists conceptualized RHM as a means to measure and communicate health indicators and while patients and caregivers conceptualizations of RHM also included how having it would make them feel. The second major finding was HF is a challenging disease to manage because of the nature of the disease, and the complexity of the self-management protocol. This finding was apparent in all cardiologist and caregiver discussions and many patient discussions. Third, it was found that perceptions of RHM for HF management were influenced by attitude towards health management. Attitude towards health management existed across a spectrum that had individualistic attitudes toward health management on one end and family centered attitudes towards health management on the other end. These attitudes toward health management influenced how participants wanted to use and saw benefit in RHM. Lastly, RHM emerged as a partner in care for caregivers that could ease caregiver concerns through its potential to provide educational support to caregivers, by providing a second way for caregivers to gauge whether they were interpreting patient signs and symptoms correctly, and by providing alerts when their family member’s health indicators were outside of normal ranges.

5.2 Discussion of Aim 1 Results

Cardiologists, patients, and caregivers in this study described what they thought RHM was and how it could be useful in their lives in different ways. Participants described RHM in ways that were consistent with current recommendations from the American Heart Association which included having patients keep track of weight and blood pressure and communicate that information back to physicians (Riegel et al., 2009). Some particpant discussions also incorporated collecting data from implantable devices such as the CardioMEMs, a recently FDA approved hemodynamic monitoring device that has been shown to assist in the reduction of HF hospital readmissions (Araujo-Gutierrez et al., 2016). Participants who were less familiar with implantable devices, described RHM more in terms of the individual devices and technologies they used in their daily health management routines. These patients and caregivers talked about blood pressure monitors and scales, and MA participants also talked about cell phones as parts of RHM. Current research from the Pew Research Center has found that Latinos in the US are less likely to own a personal computer and more likely to access the internet through their cell phones (Brown, Lopez, Hugo Lopez, 2016). Many MA participants in the current study discussed internet searches as part of RHM, which may explain why MA participants included cell phones more frequently in their discussions of RHM than NHW participants. Our study's findings that cell phones are acceptable to use in RHM among MA participants is also consistent with a recent RHM study among Latino migrant farm workers with essential hyptension. In this study, Price et al. (2013) found that a majority of participants had access to cell phones and believed that RHM accessed through mobile phones would be beneficial for managing chronic diseases.

Study results also indicate that MA and NHW participants viewed RHM as something that could provide peace of mind and expanded their concept of RHM beyond just using specific devices to communicate information with physicians to include how having such a system would make them feel. Similar to findings among COPD patients that used RHM systems (Fairbrother et al., 2013; Gale & Sultan, 2013; Gorst, Coates, & Armitage, 2015), HF patients thought RHM would provide them with peace of mind because they would instantly know what their condition was and they would be watched over by their clinicians in the event that something went wrong. Philips Intensive Ambulatory Care (IAC) at Banner Health in Phoenix, Arizona recently explored the experiences of older patients with complex chronic conditions in a RHM program, and also found that patients who used RHM felt safer and had increased peace of mind (Oosterom-Calo, Vice, & Breslow, 2015). Additionally, personal emergency response systems (PERS) were frequently described as an RHM tool that provided both caregivers and HF patients with peace of mind which is consistent with previous research on PERS especially in situations when the caregiver and patient don't live together or when they need to spend time apart (Stokke, 2016).

Study participants had challenges managing HF, including interpreting HF symptoms, medication adherence, and proper diet. These kinds of challenges are well-documented in the literature on HF management. The American Heart Association has reported that fewer than half of HF patients weigh themselves daily, and most have difficulty interpreting which symptoms indicate HF exacerbations (Riegel et al., 2009). Previous research among African American and Hispanic populations investigated the impact of self-blood pressure monitoring on blood pressure control also indicated that even when participants were given devices to check their health indicators, having the device alone was not enough to improve control over symptoms. Additionally, a study of HF home management that included patients, clinicians, and family caregivers, also found support for the current study's finding that medication adherence and management was an area of crucial need for HF patients (Piamjariyakul, Smith, Werkowitch, & Elyachar, 2012). Dietary indiscretion and limited access to low-sodium foods are also well known causes of HF hospital readmissions (Gheorghiade et al., 2013) and were often discussed by current study participants. Cardiologists' discussions of challenges determining the appropriate patient protocol are also well documented in the literature. A recent patient level data meta-analysis by Jonkman and colleauges (2016) found no specific HF management program characteristics to be consistently associated with better effect on self-management. They found that for one patient a certain set of self-management guidelines would work, but for another patient, a different set of self-management guidelines would provide benefit. These findings support the current study's results that show physicians are challenged when creating self-management plans for each individual patient and help to explain why patients and caregivers find difficulties managing HF even when they follow doctor recommended management guidelines. The first management guidelines they take home, may not be the guidelines that actually end up helping them control their disease best. Additionally, studies have found that symptoms of HF exacerbation such as impairments in cognition, hearing and eye sight can make it difficult for patients to follow recommended self-care instructions and have diminished their ability to know when to ask caregivers for support (Clark et al., 2009). Caregivers in the current study discussed challenging times when their family member was feeling ill but did not tell them and instances when they suspected something was wrong with their family member, but the family member told them they were feeling fine. These caregivers' family members could have been experiencing HF induced impairments in cognition that made the caregiving situation even more challenging for the caregiver.

5.3 Discussion of Aim 2 Results

The finding that perceptions about RHM use for HF were influenced by attitude towards health management is little explored in current research; however, there is research that supports the existence of individualistic and family centered attitudes towards health management and HF. HF patients and caregivers in the current study who tended to have an individualistic attitude towards health management were similar to those in other studies who placed value on personal responsibility and self-reliance in managing their health (Bardach, Tarasenko, & Schoenberg, 2011). The current study's finding that NHW participants tended to have individualistic attitudes towards health management is also consistent with previous research that has found Western cultures to place more emphasis on indepenedence and individualism than on interdependence (Pinquart & Sorenson, 2003). While an individualistic approach was popular among NHW study participants, this approach is not always found to provide the most benefit to all patients. In 2001 the Institute of Medicine (IOM) identified a patient and family centered approach to care as one of the six fundamental aims of the U.S. healthcare system (Institute of Medicine, Committee on Quality of Health Care in America, 2001). Since then, caregivers have been seen as important partners in achieving patient centered care that should be integrated into the process early on to support patient decision making (Gillick, 2013). These initiatives to integrate families into patient care and decision making align well with the family centered health management attitudes of MA participants in the current study and current HF research that has found that HF patients view that other people have a large influence on their health status (Rydlewska et al., 2013). Family centered health management approaches shared by MA participants in the present study, which include family member attendance at routine medical visits, have also been found to result in better HF patient self-care (Cene et al., 2015; Sayers et al., 2008).

The finding that MA participants tended to have family centered health management attitudes can be broadly linked to the Mexican cultural concept of *familism* which refers to placing value on the family as an institution, with family members having interdependence on one another (Flores, Hinton, Barker, Franz, & Velasquez, 2009). Interdependence on family members emerged in several areas of the current study. One area was when MA patients discussed how they would share RHM information with their caregivers so their caregiver would know how to best help them. Another area where this emerged was when caregivers dicussed how they attended all of their family member's doctor appointments, cooked all their meals, and managed all of their family member's medications. Other studies have also found that among older Latino patients, family is often included in managing health-care (Becker et al., 1998; Melton, Foli, Yehle, Griggs, 2015; Pinquart & Sorensen, 2003). An additional cultural trait that emerged in MA participant discussions was how MA HF patients deferred responsibility for their care to the caregiver. Examples of this were found when MA patients discussed how their caregiver took care of everything for them. This is consistent with previous studies that have found that Latino cultural views conflict with the notion of personal responsibility for illness self-care (Becker et al., 1998). While familism is one cultural view that may conflict with taking personal responsibility for self-care, religion and *marianismo* may also play a role. Hispanic religious beliefs are often used to explain illness causation and treatment and many Lations have been found to use religion as a way to cope with health problems (Gallant, Spitze, & Grove, 2010). These beliefs could influence self-care behaviors. *Marianismo*, a traditional female role that is central in Latino families, places value on self-sacrificing behaviors that benefit the family (Mendez-Luck & Anthony, 2015). In instances where MA patients had female caregivers, the caregiver could have been fulfilling the family's cultural expectations by taking on all aspects of HF management for the older family member.

Additional explanations for MA participants' family centered health management attitude may be more structural in nature. In the current study, many MA patients did not speak, read, or write in English. While all MA patients spoke Spanish, many could not read or write in Spanish. They explained that these language barriers made it difficult for them to understand the requests and instructions they were given by clinicians. This is consistent with studies that have found that immigrant Latinos in the US speak English less fluently, have lower health literacy, and are less likely to follow recommended treatments than non-Hispanic whites (Kaplan, 2014). Thus these patients may have strongly relied on their family caregiver to attend appointments, manage medications, and prepare appropriate foods in order to overcome language barriers that prevented them from completely understanding their self-care protocols. Another explanation for the tendency of MA participants to have family centered attitudes towards health management could have been that their experiences and beliefs were greatly influenced by their living situations. The average MA partient income was around $1,000 a month and patients may have been living with their family member for financial reasons. All MA patients in the study lived with their caregiver and all MA caregivers lived with the family member they cared for. Their tendency to make healthcare a family centered affair could have been influenced by family dynamics that occur when living together in combination with cultural beliefs and traits.

5.4 Discussion of Aim 3 Results

A study finding that was shared by both caregiver groups was the theme of RHM as a partner in care. While few studies have specifically investigated RHM perceptions among caregivers of HF patients, studies that have investigated benefits of RHM among HF patients have reported similar findings. Evangelista and colleagues' (2015) RHM intervention study among HF patients, explored older adults' perceptions of usability and acceptability of RHM to manage HF, and included a subsample of Latino participants. Their results indicated that participants felt the feedback they received from the health care provider related to health data assisted in better understanding their heart condition and the treatment plan. Similar to how the current study's participants wanted feedback and educational support to be provided by RHM, participants in Evangelista's study appreciated the dynamic connection between patients and health care providers which improved care by including health data, communicating health reminders, and providing feedback (Evangelista et al., 2015). Research in the area of human-computer interaction, has found that monitoring systems that communicate with networks of people have been able to increase awareness about situations of interest and peace of mind without requiring substantial effort on the parts of the people within the network (Mynatt, Rowan, Jacobs, & Craighill, 2001) which is congruent with the discussions of caregivers in the current study.

This study was also able to provide insight into how RHM can potentially ease caregiver burden when participants discussed the challenges, difficulties, and struggles they encountered as HF caregivers. Previous HF caregiver intervention research supports our study's finding that having more information about the patient's condition could ease caregiver concerns, can contribute to caregiver sense of control over the situation, and can increase their peace of mind. Agren and colleagues (2012) conducted an evaluation of a HF caregiver education program aimed at reducing caregiver burden and found caregivers benefited from additional skill-building and problem-solving education and recommended that future interventions should increase professional contact as well. Agren’s findings support the current study’s finding that RHM systems that incorporate correct interpretation of HF symptoms combined with knowledge on how to react to those symptoms can ease caregiver burden and worries. Other studies have also found a relationship between sense of control over HF management and reducing caregiver burden. Lofvenmark and colleauges (2013) found that increasing caregiver sense of control over HF management should be targeted in order for caregiver supports to be effective in reducing anxiety and depression.

5.5 Public Health Significance

The need for interventions among MA HF patients to include the patient’s social network emerges when looking at the current study’s findings in relation to the literature on HRQoL, family centered care, social support for HF patients, and the relationship between social support and mortality risk among MA older adults. Family centered care and the influence of social support for older adults have been increasingly cited as important to public health approaches to chronic disease management (Feinberg, 2014). Additionally, increasing the HRQoL of older adults manageing chronic diseases and the family members that assist them has been deemed a public health priority (Office of Disease Prevention and Health Promotion, 2010). The importance of family based social support and social engagement emerged in participants’ discussions of how they managed their disease and how they discussed using RHM. For example, participants wanted to engage family members in communication, education, and better health management, through RHM devices and programs. Particpants also described how these tools would provide them with increased peace of mind and better control over HF symptoms. Research has found that increased peace of mind and perception of control over HF symptoms are related to better HRQoL (Arestedt, Saveman, Johansson, and Blomqvist, 2012). Furthmore, investigations of the influence of social support on HRQoL among HF patients have found a positive relationship between social support and HRQoL (Arestedt, Saveman, Johansson, and Blomqvist, 2012). Hill and colleauges (2015) recently examined the role social support among MA older adults in an analysis of seven waves of data from the Hispanic Established Populations for the Epidemiologic Study of the Elderly (H-EPESE). They found that among Mexican Americans, older adults with low social support exhibited a higher mortality risk than those with high levels of social support (Hill, Uchino, Eckhardt, and Angel, 2015).

These findings have implications for public health practice. Current research in person- and family-centered care has recommended that public health programs that assist with the management of chronic diseases such as heart failure should work to engage and include family members that support the patient at home (Gillick, 2013). Healthcare and social service professionals should reach out and engage MA patient family caregivers at the beginning of HF treatment because caregivers need information and support to provide effective care once the patient arrives home. Public health programing support for these caregivers should include education, training, and access to respite services (Feinberg, 2014) and these supports should be provided in English and Spanish. Additionally, supportive services and programming for patients and caregivers should foster and encourage social interaction, which was described as an important feature of RHM among the current study's participants. MA patients with HF and their family caregivers have a desire to better manage HF at home. Public health practioners should work to learn the best ways to engage MA patients and caregivers to best meet their needs. Increasing programing that fosters social engagement around HF management, such as RHM, may contribute to reduced HF hospital readmissions among this group and should be further investigated as a potential public health approach.

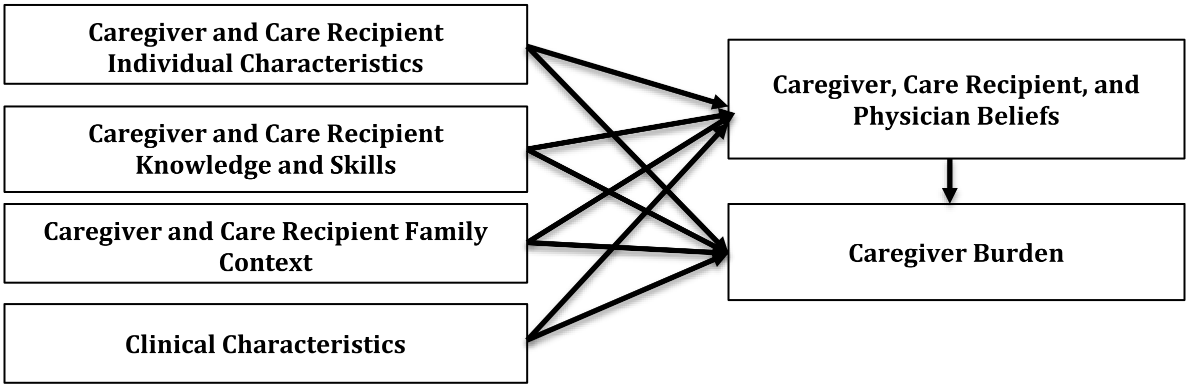
5.6 Conceptual Model

When looking at the study's findings through the lense of the conceptual model, the study's results fall in line with the prediction that caregiver and patient family context, which includes cultural values, family structure, and social support, contribute to perceptions of how RHM will be useful in HF care. For example, those caregivers with invidualistic attitudes toward health management sometimes mentioned that they worried about their family member in the night, especially if they did not live together. Some of these caregivers described how they would go visit their family member during the night to check on them. These caregivers discussed that this was tiring and they liked the idea of RHM including a personal emergency response system (PERS) for their family member. They thought RHM with a PERS would ease some of their worries and provide them with peace of mind in the night and they would sleep better.

The current study's results also align with another pathway in the conceptual model to show how individual participant characteristics such as previous use of technology in the home, and understanding of HF management converge with demographic characteristics to form participant beliefs around RHM. For example, many MA participants discussed currently using their smart phones as a part of RHM when they needed to obtain health information. These participants would text their physicians or do internet searches on the phone for information they might need. Since these participants were familiar with text messaging and browsing the internet on the phone for information, they tended to believe that RHM should include accessible educational information for both patients and caregivers and that this could be accessible to them through the phone.

After the results of the study were examined through the lens of the conceptual model, it was found that the original conceptual model could benefit from an additional pathway that links caregiver, care recipient, and physician beliefs to caregiver burden. In the current study, beliefs around RHM use were influenced by attitude towards health management which influenced caregiver challenges and how they described wanting to use RHM. This pathway emerged in the thematic analysis where we saw that attitude towards health management influenced how caregivers assisted their family member, the challenges they encountered while helping them, and which forms of RHM they thought would be useful. While the original conceptual model clearly shows how burden can be influenced by multiple factors, the results of the Aim 3 (shown in Figure 4.3) reveal an additional pathway that consists of those existing factors combined with the beliefs and perceptions they converge to form that also contributed to whether or not caregivers perceived that RHM would provide relief for their challenging situations, worries, and concerns. A new conceptual model (Figure 5.1) has been developed to incorporate the findings of the current study into the model.

Figure 5.1 Revised Conceptual Model



5.7 Recommendations for future research

This was a large formative study that covered a broad range of topics related to HF management and technology use. One goal of this study was to generate hypotheses for future research, therefore, three new research questions have been created based on the results of this research. First, future research should investigate whether providing RHM for HF that includes an educational component for caregivers impacts hospital readmissions among MA patients. Second, the hypothesis that RHM that facilitates social interaction will contribute to better HF management for MA patients and caregivers should be further investigated. Third, the extent to which family centered versus individualistic attitude towards health management influences HF hospital readmissions should be investigated.

5.8 Limitations

This study had several limitations that deserve mention. The views, beliefs, and experiences of the participants may differ from those of other caregivers, patients, and providers; further research is needed to examine the extent to which the views and beliefs reported here are shared by others. An additional limitation that is present in this study was discovered during data analysis. All MA patients that participated in the study lived with their caregiver, but this was not the case among NHW patients. The difference in living arrangements between the two groups presented issues during analysis when we began looking for common charateristics among patients who seemed to share similar beliefs. For example we could not say that all patients who did not live with their caregiver had something in common, because we did not recruit any MA patients that did not live with their caregiver. In future studies that investigate cultural differences between two different groups, this limitation can be avoide by more closely matching characteristics of participants in both groups. Another limitation that was encountered was during study recruitment. We encountered difficulties recruiting a sufficient number of MA participants in Oregon. To address this we expanded the study to include participants from Los Angeles, CA. While this enabled us to increase our sample size, it may have also influenced our results. One final limitation was that the lead researcher of this study was not a fluent speaker of Spanish. This was a limitation during Spanish language interviews if the bilingual research assistant did not ask follow up questions during certain participant discussions where, had the interview been in English, the lead researcher would have asked additional probing questions.

5.9 Reflexivity

Upon looking back and reflecting on my experiences conducting this research there are several things that stand out as important to me. First, I would anticipate the variable length of time that IRB review can take. When I submitted the protocol and paperwork to IRB for this study I thought the process would take around 6 weeks. The IRB submission and approval process ended up taking around 5 months. This was much longer than I anticipated and could have influenced the funding of my study. In the future I will consider the length of time the IRB approval process can take and be sure that my study funding is scheduled accordingly.

Another important lesson I learned during this process was that I had a limit to the number of interviews I should do in a day. Conducting the interviews with participants was very interesting, but also required a lot of concentration and focus. I learned that doing two interviews in one day was the best for me. Limiting myself to this number of interviews allowed me to be fully present with participants. If I conducted more than two interviews I tended to ask fewer probing questions in the last interview and became very tired by the end of the last interview. As a researcher, I feel that it is important to be fully present and engaged with interview participants, therefore I will limit myself to two interviews per day in the future.

I also learned that using pictures and visual aids to assist in explaining concepts was extremely helpful. I created visual aids to accompany several questions in my interview guides. Participants seemed to engage more when they had something tactile that could help them visualize the concepts I was discussing with them. In the future, I will continue to include diagrams and photos with my interview questions to help participants better understand the questions.

This study involved conducting interviews in English and in Spanish. During the Spanish language interviews I listened and followed along with the Spanish language interview guide while my bilingual research assistants conducted the interviews. During these interviews I often wished that my Spanish speaking skills were stronger. While sitting there quietly next to my research assistant, I wondered if I was making the participants uncomfortable by not speaking. I also wondered if they would have shared more about their experiences if I spoke Spanish with them. At the beginning of the interviews I introduced myself and told them that my Spanish speaking skills were not very good, but that I understood more Spanish than I could speak. They seemed to be understanding and sometimes shared that was how they felt about speaking English and that we could learn from each other. However, I still felt that it would have been better if I could have spoken more fluent Spanish.

When analyzing the data from this study, it was important to me to represent the results in a way that captured the lived experiences of participants. However, I also realize that I guided these discussions by creating the interview guides and that in doing so influenced the focus of participant discussions. I also personally coded all of the transcripts and interpreted the results and their potential meanings. In order to reduce my own personal influence on participant's discussions and my analysis, my interview guides and study results mapped back to my conceptual model which was based on several theories and frameworks. I feel that grounding my questions in theoretical frameworks, helped to remove some of my personal influence on study results. In the future, I think it will be important for me to incorporate theory in the design of my studies to limit the extent of my influence on the results.

Now that this study is complete, I have a strong feeling of gratitude for all of the participants that met with me for interviews and shared their stories. This feeling of gratitude for their assistance has made me also want to ensure that their stories are heard. I plan to present these findings at conferences and in publications. I am also grateful for the help of the bilingual research assistants who helped to recruit and interview participants. Their assistance made it possible for this study to include the experiences of participants who are often difficult to recruit and whom I would not have otherwise been able to interview.

I feel very lucky to have had the experience of completing primary data collection for my dissertation research. It was not always an easy going process, but the lessons I learned while completing this study will inform my future research projects. I am thankful to have had this opportunity and hope that the findings from this study contribute to improving the experiences of MA and NHW HF patients and their caregivers.

CHAPTER 6 CONCLUSION

6.1 Conclusion

The findings from this study add much to our current understanding of perceptions of remote health monitoring (RHM) among Mexican-origin (MA) and non-Hispanic white (NHW) heart failure (HF) patients and their informal caregivers. This study included an under studied population, Latino HF patients and caregivers, in order to contribute to knowledge around their beliefs and goals for using RHM to manage HF and to allieviate caregiver burden. In the short term, findings from this study can be used in new RHM programs and interventions for HF that can be explored further in these specific populations. In the long term, we should continue to investigate how to best meet the needs of MA HF patients and their caregivers by further engaging them in research and discussions around their needs for HF management to be sure their opinions and preferences are included in the development of new RHM interventions.

The findings from this study have assisted in the formation of recommendations for future RHM interventions that can be explored with MA HF patients and their informal caregivers. First, when considering MA HF patients, RHM systems should include the ability to monitor blood pressure, medications, heart function in general, breathing, and all vital health indicators. MA patients, mostly rely on their informal caregivers to manage their disease (Gallant, Spitze, & Grove, 2010) but they also have a desire to better understand their condition and follow physician instructions. For this reason, RHM interventions designed for use among MA patients should also include educational materials about many aspects of HF. These materials and the patient interfaces with technology need to be presented in Spanish and in English to assist more patients (Hsieh, 2013). Additionally, in order to fully take advantage of the data that is being collected and to better meet the RHM goals of MA patients, RHM should utilize machine learning to identify patient patterns and normal/baseline health indicators so that when a patient's health indicators are outside of the normal range, patients can be alerted (Holzinger, 2016). Machine learning, the ability of computers to recognize patterns and act without direct programming (Holzinger, 2016), will be a necessary component of RHM if it is to meet MA patients' goal of being alerted to situations when their health indicators are outside of normal range.

If RHM is to be the partner in care that MA caregivers believe it will be, there are many components that need to be included to meet their needs. MA Caregivers shared a need to be able to monitor everything that patients would like to monitor with the addition of patient blood thinner levels, effects of medication on vitals, pacemaker functioning, and patient location. MA caregivers would also like RHM to include instruction on better meeting the dietary needs of their family member. MA caregivers would like RHM to include these aspects so that they can be prepared, aware, and efficient in taking care of their family member. For MA caregivers, having early awareness of health deterioration was also important, therefore machine learning, which can detect changes in health indicators (Holzinger, 2016), should be incorporated into RHM interventions targeted at MA caregivers.

Those developing RHM interventions for MA HF patients and caregivers should also consider that receiving health information among Latino families should not be a one-way communication (Morales, Cunningham, Brown, Liu, & Hays, 1999; Villani, & Mortensen, 2014). Having RHM technology and knowing that someone else was on the other end checking on the patient was discussed as bringing patients and caregivers greater peace of mind. Both MA patients and caregivers shared that it was important to them to be able to speak with a person regarding information they were getting from an RHM system. When designing RHM interventions for use in this population, it may be important to build human or humanlike interactions into the RHM system to create a health information environment that is acceptable (Brown, 2008). A technological solution without a person at the other end, may not work with MA patients and caregivers. In order to accommodate this, the ability to Skype with a nurse connected to the health monitoring system if a concern arises, might be necessary (Jimison, Klein, & Marcoe, 2013). Additionally, those designing RHM interventions for this population need to consider who will be on the other end of the system communicating with patients. Those that will be interacting with patients and caregivers need to be able to speak Spanish and communicate technical and health information in an accessible manner (Morales, Cunningham, Brown, Liu, & Hays, 1999). RHM interventions designed for this population might also consider incorporating a chat system to further encourage social interaction around healthcare information.

In conclusion, HF management among MA patients and caregivers is a team effort. RHM interventions targeted at this population should include patients, caregivers, and extended family members in care discussions, education on self-care, and RHM technology use in order to facilitate the use of the intervention. Previous RHM interventions among Latino HF patients may have failed due to lack of engaging informal family caregivers and/or providing little accessible educational support for caregivers. Future RHM interventions should incorporate the findings of the current study to better meet the goals this population has for HF management.

Bibliography

Adler, R., & Mehta, R. (2014). Catalyzing technology to support family caregiving. National Alliance for Caregiving. Retrieved from: http://www.caregiving.org/wp-content/uploads/2010/01/Catalyzing-Technology-to-Support-Family-Caregiving_FINAL.pdf

Affordable Care Act, 42 U.S.C. § 18001 (2010).

Agboola, S., Jethwani, K., Khateeb, K., Moore, S., & Kvedar, J. (2015). Heart Failure Remote Monitoring: Evidence From the Retrospective Evaluation of a Real-World Remote Monitoring Program. *J Med Internet Res*, *17*(4), e101. http://doi.org/10.2196/jmir.4417

Ågren, S., Evangelista, L. S., Hjelm, C., & Strömberg, A. (2012). Dyads affected by chronic heart failure: a randomized study evaluating effects of education and psychosocial support to patients with heart failure and their partners. *Journal of cardiac failure*, *18*(5), 359-366.

Alexander, M., Grumbach, K., Remy, L., Rowell, R., & Massie, B. M. (1999). Congestive heart failure hospitalizations and survival in California: patterns according to race/ethnicity. *American Heart Journal*, *137*(5), 919–927.

American Diabetes Association (2011). Living healthy with diabetes: A guide for adults 55 and up. American Diabetes Association. Retrieved from: http://main.diabetes.org/dorg/PDFs/living-with-diabetes/living-healthy-with-diabetes-guide.pdf

American Diabetes Association (2013). Living healthy with diabetes: Your easy-to-use guide for living healthy with diabetes. American Diabetes Association. Retrieved from: http://www.diabetes.org/living-with-diabetes/treatment-and-care/seniors/living-healthy-with-diabetes.html

American Association of Retired Persons (AARP) (2011). *Healthy @ home 2.0.* Washington, DC: American Association of Retired Persons.

American Heart Association (2015a). Advanced heart failure. American Heart Association. Retrieved from: http://www.heart.org/HEARTORG/Conditions/HeartFailure/Advanced-Heart-Failure_UCM_441925_Article.jsp

American Heart Association (2015b). Classes of heart failure. American Heart Association. Retrieved from: http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/Classes-of-Heart-Failure_UCM_306328_Article.jsp

American Heart Association (2015c). Common tests for heart failure. American Heart Association. Retrieved from: http://www.heart.org/HEARTORG/Conditions/HeartFailure/SymptomsDiagnosisof HeartFailure/Common-Tests-for-Heart-Failure_UCM_306334_Article.jsp

American Heart Association (2015d). Ejection fraction heart failure measurement. American Heart Association. Retrieved from: http://www.heart.org/HEARTORG/Conditions/HeartFailure/SymptomsDiagnosisof HeartFailure/Ejection-Fraction-Heart-Failure-Measurement_UCM_306339_Article.jsp

American Heart Association (2014). Hispanics and heart disease, stroke. Retrieved from: http://www.heart.org/HEARTORG/Conditions/More/MyHeartandStrokeNews/Hispanics-and-Heart-Disease-Stroke_UCM_444864_Article.jsp

American Telemedicine Association (2012). What is telemedicine? Retrieved from: http://www.americantelemed.org/about-telemedicine/what-is-telemedicine#.VWZRusaWthN

Ammar, K. A., Jacobsen, S. J., Mahoney, D. W., Kors, J. A., Redfield, M. M., Burnett, J. C., & Rodeheffer, R. J. (2007). Prevalence and prognostic significance of heart failure stages: application of the American College of Cardiology/American Heart Association heart failure staging criteria in the community. *Circulation*, *115*(12), 1563–1570. http://doi.org/10.1161/CIRCULATIONAHA.106.666818

Anand, I. S., Tang, W. H. W., Greenberg, B. H., Chakravarthy, N., Libbus, I., & Katra, R. P. (2012). Design and performance of a multisensor heart failure monitoring algorithm: Results from the Multisensor Monitoring in Congestive Heart Failure (MUSIC) study. *Journal of Cardiac Failure*, *18*(4), 289–295. http://doi.org/10.1016/j.cardfail.2012.01.009

Angel, J. L., Rote, S. M., Brown, D. C., Angel, R. J., & Markides, K. S. (2014). Nativity status and sources of care assistance among elderly Mexican-Origin adults. *Journal of Cross-Cultural Gerontology*, *29*(3), 243-258. doi: 10.1007/s10823-014-9234-9

Anthony, K. P., Gelhof, G. J., & Mendez-Luck, C.A. (2016). Characterizing caregiving intensity and emotional drain among Mexican-origin women caregivers.*The Gerontologist*, gnw090.

Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist*, *37*(3), 342–354. http://doi.org/10.1093/geront/37.3.342

Araujo-Gutierrez, R., Ibarra-Cortez, S. H., Park, M. H., Estep, J. D., Guha, A., Trachtenberg, B. H., ... & Bhimaraj, A. (2016). Reduction in Healthcare Utilization in Patients with Remote Hemodynamic Pulmonary Artery Pressure Monitoring Device: A Real-World, Post Clinical Trial Single Center Experience. *Journal of Cardiac Failure*, *22*(8), S105.

Årestedt, K., Saveman, B. I., Johansson, P., & Blomqvist, K. (2013). Social support and its association with health-related quality of life among older patients with chronic heart failure. *European Journal of Cardiovascular Nursing, 12(1)*, 69-77.

Armstrong, P. W. (2000). Left ventricular dysfunction: causes, natural history, and hopes for reversal. *Heart*, *84*(suppl 1), i15–i17. http://doi.org/10.1136/heart.84.suppl_1.i15

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, *50*(2), 179–211.

Bahrami H., Kronmal R., Bluemke D.A., & et al. (2008). Differences in the incidence of congestive heart failure by ethnicity: The multi-ethnic study of atherosclerosis. *Archives of Internal Medicine*, *168*(19), 2138–2145. http://doi.org/10.1001/archinte.168.19.2138

Bakas, T., Pressler, S. J., Johnson, E. A., Nauser, J. A., & Shaneyfelt, T. (2006). Family caregiving in heart failure. *Nursing Research*, *55*(3), 180–188.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American psychologist*, *37*(2), 122.

Bardach, S. H., Tarasenko, Y. N., & Schoenberg, N. E. (2011). The role of social support in multiple morbidity: self-management among rural residents.*Journal of health care for the poor and underserved*, *22*(3), 756.

Bernard, H. R. (2012). *Social research methods: Qualitative and quantitative approaches*. Sage.

Beyene, Y., Becker, G. & Mayen, N. (2002). Perception of aging and sense of well-being among Latino elderly. *Journal of Cross-Cultural Gerontology*, 17(2), 155-172. doi: 10.1023/A:1015886816483

Bhimaraj, A. (2013). Remote Monitoring of Heart Failure Patients. *Methodist DeBakey Cardiovascular Journal*, *9*(1), 26–31.

Black, J. T., Romano, P. S., Sadeghi, B., Auerbach, A. D., Ganiats, T. G., Greenfield, S., … Ong, M. K. (2014). A remote monitoring and telephone nurse coaching intervention to reduce readmissions among patients with heart failure: study protocol for the Better Effectiveness After Transition-Heart Failure (BEAT-HF) randomized controlled trial. *Trials*, *15*(1), 124.

Brown, S. J. (2008). U.S. Patent No. 7,320,030. Washington, DC: U.S. Patent and Trademark Office.

Brown, D. W., Haldeman, G. A., Croft, J. B., Giles, W. H., & Mensah, G. A. (2005). Racial or ethnic differences in hospitalization for heart failure among elderly adults: Medicare, 1990 to 2000. *American Heart Journal*, *150*(3), 448–454. http://doi.org/10.1016/j.ahj.2004.11.010

Bueno, H., Ross, J. S., Wang, Y., Chen, J., Vidán, M. T., Normand, S.-L. T., … Keenan, P. S. (2010). Trends in length of stay and short-term outcomes among Medicare patients hospitalized for heart failure, 1993-2006. *Jama*, *303*(21), 2141–2147.

Bui, A. L., Fonarow, G. C., & Horwich, T. B. (2011). Epidemiology and risk profile of heart failure. *Nature Reviews Cardiology*, *8*(1), 30+.

Calderon, V., & Tennstedt, S. L. (1998). Ethnic differences in the expression of caregiver burden: Results of a qualitative study. *Journal of Gerontological Social Work*, *30*, 159-178. doi: 10.1300/J083v30n01_10

Cardona, J. (2007). Elder abuse and neglect in Latino families: An ecological and culturally relevant theoretical framework for clinical practice. *Family Process*, 46(4), 451-470. doi:10.1111/j.1545-5300.2007.00225.x

Cené, C. W., Haymore, L. B., Lin, F. C., Laux, J., Jones, C. D., Wu, J. R., ... & Corbie-Smith, G. (2014). Family member accompaniment to routine medical visits is associated with better self-care in heart failure patients. *Chronic illness*, 1742395314532142.

Centers for Medicare and Medicaid Services (2014). Chronic conditions prevalence state level: All beneficiaries by race/ethnicity and age, 2008-2012. Retrieved from: http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/CC_Main.html

Charmaz, K. (2006). Constructing grounded theory: A practical guide through qualitative research. *SagePublications Ltd, London*.

Chaudhry, S. I., McAvay, G., Chen, S., Whitson, H., Newman, A. B., Krumholz, H. M., & Gill, T. M. (2013). Risk Factors for Hospital Admission Among Older Persons With Newly Diagnosed Heart Failure: Findings From the Cardiovascular Health Study. *Journal of the American College of Cardiology*, *61*(6), 635–642. http://doi.org/10.1016/j.jacc.2012.11.027

Chaudhry, S. I., Mattera, J. A., Curtis, J. P., Spertus, J. A., Herrin, J., Lin, Z., … Krumholz, H. M. (2010). Telemonitoring in patients with heart failure. *New England Journal of Medicine*, *363*(24), 2301–2309. http://doi.org/10.1056/NEJMoa1010029

Chen J, Normand ST, Wang Y, & Krumholz HM. (2011). National and regional trends in heart failure hospitalization and mortality rates for medicare beneficiaries, 1998- 2008. *JAMA*, *306*(15), 1669–1678. http://doi.org/10.1001/jama.2011.1474

Clark, A. M., Freydberg, C. N., McAlister, F. A., Tsuyuki, R. T., Armstrong, P. W., & Strain, L. A. (2009). Patient and informal caregivers' knowledge of heart failure: necessary but insufficient for effective self‐care. *European Journal of Heart Failure*, *11*(6), 617-621.

Cleland, J. G. F., Louis, A. A., Rigby, A. S., Janssens, U., & Balk, A. H. M. M. (2005). Noninvasive home telemonitoring for patients with heart failure at high risk of recurrent admission and death: The Trans-European Network-Home-Care Management System (TEN-HMS) study. *Journal of the American College of Cardiology*, *45*(10), 1654–1664. http://doi.org/10.1016/j.jacc.2005.01.050

Copeland, L., Berg, G., Johnson, D., & Bauer, R. (2010). An intervention for VA patients with congestive heart failure. *The American Journal of Managed Care*, *16*(3), 158.

Cox, C. & Monk, A. (1996). Strain among caregivers: Comparing the experiences of African American and Hispanic caregivers of Alzheimer's relatives. *International Journal of Aging and Human Development*, *43*(2), 93-105.

Crist, J. D., Morris McEwen, M., Herrera, A. P., Kim, S., Pasvogel, A., & Hepworth, J. T. (2009). Caregiving burden, acculturation, familism, and Mexican American elders' use of home care services. *Research and Theory for Nursing Practice: An International Journal*, *23*(3), 165-180. doi: 10.1891/1541-6577.23.3.165

Czaja, S. J., Lee, C. C., Arana, N., Nair, S. N., & Sharit, J. (2014). Use of a telehealth system by older adults with hypertension. *Journal of Telemedicine and Telecare*, *20*(4), 184–191. http://doi.org/10.1177/1357633X14533889

Dang, C. M., Estrada, S., Bresee, C., & Phillips, E. H. (2013). Exploring potential use of internet, e-mail, and instant text messaging to promote breast health and mammogram use among immigrant Hispanic women in Los Angeles County. *The American Surgeon*, *79*(10), 997–1000.

Davidson, P. M., Abernethy, A. P., Newton, P. J., Clark, K., & Currow, D. C. (2013). The caregiving perspective in heart failure: a population based study. *BMC Health Services Research*, *13*(1), 342.

Davis, F. D. (1986). A technology acceptance model for empirically testing new end-user information systems: Theory and results. Doctoral dissertation, Sloan School of Management, Massachusetts Institute of Technology.

Davis, F. D., Bagozzi, R. P., & Warshaw, P. R. (1989). USER ACCEPTANCE OF COMPUTER TECHNOLOGY: A COMPARISON OF TWO THEORETICAL MODELS. *Management Science*, *35*(8), 982–1003.

Deng, Z., Mo, X., & Liu, S. (2014). Comparison of the middle-aged and older users' adoption of mobile health services in China. *International Journal of Medical Informatics*, *83*(3), 210–224. http://doi.org/10.1016/j.ijmedinf.2013.12.002

Desai, A. S. (2012). Does home monitoring heart failure care improve patient outcomes? Home monitoring heart failure care does not improve patient outcomes looking beyond telephone-based disease management. *Circulation*, *125*(6), 828-836.

Dunbar, S. B., Clark, P. C., Quinn, C., Gary, R. A., & Kaslow, N. J. (2008). Family influences on heart failure self-care and outcomes. *The Journal of Cardiovascular Nursing*, *23*(3), 258.

Durstenfeld, M. S., Park, H., Katz, S. D., & Blecker, S. B. (2015). Abstract 108: Racial and Ethnic Disparities in Heart Failure Readmissions and Mortality in a Large Municipal Healthcare System. *Circulation: Cardiovascular Quality and Outcomes*, *8*(Suppl 2), A108–A108.

Evans, B. C., Coon, D. W., & Belyea, M. J. (2014). Worry among Mexican American caregivers of community-dwelling elders. *Hispanic Journal of Behavioral Sciences*, *36*(3), 344–365. doi:10.1177/0739986314536684

Fairbrother, P., Pinnock, H., Hanley, J., McCloughan, L., Sheikh, A.,Pagliari, C., & McKinstry, B. (2013). Exploring telemonitoring andself-management by patients with chronic obstructive pulmonary disease: A qualitative study embedded in a randomized controlled trial. *Patient Education and Counseling, 93*, 403–410.

Federal Interagency Forum on Aging-Related Statistics (2012). *Older Americans 2012: Key Indicators of Well-Being*. Federal Interagency Forum on Aging-Related Statistics, Editor. 2012, U.S. Government Printing Office: Washington, D.C.

Feinberg, L. F. (2014). Moving toward person-and family-centered care. *Public Policy & Aging Report, 24(3),* 97-101.

Flores, Y. G., Hinton, L., Barker, J. C., Franz, C. E., & Velasquez, A. (2009). Beyond familism: A case study of ethics of care of a Latina caregiver of an elderly patient with dementia. *Health Care for Women International*, 30(12), 1055-1072. doi:10.1080/07399330903141252

Fonarow, G. C., Yancy, C. W., & Heywood, J. T. (2005). Adherence to heart failure quality-of-care indicators in US hospitals: analysis of the ADHERE Registry. *Archives of Internal Medicine*, *165*(13), 1469–1477.

Fontana, A., & Frey, J. H. (2000). The interview: From structured questions to negotiated text. In Denzin, N. K. & Lincoln, Y. S. (Eds) Handbook of Qualitative Research, 2nd Ed. Sage Publications: Thousand Oaks.

Francis, J., Eccles, M. P., Johnston, M., Walker, A. E., Grimshaw, J. M., Foy, R., Kaner, E. F. S., Smith, L. & Bonetti, D. (2004). Constructing questionnaires based on the theory of planned behaviour: A manual for health services researchers. Newcastle upon Tyne, UK: Centrefor Health Services Research, University of Newcastle upon Tyne.

Gaikwad, R. & Warren, J. (2009). The role of home-based information and communications technology interventions in chronic disease management: a systematic literature review. *Health Informatics Journal, 15*(2), 122-146.

Gale, N., & Sultan, H. (2013). Telehealth as ‘peace of mind’: embodiment, emotions and the home as the primary health space for people with chronic obstructive pulmonary disorder. *Health & place, 21*, 140-147.

Gallagher-Thompson, D., Solano, N., Coon, D., & Arean, P. (2003). Recruitment and retention of Latino dementia family caregivers in intervention research: Issues to face, lessons to learn. *The Gerontologist, 43*, 45-51.

Gallant, M., Spitze, G., & Grove, J. (2010). Chronic Illness Self-care and the Family Lives of Older Adults: A Synthetic Review Across Four Ethnic Groups. *Journal of Cross-Cultural Gerontology*, *25*(1), 21–43. http://doi.org/10.1007/s10823-010-9112-z

Gellis, Z. D., Kenaley, B., McGinty, J., Bardelli, E., Davitt, J., & Ten Have, T. (2012). Outcomes of a telehealth intervention for homebound older adults with heart or chronic respiratory failure: A randomized controlled trial. *The Gerontologist*, *52*(4), 541– 552. http://doi.org/10.1093/geront/gnr134

George, S., Hamilton, A., & Baker, R. S. (2012). How do low-income urban African Americans and Latinos feel about telemedicine? A diffusion of innovation analysis. *International Journal of Telemedicine and Applications*, *2012*, 1.

Gheorghiade, M., Vaduganathan, M., Fonarow, G. C., & Bonow, R. O. (2013). Rehospitalization for Heart Failure: Problems and Perspectives. *Journal of the American College of Cardiology*, *61*(4), 391–403. http://doi.org/10.1016/j.jacc.2012.09.038

Gillick, M. R. (2013). The critical role of caregivers in achieving patient-centered care. *Jama, 310(6)*, 575-576.

Ginossar, T., & Nelson, S. (2010) Reducing the health and digital divides: A model for using community-based participatory research approach to e-health interventions in low-income Hispanic communities. *Journal of Comupter-Mediated Communication, 15*, 530-551.

Giordano, A., Scalvini, S., Zanelli, E., Corrà, U., G.L., L., Ricci, V. A., … Glisenti, F. (2009). Multicenter randomized trial on home-based telemanagement to prevent hospital readmission of patients with chronic heart failure. *International Journal of Cardiology*, *131*(2), 192–199. http://doi.org/10.1016/j.ijcard.2007.10.027

Glanz, K., Rimer, B. K., & Viswanath, K. (Eds.). (2008). *Health behavior and health education: theory, research, and practice*. John Wiley & Sons.

Goldberg, L. R. (2010). Heart Failure. *Annals of Internal Medicine*, *152*(11), ITC6–1. http://doi.org/10.7326/0003-4819-152-11-201006010-01006

Goldberg, L. R., & Jessup, M. (2006). Stage B Heart Failure: Management of Asymptomatic Left Ventricular Systolic Dysfunction. *Circulation*, *113*(24), 2851–2860. http://doi.org/10.1161/CIRCULATIONAHA.105.600437

Gonzalez-Barrera, A., & Lopez, M. H. (2013). A demographic portrait of Mexican-origin Hispanics in the United States. *Pew Hispanic Center RSS. Pew Research Hispanic Center*, *1*.

Gorst, S. L., Coates, E., & Armitage, C. J. (2015). "It's sort of a lifeline": Chronic obstructive pulmonary disease patients' experiences of home health. *Health Psychology*. *35*(1), 60-68.

Gure, T. R., Kabeto, M. U., Blaum, C. S., & Langa, K. M. (2008). Degree of disability and patterns of caregiving among older Americans with congestive heart failure. *Journal of general internal medicine, 23(1)*, 70-76.

Hahn, E. A., Kim, G., & Chiriboga, D. A. (2011). Acculturation and depressive symptoms among Mexican-American elders new to the caregiving role: Results from the Hispanic-EPESE. *Journal of Aging and Health*, *23*(3), 417-432.

Heart Failure Society of America. (2006). Executive summary: HFSA 2006 Comprehensive Heart Failure Practice Guideline. *Journal of Cardiac Failure, 12,* 10-38.

Heidenreich, P. A., Albert, N. M., Allen, L. A., Bluemke, D. A., Butler, J., Fonarow, G. C., … Trogdon, J. G. (2013). Forecasting the Impact of Heart Failure in the United States: A Policy Statement From the American Heart Association. *Circulation: Heart Failure*, *6*(3), 606–619. http://doi.org/10.1161/HHF.0b013e318291329a

Hernandez, A. M., & Bigatti, S. M. (2010). Depression among older Mexican American caregivers. *Cultural Diversity and Ethnic Minority Psychology*, *16*(1), 50.

Herrera, A. P., Mendez-Luck, C. A., Crist, J. D., Smith, M. L., Warre, R., Ory, M. G., & Markides, K. (2013). Psychosocial and cognitive health differences by caregiver status among older Mexican Americans. *Community mental health journal*, *49*(1), 61-72.

Hill, T. D., Uchino, B. N., Eckhardt, J. L., & Angel, J. L. (2016). Perceived social support trajectories and the all-cause mortality risk of older Mexican American women and men. *Research on aging, 38(3),* 374-398.

Hines, A. L. (Truven Health Analytics), Barrett, M. L. (ML Barrett, Inc), Jiang, H. J. (AHRQ), & Steiner, C. A. (AHRQ) (2014). Conditions with the largest number of adult hospital readmissions by payer, 2011. HCUP Statistical Brief #172. April 2014. Agency for Healthcare Research and Quality, Rockville, MD. http://www.hcup-us.ahrq.gov/reports/statbriefs/sb172-Conditions-Readmissions-Payer.pdf.

Ho, K. K. L., Pinsky, J. L., Kannel, W. B., & Levy, D. (1993). The epidemiology of heart failure: The Framingham Study. *Mechanisms and Management of Heart Failure: Implications of Clinical Trials for Clinical Practice*, *22*(4, Supplement 1), A6–A13. http://doi.org/10.1016/0735-1097(93)90455-A

Holden, R. J. (2010). Physicians' beliefs about using EMR and CPOE: In pursuit of a contextualized understanding of health IT use behavior. *International Journal of Medical Informatics*, *79*(2), 71–80. http://doi.org/10.1016/j.ijmedinf.2009.12.003

Holzinger, A. (2016). Interactive machine learning for health informatics: when do we need the human-in-the-loop? *Brain Informatics, 3(2),* 119-131.

Hsieh, E. (2013). Health literacy and patient empowerment: The role of medical interpreters in bilingual health communication. *Reducing health disparities: Communication intervention*, 35-58.

Hughes, H. A., & Granger, B. B. (2014). Racial disparities and the use of technology for self-management in Blacks with heart failure: A literature review. *Current Heart Failure Reports*, *11*(3), 281–289. http://doi.org/10.1007/s11897-014-0213-9

Hunt, S. A., Abraham, W. T., Chin, M. H., Feldman, A. M., Francis, G. S., Ganiats, T. G., … Michl, K. (2009). 2009 Focused update incorporated into the ACC/AHA 2005 guidelines for the diagnosis and management of heart failure in adults: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines developed in collaboration with the International Society for Heart and Lung Transplantation. *Journal of the American College of Cardiology*, *53*(15), e1–e90.

Hunt, K. J., Resendez, R. G., Williams, K., Haffner, S. M., Stern, M. P., & Hazuda, H. P. (2003). All-cause and cardiovascular mortality among Mexican-American and non-Hispanic white older participants in the San Antonio Heart Study— Evidence against the "Hispanic Paradox." *American Journal of Epidemiology*, *158*(11), 1048–1057. http://doi.org/10.1093/aje/kwg249

Hwang, B., K. Fleischmann, Ayanian, J., Stotts, N., & Dracup, K. (2011). Caregiving for patients with heart failure: Impact on patients' families. *American Journal of Critical Care*, *20*(6), 431–442. http://doi.org/doi: http://dx.doi.org/10.4037/ajcc2011472

Inglis, S.C., Clark, R.A., McAlister, F.A., Ball, J., Lewinter, C., Cullington, D., Stewart, S., Cleland, J.G.F. (2011). Structured telephone support or telemonitoring programmes for patients with chronic heart failure. *Cochrane Database of Systematic Reviews*, 8, Art. No.: CD007228. DOI: 10.1002/14651858.CD007228.pub2

Inglis, S. C., Clark, R. A., McAlister, F. A., Stewart, S., & Cleland, J. G. F. (2011). Which components of heart failure programmes are effective? A systematic review and meta-analysis of the outcomes of structured telephone support or telemonitoring as the primary component of chronic heart failure management in 8323 patients: Abridged Cochrane Review. *European Journal of Heart Failure*, *13*(9), 1028–1040. http://doi.org/10.1093/eurjhf/hfr039

Institute of Medicine (US). Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: a new health system for the 21st century*. National Academy Press.

Janesick, V. J. (2000). The choreography of qualitative research design: Minuets, improvisations, and crystallization. In Denzin, N. K. & Lincoln, Y. S. (Eds.) Handbook of Qualitative Research, 2nd Ed. Sage Publications: Thousand Oaks.

Jimison, H. B., Klein, K. A., & Marcoe, J. L. (2013, July). A socialization intervention in remote health coaching for older adults in the home. In *2013 35th Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC)* (pp. 7025-7028). IEEE.

Jolicoeur, P. M., & Madden, T. (2002). The good daughters: Acculturation and caregiving among Mexican-American women. *Journal of Aging Studies*, *16*(2), 107-120. doi:10.1016/s0890-4065(02)00038-5

Joo, H., Fang, J., Losby, J. L., & Wang, G. (2014). Cost of informal caregiving for patients with heart failure. *American Heart Journal*, *169*(1), 142–148.e2. http://doi.org/10.1016/j.ahj.2014.10.010

Joynt, K. E., & Jha, A. K. (2011). Who has higher readmission rates for heart failure, and why?: Implications for efforts to improve care using financial incentives. *Circulation: Cardiovascular Quality and Outcomes*, *4*(1), 53–59. http://doi.org/10.1161/CIRCOUTCOMES.110.950964

Kaplan, R. C. (2014). An agenda to promote Hispanic cardiovascular health. National Reviews Cardiology, (11) 560-562. doi: 10.1038/nrcardio.2014.126

Katz, S. (1983). Assessing self-maintenance: Activities of daily living, mobility and instrumental activities of daily living. *Journal of the American Geriatrics Society*, *31*(12), 721-726.

Klersy, C., De Silvestri, A., Gabutti, G., Regoli, F., & Auricchio, A. (2009). A meta-analysis of remote monitoring of heart failure patients. *Journal of the American College of Cardiology*, *54*(18), 1683–1694. http://doi.org/10.1016/j.jacc.2009.08.017

Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: the updated sociocultural stress and coping model. *The Journals of Gerontology*, *65B*(1), 5–13. doi:10.1093/geronb/gbp096

Koehler, F., Winkler, S., Schieber, M., Sechtem, U., Stangl, K., Böhm, M., … Anker, S. D. (2011). Impact of remote telemedical management on mortality and hospitalizations in ambulatory patients with chronic heart failure: The Telemedical Interventional Monitoring in Heart Failure Study. *Circulation*, *123*(17), 1873–1880. http://doi.org/10.1161/CIRCULATIONAHA.111.018473

Kotb, A., Cameron, C., Hsieh, S., & Wells, G. (2015). Comparative effectiveness of different forms of telemedicine for individuals with heart failure (HF): A systematic review and network meta-analysis. *PloS One*, *10*(2), e0118681.

Krogstad, J. M., Stepler, R., Lopez, M. H. (2015). English proficiency on the rise among Latinos: U.S. born driving language changes. Pew Research Center: Hispanic Trends. Retrieved from: http://www.pewhispanic.org/2015/05/12/english-proficiency-on-the-rise-among-latinos/

Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist, 9*, 179-186. doi: 10.1093/geront/9.3_part_1.179

Leeman-Castillo, B., Beaty, B., Raghunath, S., Steiner, J., & Bull, S. (2010). LUCHAR: Using Computer Technology to Battle Heart Disease Among Latinos. *American Journal of Public Health*, *100*(2), 272–275. http://doi.org/10.2105/AJPH.2009.162115

Li, H., Morrow-Howell, N., & Proctor, E. K. (2004). Post-acute home care and hospital readmission of elderly patients with congestive heart failure. *Health and Social Work, 29*(4), 275+.

Lim, J. W., & Zebrack, B. (2004). Caring for family members with chronic physical illness: a critical review of caregiver literature. *Health and quality of life outcomes*, *2*(50), 1-9.

Löfvenmark, C., Saboonchi, F., Edner, M., Billing, E., & Mattiasson, A. C. (2013). Evaluation of an educational programme for family members of patients living with heart failure: a randomised controlled trial. *Journal of clinical nursing*, *22*(1-2), 115-126.

Lopez, M. H., Gonzalez-Barrera, A., Patten, E., & Center, P. H. (2013). *Closing the digital divide: Latinos and technology adoption*. Pew Hispanic Center Washington, DC.

Lorig, K., Ritter, P. L., Villa, F., & Piette, J. D. (2008). Spanish Diabetes Self-Management With and Without Automated Telephone Reinforcement: Two randomized trials. *Diabetes Care*, *31*(3), 408–414. http://doi.org/10.2337/dc07-1313

Mabote, T., Wong, K., & Cleland, J. G. (2014). The utility of novel non-invasive technologies for remote hemodynamic monitoring in chronic heart failure. *Expert review of cardiovascular therapy*, *12*(8), 923-928.

Madigan, E., Schmotzer, B. J., Struk, C. J., DiCarlo, C. M., Kikano, G., Piña, I. L., & Boxer, R. S. (2013). Home health care with telemonitoring improves health status for older adults with heart failure. *Home health care services quarterly*, *32*(1), 57-74.

Maile, M. D., Engoren, M. C., Tremper, K. K., Jewell, E., & Kheterpal, S. (2014). Worsening preoperative heart failure is associated with mortality and noncardiac complications, but not myocardial infarction after noncardiac surgery: a retrospective cohort study. *Anesthesia & Analgesia*, *119*(3), 522–532.

Maisel, A., Barnard, D., Jaski, B., Frivold, G., Marais, J., Azer, M., … Greenberg, B. (2013). Primary results of the HABIT Trial (Heart Failure Assessment With BNP in the Home). *Journal of the American College of Cardiology*, *61*(16), 1726–1735. http://doi.org/10.1016/j.jacc.2013.01.052

Malvey, D. M., & Slovensky, D. J. (2014). *MHealth: Transforming Healthcare*. Springer.

Markides, K. S., & Coreil, J. (1986). The health of Hispanics in the southwestern United States: an epidemiologic paradox. *Public health reports, 101(3),* 253.

Markides, K. S., Eschbach, K., Ray, L. A., Peek, M. K. (2007) Census disability rates among older people by race/ethnicity and type of Hispanic origin. In Angel, J.L., Whitfield, K.E. (Eds.), *The Health of Aging Hispanics* (26-39). New York: Springer. doi:10.1007/978-0-387-47208-9_3

Martens, K. H., & Mellor, S. D. (1997). A study of the relationship between home care services and hospital readmission of patients with congestive heart failure. *Home Healthcare Nurse*, *15*(2), 123–129.

Martin-Carrasco, M., Otermin, P., Pérez-Camo, V., Pujol, J., Agueera, L., Martín, M. J., ... & Balana, M. (2010). EDUCA study: Psychometric properties of the Spanish version of the Zarit Caregiver Burden Scale. *Aging & mental health*, *14*(6), 705-711.

Melton, K. D., Foli, K. J., Yehle, K. S., & Griggs, R. R. (2015). Heart failure in Hispanic Americans: improving cultural awareness. *The Journal for Nurse Practitioners*, *11*(2), 207-213.

Mendez-Luck, C. A., Applewhite, S. R., Vincente, L., Toyokawa, N. (2015). The concept of familism in the lived experiences of Mexican-origin caregivers. Manuscript in review.

Mendez-Luck, C. A., Kennedy, D. P., & Wallace, S. P. (2008). Concepts of burden in giving care to older relatives: a study of female caregivers in a Mexico City neighborhood. *Journal of Cross-Cultural Gerontology*, *23*(3), 265-282. doi:10.1007/s10823-008-9058-6

Metra, M., Felker, G. M., Zacà, V., Bugatti, S., Lombardi, C., Bettari, L., … Dei Cas, L. (2010). Acute heart failure: Multiple clinical profiles and mechanisms require tailored therapy. *International Journal of Cardiology*, *144*(2), 175–179. http://doi.org/10.1016/j.ijcard.2010.04.003

Minutello, R. M., Chou, E. T., Hong, M. K., & Wong, S. C. (2006). Impact of race and ethnicity on inhospital outcomes after percutaneous coronary intervention (report from the 2000-2001 New York State Angioplasty Registry). *American Heart Journal*, *151*(1), 164–167.

Morales, L. S., Cunningham, W. E., Brown, J. A., Liu, H., & Hays, R. D. (1999). Are Latinos Less Satisfied with Communication by Health Care Providers? *Journal of General Internal Medicine*, *14*(7), 409–417. http://doi.org/10.1046/j.1525-1497.1999.06198.x

Mozaffarian, D., Benjamin, E. J., Go, A. S., Arnett, D. K., Blaha, M. J., Cushman, M., … Turner, M. B. (2015). Executive Summary: Heart Disease and Stroke Statistics—2015 Update: A Report From the American Heart Association. *Circulation*, *131*(4), 434–441. http://doi.org/10.1161/CIR.0000000000000157

Mynatt, E. D., Rowan, J., Craighill, S., Jacobs, A. J. (2001). Digital family portraits: support peace of mind for extended family members. *CHI '01 Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 333-340.

National Alliance for Caregiving & Evercare (2008). *Evercare study of Hispanic family caregiving in the U.S.* Minnetonka, MN: National Alliance for Caregiving & Evercare.

National Heart, Blood, and Lung Institute (2014). What is Heart Failure? Retrieved from: http://www.nhlbi.nih.gov/health/health-topics/topics/hf

Neary, S. R., & Mahoney, D. F. (2005). Dementia caregiving: the experiences of Hispanic/Latino caregivers. *Journal of Transcultural Nursing*, *16*(2), 163–70. doi:10.1177/1043659604273547

Office of Disease Prevention and Health Promotion (2010). Healthy People 2020: Foundation Health Measure Report Health-Related Quality of Life and Well-Being. Retrieved from: https://www.healthypeople.gov/sites/default/files/HRQoLWBFullReport.pdf

Ono, H. & Zavodny, M. (2008). Immigrants, English ability and the digital divide. *Social Forces*, *86*(4), 1455-1480.

Oosterom-Calo, R., Vice, K., & Breslow, M. (2015, August). Experiences of Older Patients with Multiple Chronic Conditions in the Intensive Ambulatory Care Home Telehealth

Program. In International Conference on Human-Computer Interaction (pp. 311-316). Springer International Publishing.

Pandor, A., Gomersall, T., Stevens, J. W., Wang, J., Al-Mohammad, A., Bakhai, A., … Wong, R. (2013). Remote monitoring after recent hospital discharge in patients with heart failure: a systematic review and network meta-analysis. *Heart*, heartjnl–2013.

Phillips, C. O., Wright, S. M., Kern, D. E., Singa, R. M., Shepperd, S., & Rubin, H. R. (2004). Comprehensive discharge planning with postdischarge support for older patients with congestive heart failure: a meta-analysis. *Jama*, *291*(11), 1358–1367.

Piamjariyakul, U., Smith, C. E., Werkowitch, M., & Elyachar, A. (2012). Part I: heart failure home management: patients, multidisciplinary health care professionals and family caregivers' perspectives. Applied nursing research, 25(4), 239-245.

Piette, J. D., Marinec, N., Gallegos-Cabriales, E. C., Gutierrez-Valverde, J. M., Rodriguez-Saldaña, J., Mendoz-Alevares, M., & Silveira, M. J. (2013). Spanish-speaking patients' engagement in interactive voice response (IVR) chronic disease self-management support calls: Analyses of data from three countries. *Journal of Telemedicine and Telecare*, *19*(2), 89–94. http://doi.org/10.1177/1357633X13476234

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging*, *18*(2), 250.

Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, *45*(1), 90–106.

Plaza, I., Martín, L., Martin, S., & Medrano, C. (2011). Mobile applications in an aging society: Status and trends. *Journal of Systems and Software*, *84*(11), 1977-1988.

Price, M., Williamson, D., McCandless, R., Mueller, M., Gregoski, M., Brunner-Jackson, B., … Treiber, F. (2013). Hispanic migrant farm workers' attitudes toward mobile phone-based telehealth for management of chronic health conditions. *Journal of Medical Internet Research*, *15*(4).

Rich, M. W., Beckham, V., Wittenberg, C., Leven, C. L., Freedland, K. E., & Carney, R. M. (1995). A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure. *New England Journal of Medicine*, *333*(18), 1190–1195.

Riegel, B., Carlson, B., Kopp, Z., LePetri, B., Glaser, D., & Unger, A. (2002). Effect of a standardized nurse case-management telephone intervention on resource use in patients with chronic heart failure. *Archives of Internal Medicine*, *162*(6), 705–712.

Riegel, B., Carlson, B., Glaser, D., & Romero, T. (2006). Randomized controlled trial of telephone case management in Hispanics of Mexican origin with heart failure. *Journal of Cardiac Failure*, *12*(3), 211–219.

Riegel, B., Moser, D.K., Anker, S.D., Appel, L.J., Dunbar, S.B., Grady, K.L., Gurvitz, M.Z., Havranek, E.P., Lee, C.S., Lindenfeld, J., Peterson, P.N., Pressler, S.J., Schocken, D.D., Whellan, D.J.; on behalf of the American Heart Association Council on Cardiovascular Nursing, Council on Clinical Cardiology, Council on Nutrition, Physical Activity, and Metabolism, and Interdisciplinary Council on Quality of Care and Outcomes Research (2009). State of the science: promoting self-care in persons with heart failure: a scientific statement from the American Heart Association. *Circulation*. 120:1141–1163.

Roccaforte, R., Demers, C., Baldassarre, F., K. Teo, K., & Yusuf, S. (2005). Effectiveness of comprehensive disease management programmes in improving clinical outcomes in heart failure patients. A meta-analysis. *European Journal of Heart Failure*, *7*(7), 1133–1144. http://doi.org/10.1016/j.ejheart.2005.08.005

Rodriguez, F., Joynt, K. E., López, L., Saldaña, F., & Jha, A. K. (2011). Readmission rates for Hispanic Medicare beneficiaries with heart failure and acute myocardial infarction. *American Heart Journal*, *162*(2), 254–261.

Roger, V. L., Weston, S. A., Redfield, M. M., Hellermann-Homan, J. P., Killian, J., Yawn, B. P., & Jacobsen, S. J. (2004). Trends in heart failure incidence and survival in a community-based population. *Jama*, *292*(3), 344–350.

Rosamond, W., Flegal, K., Friday, G., for the American Heart Association Statistics Committee and Stroke Statistics Subcommittee (2008). Heart disease and stroke statistics—2008 update. A report from The American Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation, 117,* e25–146.

Rote, S., Angel, J. L., & Markides, K. (2014). Health of elderly Mexican American adults and family caregiver distress. *Research on Aging, 37*(3), 306–331. doi:10.1177/0164027514531028

Rydlewska, A., Krzysztofik, J., Libergal, J., Rybak, A., Banasiak, W., Ponikowski, P., & Jankowska, E. A. (2013). Health locus of control and the sense of self-efficacy in patients with systolic heart failure: a pilot study. *Patient Prefer Adherence, 7,* 337-343.

Sayers, S. L., Riegel, B., Pawlowski, S., Coyne, J. C., & Samaha, F. F. (2008). Social support and self-care of patients with heart failure. *Annals of Behavioral Medicine. (35)* 70-79.

Scheibe, M., Reichelt, J. Bellman, M., Kirch, W. (2015). Acceptance factors of mobile apps for diabetes by patients aged 50 or older: A qualitative study. *Medicine 2.0, 4*(1), e1.

Sebern, M. (1996). Explication of the construct of shared care and the prevention of pressure sores in home health care. *Research in Nursing and Health, 19,* 183-192.

Sebern, M., & Woda, A. (2012). Shared Care Dyadic Intervention: Outcome patterns for heart failure care partners. *Western Journal of Nursing Research, 34*(3), 289-316.

Shah, B., Hernandez, A. F., Liang, L., Al-Khatib, S. M., Yancy, C. W., Fonarow, G. C., & Peterson, E. D. (2009). Hospital variation and characteristics of implantable cardioverter-defibrillator use in patients with heart failure: Data from the GWTG-HF (Get With The Guidelines–Heart Failure) Registry. *Journal of the American College of Cardiology, 53*(5), 416–422. http://doi.org/10.1016/j.jacc.2008.09.045

Sherwood, A., Blumenthal, J. A., Hinderliter, A. L., Koch, G. G., Adams, J., Kirkwood F., Dupree, C. S., … O'Connor, C. M. (2011). Worsening depressive symptoms are associated with adverse clinical outcomes in patients with heart failure. *Journal of the American College of Cardiology, 57*(4), 418–423. http://doi.org/10.1016/j.jacc.2010.09.031

Shi. L. & Singh, D. A. (2014). *Delivering Health Care In America: A Systems Approach* (6th ed.). Burlington, MA: Jones & Bartlett Learning.

Stokke, R. (2016). The Personal Emergency Response System as a Technology Innovation in Primary Health Care Services: An Integrative Review. *Journal of Medical Internet Research, 18*(7).

Suh, M., Chen, C.-A., Woodbridge, J., Tu, M. K., Kim, J. I., Nahapetian, A., … Sarrafzadeh, M. (2011). A remote patient monitoring system for congestive heart failure. *Journal of Medical Systems*, *35*(5), 1165–1179.

Swenson, C. J., Trepka, M. J., Rewers, M. J., Scarbro, S., Hiatt, W. R., & Hamman, R. F. (2002). Cardiovascular disease mortality in Hispanics and non-Hispanic whites. *American journal of epidemiology*, *156(10)*, 919-928.

Trief, P. M., Izquiredo, R., Eimicke, J., Teresi, J., .Goland, R., Palmas, W., Shea, S., Weinstock, R. (2013). Adherence to diabetes self care for white, African-American and Hispanic American telemedicine participants: 5 year results from the IDEATel project. *Ethnicity & Health*, *18*(1), 83–96.

United States Census Bureau (2016). Quick facts: Los Angeles city, Califorina. Retrieved from: http://www.census.gov/quickfacts/table/PST045215/0644000,06037

Villani, J., & Mortensen, K. (2014). Decomposing the gap in satisfaction with provider communication between English-and Spanish-speaking Hispanic patients. *Journal of immigrant and minority health, 16*(2), 195-203.

Vissman, A. T., Hergenrather, K. C., Rojas, G., Langdon, S. E., Wilkin, A. M., & Rhodes, S. D. (2011). Applying the theory of planned behavior to explore HAART adherence among HIV-positive immigrant Latinos: Elicitation interview results. *Patient Education and Counseling*, *85*(3), 454–460.

Vivo, R. P., Krim, S. R., Cevik, C., & Witteles, R. M. (2009). Heart failure in Hispanics. *Journal of the American College of Cardiology*, *53*(14), 1167–1175.

Ward, B. & Schiller, J. (2013). Prevalence of multiple chronic conditions among US adults: Estimates from the National Health Interview Survey, 2010. *Preventing Chronic Disease, 10*, 120203. doi: http://dx.doi.org/10.5888/pcd10.120203

Wells, J. N., Cagle, C. S., Marshall, D., & Hollen, M. L. (2009). Perceived mood, health, and burden in female Mexican American family cancer caregivers. *Health Care for Women International*, *30*, 629-654. doi:10.1080/07399330902928857

West, J. A., Miller, N. H., Parker, K. M., Senneca, D., Ghandour, G., Clark, M., … DeBusk, R. F. (1997). A comprehensive management system for heart failure improves clinical outcomes and reduces medical resource utilization. *The American Journal of Cardiology*, *79*(1), 58–63.

Willacy, H. (2012). Heart Failure. Retrieved from: http://www.patient.co.uk/health/heart- failure-leaflet

Yancy, C. W., Jessup, M., Bozkurt, B., Butler, J., Casey, D. E., Drazner, M. H., … Wilkoff, B. L. (2013). 2013 ACCF/AHA Guideline for the Management of Heart Failure: A Report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. *Circulation*, *128*(16), e240–e327. http://doi.org/10.1161/CIR.0b013e31829e8776

Yeo, K. K., Li, Z., & Amsterdam, E. (2007). Clinical characteristics and 30-day mortality among non-Hispanic whites, Hispanics, Asians, and African-Americans in the 2003 California coronary artery bypass graft surgery outcomes reporting program. *The American Journal of Cardiology*, *100*(1), 59–63.

Zhang, J., Goode, K. M., Cuddihy, P. E., Cleland, J. G. F., & the TEN-HMS Investigators. (2009). Predicting hospitalization due to worsening heart failure using daily weight measurement: analysis of the Trans-European Network-Home-Care Management System

(TEN-HMS) study. *European Journal of Heart Failure*, *11*(4), 420–427. http://doi.org/10.1093/eurjhf/hfp033

Appendices

Appendix A: Interview Guides

Patient Interview Questions

	Category	PART ONE: Background Information	Primera Parte: Información de trasfondo
1.00	Patient	Can you tell me about your heart condition?	¿Cuál es su condición del corazón ?
1.01	Caregiver	What family member takes care of you?	¿Quién de sus familiares cuida de usted?
1.02	Length of receiving care	More or less, how long have they been caring for you?	Más o menos, ¿Desde hace cuánto tiempo han cuidado de usted?
1.03	CR age	How old are you?	¿Cuántos años tiene usted?
1.04	CR educational attainment	How many years did you attend school?	¿Por cuántos años usted fue a la escuela?
1.05	Nativity	What country were you born in? [If not born in the USA ask: “Tell me a little about the town you grew up in…was it a small village or a big city? Did you have to travel far to go to the doctor?”]	¿Dónde nació usted? [If not born in the USA ask: “Tell me a little about the town you grew up in…was it a small village or a big city? Did you have to travel far to go to the doctor?”]
1.06	CG residence	Does your caregiver (husband/wife/uncle…) live with you?	El familiar (pareja, hija…) que cuida de usted, ¿Vive con usted?
1.07	CG residence	Has your relative always lived with you or only since he/she started to take care of you?	El familiar que está al tanto o cuida de usted, ¿siempre ha vivido con usted o solo desde que la/o comenzó a cuidar?
		For non-spousal care recipients:	*Para personas no-casadas*
1.08	CR Marital Status	What is your marital status?	¿Cuál su estado civil?
1.09	CR’s children	*Do you have children? How many children do you have and how old are they?	¿Tiene usted hijos? y si, es así, ¿Cuántos hijos tiene usted y qué edades tienen ellos?

1.10	CR's family	Do you have any brothers or sisters? If yes, how many and what are their ages? Do they live nearby?	Usted tiene hermanos o hermanas? Cuantos son, y de qué edades? Viven cerca?
1.11	CR Monthly income	What is your monthly income?	¿Cuál su ingreso mensual? más o menos una estimación.
1.12	CR Sources of Income	What are the total sources of this income? (Social Security, retirement pension, etc.)	¿Cuál es el total de todos sus recursos de ingreso? (ej. seguro social, pensión de retiro, etc.)
1.13	CR work	Do you currently work outside the home? What is/was your profession?	Usted trabaja fuera de casa? A que se dedica/dedicaba?
1.14	Outside Financial Help	Do your children/siblings help you financially?	Sus hijos o familiares, ¿le sustentan financieramente?
1.15	CR Health Insurance	Do you have health insurance? (probe type of insurance)	¿Tiene algún seguro médico?
1.16	CG Age	*How old is your caregiver?	¿Qué edad tiene la persona que lo cuida?
1.17	CG Nativity	*What country was your caregiver born in?	¿Dónde nació la persona que lo cuida?
1.18	CG Educational Attainment	*How many years did your caregiver attend school?	¿Por cuántos años fue a la escuela, la persona que lo cuida?
1.19	Paid Employment	*Does your caregiver work outside of the home?	La persona que lo cuida ¿tiene un trabajo fuera de la casa, aparte de cuidarle?
1.20	CG's marital status	*What is your caregiver's marital status?	¿Cuál es el estado civil de la persona que lo/a cuida?
1.21	CG's children	*Does your caregiver have children?	¿La persona que lo/a cuida, cuantos años tienes hijos? si es así, ¿Cuántos? Y ¿Qué edades tienen ellos?

		How many and how old are they?	
1.22	Time lived in current house	*Have you always lived in the house you live in now?	¿Usted, siempre ha vivido en el hogar donde vive ahora?
1.23	Household composition	*Who lives in your house aside from you?	¿Quiénes más viven en esta casa, aparte de usted?
1.24	CG Extended family/friends	*Aside from persons who live in your home, who comes over to visit frequently? Anyone else you forgot to mention?	Aparte de las personas que viven en esta casa, ¿Quién más le visita con frecuencia? ¿Hay alguien más que se le ha olvidado mencionar?
1.25	CG has help	Does anyone else help provide care to you besides this relative?	¿Hay alguien más que le brinda atención de cuidado, aparte de este familiar?
1.26	Languages spoken at home	What language is primarily spoken in your home?	¿Qué idioma hablan principalmente en su casa?

	Category	PART 2: Current Health Status	Segunda Parte: Estado de Salud Actual
2.1	Self Rated Health	How would you describe your current physical health? (Excellent, Very Good, Good, Fair, or Poor)	Actualmente, ¿Cómo describiría su estado de salud física? (excelente, muy buena, buena, normal, o mala)
2.2	Self Rated Health	How would you describe your current emotional/mental health? (Excellent, Very Good, Good, Fair, or Poor)	Actualmente, ¿Cómo describiría su estado de salud mental o emocionalmente? (excelente, muy buena, buena, normal, o mala)

2.3	Health Status-doctor visits	In the past 12 months, about how many times have you needed to go to the doctor?	En los últimos 12 meses, ¿cuántas veces ha necesitado ir al doctor?
2.4	Health Status-hospitalizations	Have you been hospitalized in the past year? If yes, what for?	¿Ha estado hospitalizado(a) en el último año? Si fue así, ¿cuál fue la razón?
2.5		Have you ever been hospitalized? What for?	Alguna vez ha sido hospitalizado ? ¿Por cual razon?
2.6 2.7		In the future, some illnesses that you go to the hospital for now may be treated at home instead. What do you think about that? Would you like it better if you did not have to stay at the hospital? Why?	En el futuro, algunas enfermedades que ahorita requieren ir al hospital, podran ser tratados en casa. ¿Qué piensa sobre eso? ¿Le gustaría más si no tener que quedarse en el hospital? ¿Por qué?
2.8	Caregiver's health status	How would you rate your [relative's] current health status…excellent, very good, good, fair, or poor?	¿Cómo calificaría el estado de salud de la persona que lo cuida... excelente, muy buena, buena, normal, o mala?
2.9	CR's main illness	What are your main problems or illnesses? Do you have any other medical conditions that you are managing?	¿Cuáles son sus mayores problemas de salud o enfermedades? Tiene alguna otra condición médica que esté tratando?
2.10	Year of Diagnosis	When were you diagnosed with heart failure? [probe: what year was that?]	¿Cuándo fue usted diagnosticado con insuficiencia cardiaca? (en qué año)
2.11	Heart condition	What did the doctor tell you is wrong with your heart?	Qué ha dicho el médico que está mal con su corazón?

2.12	Change in HF symptoms?	Have your symptoms changed over time?	¿Sus síntomas han cambiado con el tiempo?

	Category	PART 3: Self-care and receiving care	**Tercera Parte**: Cuidado Personal y Recibiendo atención
3.1	What is HF?	What does having HF mean for you physically? And emotionally?	Físicamente, ¿qué significa tener insuficiencia cardiaca para usted? Y ¿emocionalmente?
3.2	HF management plan	Describe the tasks that must be done to manage your heart condition?	Describe las tareas que tiene que hacer para controlar la condición cardiaca?
3.3		Do you have to watch what you eat? Are their certain foods you are supposed to limit? How about salt?	¿Tiene que cuidar lo que come ? Hay ciertos alimentos que debe limitar ? ¿Y sal?
3.4	HF management plan	What types of symptoms or physical traits do you measure on a regular basis? Do you check your weight? Do you check your blood pressure? Do you have to check your blood sugar?	Qué tipo de síntomas o rasgos físicos se chequea regularmente? Cómo se comprueba su peso? Cómo se comprueba la presión arterial ? ¿Tiene que comprobar su nivel de azúcar en la sangre?
3.5	HF management plan	Who gives you instructions on how to properly care for yourself?	¿Quién le da indicaciones de cómo cuidarse apropiadamente?
3.6	Control Beliefs	How helpful/easy to follow and maintain have you found these instructions?	¿Qué tan útil o fácil se le hace seguir y mantener estas indicaciones?
3.7		What is your biggest struggle as a patient?	Cual es su mayor lucha como paciente?
3.8	ADL/IADL supports	Can you describe for me what you usually do on an average day, starting from the time you get up in the morning?	¿Me puede describir lo que regularmente hace en un día normal, empezando desde que se levanta por la mañana?

3.9	ADL/IADL supports	Please describe for me what a typical day has been like in the past week.	Explíqueme, ¿Cómo sería un día típico para usted, por ejemplo un día durante la semana pasada?
3.10	Home environment	How would you describe the activity level in your home? [Probe: How many people are coming to visit you on a daily basis, how busy is your home?]	¿Cómo describiría el nivel de actividades diarias en su casa? (demostrar: ¿Cuánta gente le visita regularmente, y que tan ocupada se mantiene su casa?
3.11	ADL/IADL supports	Can you tell me what things your relative does to help you? [bathe, clothe, feed, transfer, etc.] And to help you manage your heart condition?	¿Me puede explicar, qué clase de cosas hace su familiar para ayudarle a controlar su condición cardiaca? (bañando le, vistiendo le, alimentando le, transfiriendo le, etc.)
3.12	Normative beliefs; most important activity/task	Of all the things your [relative] does, which do you think is the most important?	De todas las cosas que hace por su familiar, ¿cuáles cree que son las más importantes para usted?
3.13	Emotional/ physical caregiving	Would you say that activity meets your emotional or physical needs most?	¿Cree usted que estas actividades satisfacen o le ayudan a en sus necesidades físicas o emocionalmente?
3.14	Unmet needs	Are there needs that your relative can't meet?	¿Tiene usted otras necesidades que su familiar no las puede hacer?
3.15	Likes	What activity do you like doing the most with your relative?	¿Qué actividad o cosas disfruta hacer más con su familiar?
3.16	Dislikes	And what do you like the least?	¿Y cuál actividad disfruta menos?
3.17	Control Beliefs	What aspect of getting support from your relative works best for you?	De qué manera, al recibir apoyo de su familiar, ¿es mejor para usted?

3.18	Good Days	Describe what a good day getting help from your family member is like?	Describa, ¿cómo sería un buen día, recibiendo ayuda de su familiar?
3.19	Difficult Days	What stands out in your mind about difficult days?	¿Que se le viene a su mente cuando piensa que tuvo un dia dificil?
3.20	Difficult Days	What contributes to or causes difficult days?	¿Qué causa que usted tenga días difíciles?
3.21	Coping	What helps you overcome difficult days?	¿Qué le ayuda a sobrellevar los días difíciles? [Religión, oración, actividad física, estar sola, compañía]
3.22	Worry	What do you worry about as a care recipient?	¿Qué le preocupa más como persona que recibe cuidado?
3.23	Constant Vigilance	Do you feel like your (relative) is always keeping an eye on you? What does it mean for your relative to always be keeping an eye on you?	Usted siente que su familiar siempre está al pendiente de usted? Y ¿Qué significa para su familiar, que siempre esté al tanto de usted?
3.24	Sleep through the night	How often do you wake up in the night and need help from your relative?	¿Qué tan seguido, usted despierta durante la noche y necesita asistencia de su familiar?

	Category	PART 4: Technology in the home	**Cuarta Parte: Tecnología en casa**
4.1	Technology Use in the home	How do you use technology such as smartphones, cell phones, tablets, or computers in your home?	¿Cómo utiliza la tecnología, por ejemplo: Smartphone, teléfonos celulares, Tablets, o computadoras en su casa? Cuales son los beneficios?
4.2	Technology ownership	How many of these [devices] do you have in your home?	Cuántos de estos artículos electrónicos tiene en su casa?
4.3	Technology ownership	About how many wireless devices (phones, computers, tablets, etc.) do you have in your home?	Más o menos, ¿cuantos aparatos electrónicos tiene en su casa? (teléfonos, computadoras, Tablets, etc.)
4.4	Perceived Usefulness	What are the benefits of wireless device use in your home?	¿Cuáles son los usos los electrónicos inalámbricos?
4.5	Perceived Ease of Use	What are the problems you have encountered using wireless devices in your home?	¿Cuáles son las dificultades que usted ha tenido, usado aparatos electrónicos en casa?
4.6	Social Support	Who do you ask for help if you have a question about technology in your home?	¿Cómo pide usted ayuda, si usted tiene preguntas acerca de la tecnología en su casa?
4.7	Beliefs	What kinds of technology do the people around you use?	¿Qué tipo de tecnología la gente su alrededor suelen usar?
4.8	Perceived Usefulness	What comes to mind when you think of technology that can monitor your health?	¿Que se le viene a la mente, cuando piensa en la tecnología que puede chequear o monitorear su salud?
4.9	Beliefs	What kinds of concerns do you have about technology that is used to monitor health inside the home?	¿Qué tipo de preocupaciones tiene usted acerca de la tecnología que se utiliza en casa?
		Show health information flowchart to CR and explain the chart: This picture shows how remote health monitoring	*Muestre a CR el diagrama de información de salud y explica lo:* Este diagrama demuestra cómo monitorear la salud en casa. El paciente y el cuidador están de este

		works. The patient and caregiver are on this end. These are examples of the devices you may use and pictures of data that may be collected. At the other end is you, your doctor, and your caregiver looking at the health information collected by the devices.	lado. Estos son ejemplos de aparatos que pudieran usar y datos que pudieran obtener. Y al final del diagrama se encuentra usted, su doctor, y su cuidador que juntos están analizando la información que fue obtenida por el aparato electrónico.
4.10	Perceived Usefulness	Describe how you think technology may be able to help you manage your illness? What would you like help with in managing your heart condition or your other illnesses?	Cómo piensa que la tecnología le puede ayudar con su enfermedad? Con que necesita ayuda para controlar su enfermedad u otras condiciones?
4.11	Perceived Usefulness	If you could keep track of specific heart failure related physical symptoms, what would you like to monitor or keep track of?	Si usted pudiera mantener un control de los síntomas físicos, relacionados a la insuficiencia cardiaca, que le gustaría monitorear o estarse checando?
4.12	Beliefs	How would being able to monitor and track health information help you?	¿Cómo cree que le ayudaría, tener la capacidad de monitorear o estarse revisando su estado de salud?
4.13	Beliefs	How would you use this health information?	¿Cómo utilizaría esta información de su salud?
4.14	Beliefs	What do you think the doctor will do with this information?	Que cree, que el doctor hará con esta información?
4.15	Beliefs	How is tracking this information helpful to your doctor?	¿Cómo cree que usted, que manteniendo la información registrada, le puede ayudar a su doctor?

4.16	Perceived Ease of Use, Beliefs	If you were to use these devices, how would you like to get the information collected by the devices given/presented back to you? (would you like it on a website, text message, an app on a phone or a tablet, a phone call from a nurse or automated system, Skype, a video, or on a piece of paper?)	Si pudiera obtener estos aparatos electrónicos, ¿cómo le gustaría obtener la información recolectada? (Le gustaría recibirla en una página de internet, mensaje de texto, una aplicación en su teléfono celular o una Tablet, o que una enfermera le llame por teléfono, o por un sistema de llamadas automáticas, Skype, o video, o impresas en un documento).
4.17	Social Support	If you had (show photos) this type of health technology in your home, who would you want to be able to use it?	Si usted tuviera (muestre las fotos) este tipo de tecnología para monitorear su salud en su casa, ¿quién le gustaría que la pudiera usarla?
4.18	Environment	If you had (show photos) this type of health monitoring technology in your home, where would you put it? Would you have room for it?	Si usted tuviera (mostrar fotos) este tipo de tecnología de monitoreo de salud disponible en su casa, ¿dónde la pondría? ¿Usted tuviera espacio en su casa?
4.19	Environment, Beliefs	If you had (show photos) this type of health technology in your home, what would you do with it when other people come over to your house? Would you feel comfortable with other people seeing it?	Si usted tuviera, (mostrar fotos) este tipo de tecnología en su casa, ¿qué haría con esto cuando la gente viene de visita a su casa? Se sentiria comodo si otra gente los vieran?
4.20	Environment, Beliefs	If you were using (show photos) this type of health technology in your home every day to monitor your health, would you bring it with you on vacations? What	Si usted estuviera usando (mostrar fotos) este tipo de tecnología todos los días en su casa, para monitorear su salud, ¿se lo llevará con usted cuando fuera de vacaciones? y qué tal, ¿si usted viajara fuera del país?

		about it you went out of the country?	
4.21	Environment	If you had this type of technology (show photos) in your home, how would you prefer it to be powered? By battery or by plugging it in?	Si usted tuviera este tipo de tecnología en su casa (mostrar fotos), ¿cómo le gustaría que se cargará? con ¿pilas? ¿Batería? o ¿enchufándola?
4.22	Beliefs	How do you feel about wearing health monitoring technology all day long such as a watch or band?	¿Cómo se sentiría si tuviera que llevar con sigo mismo, un reloj o un brazalete que monitoree su salud todo el día?
4.23	Beliefs	How would you feel about getting text messages from a nurse when your health is presenting concerns to the medical team?	¿Cómo se sentiría si usted recibiera un mensaje de texto de una enfermera, cuando su salud presente preocupaciones a su equipo de salud?
4.24	Beliefs	Have you ever seen anyone use a blood sugar monitoring device where they prick their finger and the device reads the blood for its glucose levels?	Alguna vez, usted ha visto a alguien usar un dispositivo para monitorear los niveles de azúcar en la sangre, ¿dónde se pican el dedo y la maquinita lee los niveles de azúcar en la sangre?
4.25	Beliefs	How do you feel about pricking your finger and putting a drop of blood into a monitoring device like that? How would you feel about it if you could gain additional health information from it such as whether you have the flu or a bacterial infection? Do you think you would use it?	¿Cómo se siente usted, acerca de estarse picando su dedo y poniendo una gota de sangre en un dispositivo así? ¿Cómo se sentiría, si usted recibiera información de salud aparte de estos resultados que ya recibe, como, la tuviera la gripe o una infección bacterial? ¿Cree usted que la usaría? Si el dispositivo le dijera, si usted tuviera o no, una infección, ¿qué haría usted, si se da cuenta que usted tiene una infección?

		If the device was able to tell you whether or not you had an infection, what would you do if you found out you have an infection?	
4.26	Beliefs	How would you feel about putting a little bit of saliva on a plastic swab and then putting that into the device if you could find out similar information?	¿Cómo se sentiría acerca de la posibilidad de poner un poco de saliva en un aplicador de plástico y, luego, ponerlo dentro del dispositivo, para saber la misma información?
4.27	Beliefs	How do you think your relative would like using this type of technology?	¿Cómo cree usted a su familiar le gustaría utilizar este tipo de tecnología?
4.28	Beliefs	How do you think technology could help give you and your caregiver peace of mind? [ask them if they have a friend that has, or if they have, one of those emergency response buttons that you can press in case of an emergency. If they say no, ask them if they have heard of it and if something like that might give someone peace of mind]	¿Cómo cree que la tecnología, les ayudaría a tener paz y tranquilidad, a usted y a su cuidador? [ask them if they have a friend that has, or if they have, one of those emergency response buttons that you can press in case of an emergency. If they say no, ask them if they have heard of it and if something like that might give someone peace of mind]
4.29	Beliefs	[Ask only if they mention they have trouble sleeping earlier in the interview] How do you think technology could help you sleep through the night better?	[Ask only if they mention they have trouble sleeping earlier in the interview] ¿Cómo cree usted que la tecnología, le pudiera ayudar a su familiar a dormir más tranquilo(a) durante la noche?
4.30	Ending	That is our last question. Do you have any questions for us or	Esta es nuestra última pregunta. ¿Tiene alguna pregunta para nosotras o algo más que quisiera agregar? y no

		anything you would like to add? Thank you so much for your time today.	es así, le agradecemos mucho por su tiempo y por permitirnos hacerle estas preguntas.

Caregiver Questionnaire

	Category	PART ONE: Basic Information	Primera Parte: Información Básica
1.01	Care Recipient	What relative do you take care of?	¿A cuál familiar usted cuida?
1.02	Length of caregiving	More or less, how long have you been taking care of your relative?	Más o menos, ¿desde hace cuánto tiempo cuidad de su familiar?
1.03	CR age	How old is your relative?	¿Qué edad tiene la persona que cuida?
1.04		How many children does your relative have? How old are they?	Cuantos hijos tiene la persona que cuida? Que edad tienen?
1.05		How many brothers and sisters do they have? Do they live nearby?	Cuantos hermanos y hermanas tiene la persona que cuida? Viven cerca?
1.06	CR educational attainment	How many years did he/she attend school?	¿Cuantos años asistió a la escuela la persona que cuida?
1.07	Nativity	What country was he/she born in?? [If not born in the USA ask: “Tell me a little about the town they grew up in…was it a small village or a big city? Did they have to travel far to go to the doctor?”]	En qué país nació la persona que usted cuida? [If not born in the USA ask: “Tell me a little about the town they grew up in…was it a small village or a big city? Did they have to travel far to go to the doctor?”]
1.08	CR residence	Does your relative (husband/wife/uncle…) live with you?	Su familiar la persona que cuida) ,(esposo, esposa, tío…), vive con usted?
1.09	CR residence	Has your relative always lived with you or only since you started to take care of him/her?	¿Siempre ha vivido su familiar con usted, solo hasta que empezó a cuidar de él/ella?

1.10	CR Monthly income	What is his/her monthly income?	¿Cuál es el ingreso mensual de su familiar?
1.11	CR Sources of Income	What are the total sources of this income? (Social Security, retirement pension, etc.)	¿Cuál es el total mensual de todo sus recursos? (seguro social, pensión de retiro, etc.)
1.12	Outside Financial Help	Do your children/siblings/other family members help you financially so you can provide care for your relative?	¿Sus hijos, hermanos u otros familiares le brindan apoyo financiero por el cuidado a su familiar?
1.13	CR Health Insurance	Does your [relative] have health insurance? (probe type of insurance)	¿Su familiar tiene seguro médico? (que tipo)
1.14	CG Age	How old are you?	¿Qué edad tiene usted?
1.15	CG Nativity	What country were you born in?? [If not born in the USA ask: "Tell me a little about the town you grew up in…was it a small village or a big city? Did you have to travel far to go to the doctor?"]	En ¿Dónde nació usted? [If not born in the USA ask: "Tell me a little about the town you grew up in…was it a small village or a big city? Did you have to travel far to go to the doctor?"]
1.16	CG Educational Attainment	How many years did you attend school?	¿Cuantos años asistió usted a la escuela?
1.17	Paid Employment	Do you work outside of the home? [If the CG is retired, ask them what type of job they had before they retired]	¿Trabaja usted fuera de su casa? y si es así, qué tipo de trabajo hace? Tiempo completo o tiempo parcial? (En que trabajo antes de retirarse?)

1.18	CG's children	Do you have children? How many children do you have and how old are they?	¿Tiene usted hijos? si es así, ¿cuántos hijos tiene usted y qué edades tienen ellos?
1.19	CG's marital status	What is your marital status?	¿Cuál es su estado civil?
1.20	Time lived in current house	Have you always lived in the house you live in now?	Usted siempre ha vivido en el hogar en donde vive ahora?
1.21	Household composition	Who lives in your house aside from you?	¿Quiénes vive en este hogar aparte de usted?
1.22	CG Extended family/friends	Aside from persons who live in your home, who comes over to visit frequently? (If CR and CG do not live together, ask about who visits the CR's house instead) Anyone else you forgot to mention?	Aparte de las personas que viven en esta casa, ¿Quién más le visita con frecuencia? (Si CR and CG no viven juntos, pregunta, quien visita a CR) ¿Hay alguien más que se le ha olvidado mencionar?
1.23	CG has help	Does anyone else help you provide care to your relative?	¿Hay alguien más que le ayuda con el cuido de su familiar?
1.24	Monthly income	What is the monthly income of your household?	¿Cuál es el ingreso mensual en su hogar?
1.25	Sources of income	What are the total sources of this income? (social security, retirement pension, etc.)	¿Cuál es el total de todos los recursos en este ingreso? (seguro social, pensión de retiro, etc.)
1.26	CG Health Insurance	Do you and your family have health insurance?	¿Usted y su familia tienen seguro médico?

1.27	Languages spoken at home	What language is primarily spoken in your home? [If the CG and CR do not live together, ask what language is spoken in the CR's home as well]	¿Qué idioma hablan es su casa principalmente? (Si no viven juntos el CG y CR tambien pregunta- Que idioma se habla en la casa de su familiar?)

	Ask these questions if the CG and CR are not married	*For non-spousal caregivers:*	*Para Cuidadores que no son pareja*
1.28	CR Marital Status	What is his/her marital status?	¿Cuál es el estado civil de su familiar?

	Category	PART 2: CG and CR Current Health Status	Segunda Parte: CR and CG Estado de Salud actual
2.1	Self Rated Health	How would you describe your current physical health? (Excellent, Very Good, Good, Fair, or Poor)	Actualmente ¿Cómo describiría su estado de salud física? (excelente, muy buena, buena, normal, o mala)
2.2	Self Rated Health	How would you describe your current emotional/mental health? (Excellent, Very Good, Good, Fair, or Poor)	¿Cómo describiría su estado actual de salud mental o emocionalmente? (excelente, muy buena, buena, normal, o mala)
2.3	Health Status-doctor visits	In the past 12 months, about how many times have you needed to go to the doctor? Were these visits for routine check-ups or other issues?	En el último año, ¿cuántas veces ha necesitado ir a doctor? Estas visitas fueron exámenes de rutina o por otros problemas?
2.4	Health Status-hospitalizations	Have you been hospitalized in the past year? If yes, what for?	¿Ha estado hospitalizado(a) en el último año? Si fue así, cuál fue la razón?
2.5	CR's health status	How would you rate your [relative's] current health status…excellent, very good, good, fair, or poor?	¿Cómo diría que es el estado de salud de su familiar... excelente, muy buena, buena, normal, o mala?

2.6	CR’s main illness	What are your relative’s main problems or illnesses? Does your family member suffer from any other medical issues or illnesses?	¿Cuáles cree que son los mayores problemas de salud o enfermedades de su familiar? El/ella sufre de alguna enfermedad o problema médico?
2.7	Year of Diagnosis	When was your family member diagnosed with heart failure? [probe: what year was that?]	¿Cuando su familiar fue diagnosticado con insuficiencia cardiaca, en qué año fue?
2.8	Diagnosis	What did the doctor say is wrong with your family member’s heart?	Qué ha dicho el médico que está mal con el corazón de su familiar?
2.9	Change in HF symptoms?	Have their symptoms changed over time?	¿Cree usted que sus síntomas han cambiado con el tiempo?

	Category	PART 3: Providing Care	Tercera Parte: Brindando Atención o cuidado
3.1	Knowledge	What does having a heart condition mean for your [relative] physically? And emotionally?	¿Fisicamente, que significa tener problemas del corazón para su familiar? Y ¿emocionalmente?
3.2	HF management plan	Describe the tasks that must be done to manage your relative’s heart condition?	¿Describe las tareas, cosas o actividades que tiene que hacer para cuidar la condición cardiaca de su familiar?
3.3	HF management	Is your relative supposed to watch what they eat? What kinds of food are they supposed to limit? Are they allowed to have salt?	Es necesario que su familiar cuide la comida que consume? Cuales comidas necesita limitar? Pueden comer sal?
3.4	HF management plan	What types of symptoms or physical traits do you measure on a regular basis?	¿Qué tipo de síntomas o rasgos físicos se monitorea o chequea regularmente?
3.5	HF management plan	Who gives you instructions on how to properly care for your relative?	¿Quién le da indicaciones de cómo cuidar o atender a su familiar apropiadamente?

3.6	Beliefs	How helpful/easy to follow and maintain have you found these instructions?	¿Qué tan útil o fácil se le hace seguir y mantener estas indicaciones?
3.7	ADL/IADL supports	Can you describe for me what you usually do on an average day, starting from the time you get up in the morning, including how you help your relative?	¿Me puede describir lo que regularmente hace en un día normal, empezando desde que se levanta por la mañana, incluyendo de cómo ayuda la persona que cuida?
3.8	ADL/IADL supports	Please describe for me what a typical day has been like in the past week.	Explíqueme, ¿Cómo fue un día típico para usted, durante la semana pasada?
3.9	Home environment *(lives with CR)*	How would you describe the activity level in your home?	¿Cómo describiría el nivel de actividades diarias que hace su casa? (demostrar: Cuánta gente que la visita regularmente, y que tan ocupada se mantiene su casa?
3.10	Home environment (*does not live with CR*)	How would you describe the activity level in your family member's home?	¿Cómo describiría el nivel de actividades que regulares en la casa de su familiar?
3.11	ADL/IADL supports	Can you tell me what things you do to help your relative? [bathe, clothe, feed, transfer, etc.] And to manage their heart condition?	Me puede explicar, ¿en qué clase de cosas asiste o ayuda a su familiar? (bañando le, vistiendo le, alimentando le, transfiriendo le, etc.) ¿y para ayudarle a controlar su condición cardiaca?
3.12	Beliefs; most important activity/task	Of all the things you do for your [relative], which do you think is the most important?	¿De todas estas cosas en las que asiste o ayuda a su familiar, cuáles cree usted que son las más importantes para él/ella?
3.13	Emotional/physical caregiving	Would you say that activity meets your [relative's] emotional or physical needs most?	¿Usted cree que estas actividades satisfacen sus necesidades físicas o emocionalmente?

3.14	Unmet needs	Are there needs that you can't meet?	¿Hay necesidades que usted no puede ejercer o hacer por su familiar??
3.15	Likes	What activity do you like doing the most with your relative?	¿Qué actividad es la que disfruta hacer más con su familiar?
3.16	Dislikes	And what do you like the least?	¿Y cuál es la que disfruta menos?
3.17	Beliefs	What aspects of helping your [relative] come easy to you?	¿Qué aspectos en el cuidado de su familiar, se le hacen más fácil?
3.18	Good Days	Describe what a good day helping your family member is like?	Describa ¿cómo sería un buen día, asistiendo a su familiar?
3.19	Difficult Days	What stands out in your mind about difficult days as a caregiver?	¿Qué se le viene a la mente, cuando piensa en días dificiles como cuidador?
3.20	Difficult Days	What contributes to or causes difficult days?	¿Que hace o causa que sus días sean difíciles?
3.21	Coping	What helps you overcome difficult days?	¿Qué le ayuda a sobrellevar pasar estos días difíciles?
3.22	Worry	What do you worry about as a caregiver?	¿Qué le preocupa el ser cuidador?
3.23	Constant Vigilance	What does it mean to always be keeping an eye on your relative when you are caring for him/her? When do you feel that it is most important to keep an eye on him/her?	¿Qué significa para usted que siempre esté al pendiente de su familiar? y ¿Cuándo siente que sea más importante estar al pendiente de él o ella?
3.24	Sleep through the night	How often do you have to wake up in the night to check on your relative?	¿Qué tan seguido tiene que despertar durante la noche para estar chequeando a su pariente?

	Category	PART 4: Technology in the home	Cuanta Parte: Tecnología en casa
4.1	Technology use in the home	How do you use technology such as smartphones, cell phones, tablets, or computers in your home?	¿Cómo utiliza la tecnología? por ejemplo: Smartphone, teléfonos celulares, Tablets, o computadoras en su casa.
4.2	Technology ownership	How many of these [types of devices] do you have in your home?	¿Cuántos de estos artículos electrónicos tiene en su casa?
4.3	Technology ownership	About how many wireless devices (phones, computers, tablets, etc.) do you have in your home?	Más o menos, ¿cuantos aparatos electrónicos tiene en su casa? (teléfonos, computadoras, Tablets, etc.)
4.4	Perceived Usefulness	What are the benefits of wireless device use in your home?	¿Cuáles son los beneficios de los electrónicos inalámbricos?
4.5	Perceived Ease of Use	What are the problems you have encountered using wireless devices in your home?	¿Cuáles son las dificultades que usted ha tenido, usado aparatos electrónicos en casa?
4.6	Social Support	Who do you ask for help if you have a question about technology in your home?	¿Cómo pide usted ayuda, si usted tiene preguntas acerca de la tecnología en su casa?
4.7	Beliefs	What kinds of technology do the people around you like to use?	¿Qué tipo de tecnología la gente de su alrededor usan mas?
4.8	Perceived Usefulness	What comes to mind when you think of technology that can monitor the health of your family member?	¿Que se le viene a la mente, cuando piensa que puede utilizar tecnología para monitorear la salud su familiar?
4.9	Beliefs	Is there any technology that helps give you and your family member peace of mind?	¿Hay alguna tecnología que les ayuda a tener paz y tranquilidad, a usted y a su familiar?
4.10	Beliefs	How do you think technology could help	¿Cómo cree usted que la tecnología, le pudiera ayudar a su familiar a dormir

		caregivers sleep through the night better?	tranquilo(a) durante toda la noche?
4.11	Perceived Usefulness	What specific heart failure related physical symptoms would you like to monitor?	¿Qué tipo de síntomas físicos, relacionados a la insuficiencia cardiaca, le gustaría monitorear o estar checando?
4.12	Perceived Usefulness	Describe something that you would like help with in managing your family member's disease. Do you think a technology may be able to assist with that?	Con la tecnología avanzada de ahora, Describa, ¿cómo le gustaría que la tecnología le ayudará a mantener controlada la enfermedad de su familiar?
4.13	Behavioral Beliefs	How would being able to monitor and track health information about your CR help you?	¿Cómo cree que le ayuda, tener la capacidad de monitorear o estar revisando el estado de salud de su familiar?
4.14	Behavioral Beliefs	How would you use this health information?	¿Cómo utilizaría esta información de su salud?
		Show health information flowchart to CR and explain the chart: This picture shows how remote health monitoring works. The patient and caregiver are on this end. These are examples of the devices you may use and pictures of data that may be collected. At the other end is you, your doctor, and your caregiver looking at the health information collected by the devices.	*Muestre a CG el diagrama de información de salud y explica lo:* Este diagrama demuestra cómo monitorear la salud en casa. El paciente y el cuidador están de este lado. Estos son ejemplos de aparatos que pudieran usar y datos que pudieran obtener. Y al final del diagrama se encuentra usted, el doctor, y su pariente, que están juntos analizando la información que fue obtenida por el aparato electrónico.
4.15	Perceived Ease of Use, Beliefs	If you were to use these devices, how would you like to get the information collected by the devices given/presented back to you? (would you like it on	Si pudiera obtener estos aparatos electrónicos, ¿cómo le gustaría obtener la información recolectada? (Le gustaría recibirla en una página de internet, mensaje de texto, una

		a website, text message, an app on a phone or a tablet, a phone call from a nurse or automated system, Skype, a video, on a piece of paper?)	aplicación en su teléfono celular o una Tablet, o que una enfermera le llame por teléfono, o por un sistema de llamadas automáticas, Skype, o video, o impresas en un documento).
4.16	Beliefs	What do you think the doctor will do with this information?	¿Qué cree, que el doctor hará con esta información?
4.17	Beliefs	How is tracking this information helpful to your CR's doctor?	¿Cómo cree que usted, que manteniendo la información registrada, le puede ayudar a su doctor?
4.18	Beliefs, Cultural Values	What kinds of concerns do you have about technology that is used to monitor health inside the home?	¿Qué tipo de preocupaciones tiene usted acerca de la tecnología que se utiliza en casa?
4.19	Social Support	If you had (show photos) this type of health technology in your home, who would you want to be able to use it?	Si usted tuviera (muestre las fotos) este tipo de tecnología para monitorear su salud en su casa, ¿quién le gustaría que la pudiera usarla?
4.20	Environment	If you had (show photos) this type of health monitoring technology in your home, where would you put it? Would you have room for it?	Si usted tuviera (mostrar fotos) este tipo de tecnología de monitoreo de salud disponible en su casa, ¿dónde la pondría? ¿Usted tuviera espacio en su casa?
4.21	Environment, Beliefs	If you had (show photos) this type of health technology in your home, what would you do with it when other people come over to your house?	Si usted tuviera, (mostrar fotos) este tipo de tecnología en su casa, ¿qué haría con esto cuando la gente viene de visita a su casa?
4.22	Environment, Beliefs	If you were using (show photos) this type of health technology in your home every day to monitor your	Si usted estuviera usando (mostrar fotos) este tipo de tecnología todos los días en su casa, para monitorear la salud

		CR's health, would you bring it with you on vacations with the CR?	de su familiar, ¿se lo llevará con usted cuando fuera de vacaciones con él/ella?
4.23	Environment	If you had this type of technology (show photos) in your home, how would you prefer it to be powered? By battery or by plugging it in?	Si usted tuviera este tipo de tecnología en su casa (mostrar fotos), ¿cómo le gustaría que se cargará? ¿Con pilas? ¿Batería? o ¿enchufándola?
4.24	Beliefs	How do you feel about wearing health monitoring technology all day long such as a watch or band?	¿Cómo se sentiría si tuviera que llevar con sigo mismo, un reloj o un brazalete que monitoree su salud todo el día?
4.25	Beliefs	How do you think your relative would like using these types of technology?	¿Cómo cree usted que a su familiar le gustaría utilizar este tipo de tecnología?
4.26	Beliefs	How would you feel about getting text messages from a nurse when your relative's health is presenting concerns to the medical team?	¿Cómo se sentiría usted si recibiera un mensaje de texto de una enfermera, cuando la salud de su familiar, presenta preocupaciones al equipo de salud?
4.27	Beliefs	Have you ever seen anyone use a blood sugar monitoring device where they prick their finger and the device reads the blood for its glucose levels?	Alguna vez, usted ha visto a alguien usar un dispositivo para monitorear los niveles de azúcar en la sangre, ¿dónde se pican el dedo y la maquinita lee los niveles de azúcar en la sangre?
4.28	Beliefs	How do you feel about pricking your finger and putting a drop of blood into a monitoring device like that? How would you feel about it if you could gain additional health information from it such as	¿Cómo se siente usted, acerca de estarse picando su dedo y poniendo una gota de sangre en un dispositivo así? ¿Cómo se sentiría, si usted recibiera información de salud aparte de estos resultados que ya recibe, como, la tuviera la gripe o una infección bacterial?

		whether you have the flu or a bacterial infection? Do you think you would use it? Do you think your [relative] would use? If the device was able to tell you whether or not you had an infection, what would you do if you found out you have an infection? What do you think your [relative] would do?	¿Cree usted que la usaría? ¿Cree usted que su familiar la usaría? Si el dispositivo le dijera, si usted tuviera o no, una infección, ¿qué haría usted, si se da cuenta que usted tiene una infección? ¿Que cree que su pariente haría?
4.29	Beliefs	How would you feel about putting a little bit of saliva on a plastic swab and then putting that into the device if you could find out similar information? How do you think your [relative] would feel about doing that?	¿Cómo se sentiría acerca de la posibilidad de poner un poco de saliva en un aplicador de plástico y, luego, ponerlo dentro del dispositivo, para saber la misma información? ¿Cómo cree que se sentirá su familiar, se sienta haciendo esto?
4.30		If technology could help you in a certain area as a caregiver, what would you most want help with?	Si la tecnología le pudiera ayudar en algunas áreas, como cuidador, en que necesitaría más ayuda?
4.31		Is there something that you would want to know about when you could not be right there next to your relative?	Hay algo que a usted le gustaría que la tecnología le diera a saber de su familiar si usted no está presente?
4.32	Conclusion	That is our last question. Thank you so much for your time. Do you have any questions for us before we	Esta es nuestra última pregunta. ¿Tiene alguna pregunta para nosotras o algo

		end? Thank you again for participating.	más que quisiera agregar? Si no es así, Muchas gracias por permitirnos, tomar un poco de tiempo el día de hoy.

Clinician Questions

Question number	Category	Question
1.1	Context	How long have you worked at [hospital/clinic name]?
1.2	Context	What is your job title?
1.3	Context	Describe your typical patient population [probe: age, race, insured/uninsured]
1.4	Context	What is your specialty area?
1.5	Context	When patients with HF see you, what are some of the typical courses of treatment and management you use for their symptoms?
1.6	Context	How do you keep track of how well they are doing once they are at home? Phone calls? Emails?
1.7	Context	Do you often speak with caregivers or family members?
1.8	Context	Do you send patients home with RX for blood pressure cuffs?
1.9	Context	How do you handle multiple morbidities in older patients?
1.10	Context	What is your biggest struggle as a physician working with HF patients?
1.11	Context	How does the social support available to the patient play into your recommendations for them? What types of questions do you ask them in relationship to social support?

Question number	Category	Question
2.1	Use of RHM	When you hear the term remote health monitoring, what comes to mind?
2.2	Use of RHM	Describe how do you use RHM in your clinic/hospital? [probe: how long has this been in use?]
2.3	Perceived Usefulness Perceived Ease of Use	How has that experience been for you? [probe: have there been challenges in offering RHM?] [probe: have you seen successes as a result of offering RHM?]
2.4	Perceived Usefulness	[If they currently have RHM]: What can be changed about your RHM system to make it more efficient for you?

	Perceived Ease of Use	
2.5	Beliefs	What kinds of patients would benefit the most from RHM? [probe: is there a patient profile that best fits with RHM use?]
2.6	Beliefs Perceived Ease of Use	What types of challenges do you perceive patients having with RHM?
2.7	Perceived Usefulness	What are patient needs around managing heart failure?
2.8	Beliefs	What do you believe are the advantages of using remote health monitoring for heart failure patients?
2.9	Beliefs	What do you believe are the disadvantages of using remote health monitoring for heart failure patients?
2.10	Perceived usefulness	What symptoms would you like to remotely monitor in heart failure patients? [probe: which physical symptoms would you be interested in tracking?] [probe: which behavioral factors would you be interested in tracking?]
2.11	Beliefs	How do you envision using remote health monitoring data to help your patients?
2.12	Perceived Ease of Use	What circumstances would make it easy for you to use remote health monitoring with heart failure patients?
2.13	Perceived Usefulness Perceived Ease of Use	What comes to mind when you think of the patients who will be using the remote health monitoring technology in their homes?
2.14	Beliefs	How do you think patients will use the data collected from remote health monitoring?
2.15	Perceived Usefulness	How would you like to communicate important information to patients regarding the data they are collecting?
2.16	Conclusion	That is our last question. Do you have any questions for me? Thank you for participating in our study.

Appendix B. Consent Forms

OSU Oregon State UNIVERSITY Oregon State UNIVERSITY OSU College of Public Health and Human Sciences

CONSENT FORM (CAREGIVER VERSION)

Project Title: Remote health monitoring of heart failure patients
Principal Investigator: Carolyn Mendez-Luck, MPH, PhD
Student Researcher: Katherine Anthony, M.A.
Co-Investigator(s):
Sponsor: Internal: Center for Healthy Aging Research
External: Intel Corporation, National Science Foundation IGERT
Version Date: 10/28/2015

---

1. WHAT IS THE PURPOSE OF THIS FORM?

This form contains information you will need to help you decide whether to be in this research study or not. Please read the form carefully and ask the study team member(s) questions about anything that is not clear.

2. WHY IS THIS RESEARCH STUDY BEING DONE?

Intel Corporation ("Intel") and Oregon State University are conducting a voluntary study to learn about acceptability and perceived usefulness of remote health monitoring among Mexican-origin and non-Hispanic white heart failure patients and their informal caregivers.

This study is being conducted as part of the dissertation research of Katherine Anthony.

Up to 180 participants may be invited to take part in this study.

3. WHY AM I BEING INVITED TO TAKE PART IN THIS STUDY?

You are being invited to take part in this study because you are of Mexican-origin or non-Hispanic white, at least eighteen years old, and you are currently providing care to an elderly family member with a diagnosis of heart failure.

4. WHAT WILL HAPPEN IF I TAKE PART IN THIS RESEARCH STUDY?

If you volunteer to participate in this study, I will ask you to do the following:
You will also be asked to participate in an audio recorded interview during which you will be asked questions about your experiences as a caregiver and how you currently use and would like to use technology to assist you as a caregiver. You will also be asked demographic questions about your household. The recorded interview will last up to 90 minutes.

Recordings: Audio recordings are a part of this study. You should not participate if you do not wish to be audio recorded.

Future contact: We may contact you in the future for another similar study. You may ask us to stop contacting you at any time.

Study Results: At the completion of the study, results will also be presented at academic and professional conferences and published in academic journals. If the results of this project are published your identity will not be made public.

5. WHAT ARE THE RISKS AND POSSIBLE DISCOMFORTS OF THIS STUDY?

Because you will be asked questions about personal aspects of your life, you may feel embarrassed or uncomfortable while answering them. You are free at any time to decline to answer any question that you do not want to answer. There is a chance that we could accidentally disclose information that identifies you

6. WHAT ARE THE BENEFITS OF THIS STUDY?

You will not directly benefit from participation in this research study. However, your participation in the research may be useful in understanding heart failure caregiving and perceptions about remote health monitoring within Mexican and non-Hispanic white families and developing future support programs that help families care for their older loved ones.

7. WILL I BE PAID FOR BEING IN THIS STUDY?

You will be given a $50 gift card for your participation in the study.

8. WHO IS PAYING FOR THIS STUDY?

The Oregon State University Center for Healthy Aging Research, the National Science Foundation IGERT in Healthy Aging Sciences, and Intel Corporation are paying for this research to be done.

9. DOES ANY MEMBER OF THE STUDY TEAM HAVE A CONFLICTING INTEREST?

A conflict of interest occurs when a researcher or the University has a financial or other business interest that could affect the research. In some situations, the results of a study might lead to a financial gain or other benefit for the investigator(s) and/or the University.

- One or more of the investigators working on this study may have a potential conflict of interest:
  - Katherine Anthony, Student Investigator, is a doctoral student at Oregon State University and also an intern for Intel Corporation working under Nancy Vuckovic.

If you have questions or concerns about this, please contact the Institutional Review Board Office at (541) 737-8008.

10. WHO WILL SEE THE INFORMATION I GIVE?

The information you provide during this research study will be kept confidential to the extent permitted by law. Research records will be stored securely and only researchers will have access to the records. Federal regulatory agencies and the Oregon State University Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

If we contacted you through the Center for Healthy Aging Research (CHAR) Life Registry, we will be providing CHAR with any updates to your contact information. We will also tell them whether or not you chose to participate in this research study.

The study information will be kept in a secure location and subject to appropriate access controls. Audio recordings will be accessible by the research team during the course of the study. They will be erased after transcripts have been checked twice for accuracy.
If the results of this project are published your identity will not be made public.

This study is funded by the National Science Foundation, Oregon State University Center for Healthy Aging Research, and Intel Corporation. These sponsors may see the information collected during this study.

To help ensure confidentiality, we will use identification code numbers on data forms instead of names, use locked filing cabinets and storage areas, and use password-protected computer files to store study information.

11. WHO DO I CONTACT IF I HAVE QUESTIONS?

If you have any questions, concerns or complaints about this study or its procedures, please contact Intel's and OSU's research leads, Nancy Vuckovic, Carolyn Mendez-Luck, or you can use the Contact Us form at (http://www.intel.com/sites/sitewide/en_US/privacy/contactus.htm), or send a letter to the mailing address listed below:

Intel Corporation
ATTN: Privacy
M/S RNB4-145
2200 Mission College Blvd.
Santa Clara, CA 95054 USA

Please include your contact information, name of thestudy, the name of the Intel Lead Researcher or team conducting the study, and a detailed description of your request or privacy concern.

You may contact Carolyn Mendez-Luck here:
Carolyn A. Mendez-Luck, MPH, PhD
Oregon State University
College of Public Health and Human Sciences
541-737-4503

If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office, at (541) 737-8008 or by email at IRB@oregonstate.edu

12. WHAT DOES MY SIGNATURE ON THIS CONSENT FORM MEAN AND WHAT IF I DO NOT WANT TO PARTICIPATE?

You may refuse to participate or leave the study at any time. If you decide not to participate in the study, or withdraw before the end of the study, it will not result in any adverse consequences to you. If at any time you decide not to participate, the consent form you signed will be destroyed, and all information gathered from you will be deleted. You may also refuse to answer any questions you don't want to answer and still remain in the study.

Your signature indicates that this study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Do not sign after the expiration date: 11/5/2016

Participant's Name (printed): ____

______________________________________ ____________________________
(Signature of Participant) (Date)

______________________________________ ____________________________
(Signature of Person Obtaining Consent) (Date)

____ __________________________________
(Witness or Translator) (Date)

CONSENT FORM (PATIENT VERSION)

Project Title: Remote health monitoring of heart failure patients
Principal Investigator: Carolyn Mendez-Luck, MPH, PhD
Student Researcher: Katherine Anthony, M.A.
Co-Investigator(s):
Sponsor: Internal: Center for Healthy Aging Research
External: Intel Corporation, National Science Foundation IGERT
Version Date: 11/11/2015

---

1. WHAT IS THE PURPOSE OF THIS FORM?

This form contains information you will need to help you decide whether to be in this research study or not. Please read the form carefully and ask the study team member(s) questions about anything that is not clear.

2. WHY IS THIS RESEARCH STUDY BEING DONE?

Intel Corporation ("Intel") and Oregon State University are conducting a voluntary study to learn about acceptability and perceived usefulness of remote health monitoring among Mexican-origin and non-Hispanic white heart failure patients and their informal caregivers.

This study is being conducted as part of the dissertation research of Katherine Anthony.

Up to 180 participants may be invited to take part in this study.

3. WHY AM I BEING INVITED TO TAKE PART IN THIS STUDY?

You were selected as a possible participant in this study because you are of Mexican-origin or non-Hispanic white, at least 50 years old, currently have a diagnosis of heart failure and are receiving informal care from a family member.

4. WHAT WILL HAPPEN IF I TAKE PART IN THIS RESEARCH STUDY?

If you volunteer to participate in this study, I will ask you to do the following:

You will also be asked to participate in an audio recorded interview during which you will be asked questions about your experiences as a heart failure patient and informal care recipient and how you currently use and would like to use technology to assist you in managing your health condition. You will also be asked some demographic questions. The recorded interview will last up to 90 minutes.

Recordings: Audio recordings are a part of this study. You should not participate if you do not wish to be audio recorded.

Future contact: We may contact you in the future for another similar study. You may ask us to stop contacting you at any time.

Study Results: At the completion of the study, results will be made available in the form of a published dissertation, professional journal articles, and public presentations. If the results of this project are published your identity will not be made public.

5. WHAT ARE THE RISKS AND POSSIBLE DISCOMFORTS OF THIS STUDY?

Because you will be asked questions about personal aspects of your life, you may feel embarrassed or uncomfortable while answering them. You are free at any time to decline to answer any question that you do not want to answer. There is a chance that we could accidentally disclose information that identifies you.

6. WHAT ARE THE BENEFITS OF THIS STUDY?

You will not directly benefit from participation in this research study.

7. WILL I BE PAID FOR BEING IN THIS STUDY?

You will be given a $50 gift card for your participation in the study.

8. WHO IS PAYING FOR THIS STUDY?

The Oregon State University Center for Healthy Aging Research, the National Science Foundation IGERT in Healthy Aging Sciences, and Intel Corporation are paying for this research to be done.

9. DOES ANY MEMBER OF THE STUDY TEAM HAVE A CONFLICTING INTEREST?

A conflict of interest occurs when a researcher or the University has a financial or other business interest that could affect the research. In some situations, the results of a study might lead to a financial gain or other benefit for the investigator(s) and/or the University.

- One or more of the investigators working on this study may have a potential conflict of interest:

- Katherine Anthony, Student Investigator, is a doctoral student at Oregon State University and also an intern for Intel Corporation working under Nancy Vuckovic.

If you have questions or concerns about this, please contact the Institutional Review Board Office at (541) 737-8008.

11. WHO WILL SEE THE INFORMATION I GIVE?

The information you provide during this research study will be kept confidential to the extent permitted by law. Research records will be stored securely and only researchers will have access to the records. Federal regulatory agencies and the Oregon State University Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

If we contacted you through the Center for Healthy Aging Research (CHAR) Life Registry, we will be providing CHAR with any updates to your contact information. We will also tell them whether or not you chose to participate in this research study.

The study information will be kept in a secure location and subject to appropriate access controls. Audio recordings will be accessible by the research team during the course of the study. They will be erased after transcripts have been checked twice for accuracy.

If the results of this project are published your identity will not be made public.

This study is funded by the National Science Foundation, Oregon State University Center for Healthy Aging Research, and Intel Corporation. These sponsors may see the information collected during this study.

To help ensure confidentiality, we will use identification code numbers on data forms instead of names, use locked filing cabinets and storage areas, and use password-protected computer files to store study information.

12. WHO DO I CONTACT IF I HAVE QUESTIONS?

If you have any questions, concerns or complaints about this study or its procedures, please contact Intel's and OSU's research leads, Nancy Vuckovic, Carolyn Mendez-Luck, or you can use the Contact Us form at (http://www.intel.com/sites/sitewide/en_US/privacy/contactus.htm), or send a letter to the mailing address listed below:

Intel Corporation
ATTN: Privacy
M/S RNB4-145
2200 Mission College Blvd.
Santa Clara, CA 95054 USA

Please include your contact information, name of the study, the name of the Intel Lead Researcher or team conducting the study, and a detailed description of your request or privacy concern.

You may contact Carolyn Mendez luck here:
Carolyn A. Mendez-Luck, MPH, PhD
Oregon State University
College of Public Health and Human Sciences
541-737-4503

If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office, at (541) 737-8008 or by email at IRB@oregonstate.edu

13. WHAT DOES MY SIGNATURE ON THIS CONSENT FORM MEAN AND WHAT IF I DECIDE NOT TO PARTICIPATE?

Your signature indicates that this study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

You may refuse to participate or leave the study at any time. If you decide not to participate in the study, or withdraw before the end of the study, it will not result in any adverse consequences to you. If at any time you decide not to participate, the consent form you signed will be destroyed, and all information gathered from you will be deleted. You may also refuse to answer any questions you don't want to answer and still remain in the study.

Do not sign after the expiration date: 11/5/2016

Participant's Name (printed): ____

____ ______________________________
(Signature of Participant) (Date)

____ ______________________________
(Signature of Person Obtaining Consent) (Date)

____ ______________________________
(Witness or Translator) (Date)

VERBAL CONSENT GUIDE

Project Title:	Remote health monitoring of heart failure
Principal Investigator:	Carolyn Mendez-Luck, MPH, PhD
Student Researcher:	Katherine Anthony, M.A.
Co-Investigator(s):	
Sponsor:	Internal: Center for Healthy Aging Research External: Intel Corporation, National Science Foundation IGERT
Version Date:	10/29/2015

---

1. Purpose

Intel Corporation ("Intel") and Oregon State University are conducting a voluntary study to learn about acceptability and perceived usefulness of remote health monitoring among healthcare providers.

1. Study Activities

If you decide to participate in this study, you will be asked to participate in an audio recorded interview.

2. Time

The recorded interview will last approximately one hour.

4. Risks

Because you will be asked questions about your opinions, you may feel uncomfortable while answering them. You are free at any time to decline to answer any question that you do not want to answer. There is a chance that we could accidentally disclose information that identifies you.

5. Benefits

You will not directly benefit from participation in this research study.

6. Payment

You will be given $350 for your participation in the study.

7. Conflicts of Interest:

A conflict of interest occurs when a researcher or the University has a financial or other business interest that could affect the research. In some situations, the results of a study might lead to a financial gain or other benefit for the investigator(s) and/or the University.

- One or more of the investigators working on this study may have a potential conflict of interest:
  - Katherine Anthony, Student Investigator, is a doctoral student at Oregon State University and also an intern for Intel Corporation working under Nancy Vuckovic.

If you have questions or concerns about this, please contact the Institutional Review Board Office at (541) 737-8008.

8. Confidentiality

The study information will be kept in a secure location and subject to appropriate access controls. Audio recordings will be accessible by the research team during the course of the study. They will be erased after transcripts have been checked twice for accuracy.
If the results of this study are published, your identity will not be made public.

This study is funded by the National Science Foundation, Oregon State University Center for Healthy Aging Research, and Intel Corporation. These sponsors may see the information collected during this study.

To help ensure confidentiality, we will use identification code numbers on data forms instead of names, use locked filing cabinets and storage areas, and use password-protected computer files to store study information.

9. Voluntariness

You are free to withdraw at any time without penalty. If you choose to withdraw from this project before it ends, all information gathered from you will be deleted. You may also refuse to answer any questions you don't want to answer and still remain in the study.

10. Contact Information

If you have any questions, concerns or complaints about this study or its procedures, please contact Intel's and OSU's research leads, Nancy Vuckovic, Carolyn Mendez-Luck, or you can use the Contact Us form at (http://www.intel.com/sites/sitewide/en_US/privacy/contactus.htm), or send a letter to this mailing address:

Intel Corporation
ATTN: Privacy
M/S RNB4-145
2200 Mission College Blvd.
Santa Clara, CA 95054 USA

Please include your contact information, name of the study, the name of the Intel Lead Researcher or team conducting the study, and a detailed description of your request or privacy concern.

You may contact Carolyn Mendez luck at:
Carolyn A. Mendez-Luck, MPH, PhD
Oregon State University
College of Public Health and Human Sciences
541-737-4503

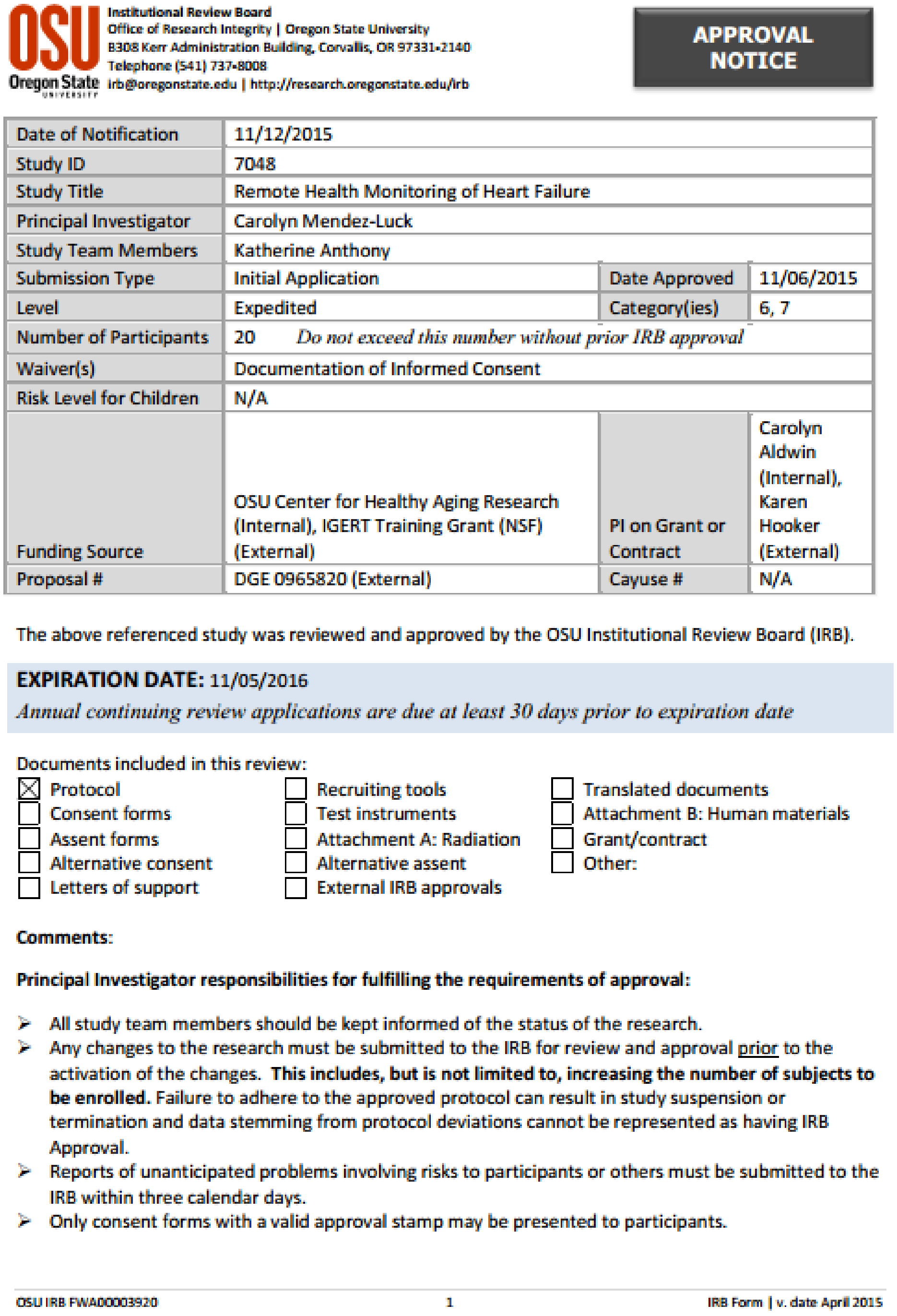
If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office, at (541) 737-8008 or by email at IRB@oregonstate.edu

11. Consent

Do you have any questions? If you have questions, please ask your questions now, prior to giving consent. If you agree with the terms of this consent please state, "Yes, I agree."

Appendix C. IRB Approval

IRB Approval



Institutional Review Board
Office of Research Integrity | Oregon State University
B308 Kerr Administration Building, Corvallis, OR 97331-2140
Telephone (541) 737-8008
irb@oregonstate.edu | http://research.oregonstate.edu/irb

APPROVAL NOTICE

Date of Notification	11/12/2015		
Study ID	7048		
Study Title	Remote Health Monitoring of Heart Failure		
Principal Investigator	Carolyn Mendez-Luck		
Study Team Members	Katherine Anthony		
Submission Type	Initial Application	Date Approved	11/06/2015
Level	Expedited	Category(ies)	6, 7
Number of Participants	20 *Do not exceed this number without prior IRB approval*		
Waiver(s)	Documentation of Informed Consent		
Risk Level for Children	N/A		
Funding Source	OSU Center for Healthy Aging Research (Internal), IGERT Training Grant (NSF) (External)	PI on Grant or Contract	Carolyn Aldwin (Internal), Karen Hooker (External)
Proposal #	DGE 0965820 (External)	Cayuse #	N/A

The above referenced study was reviewed and approved by the OSU Institutional Review Board (IRB).

EXPIRATION DATE: 11/05/2016
Annual continuing review applications are due at least 30 days prior to expiration date

Documents included in this review:

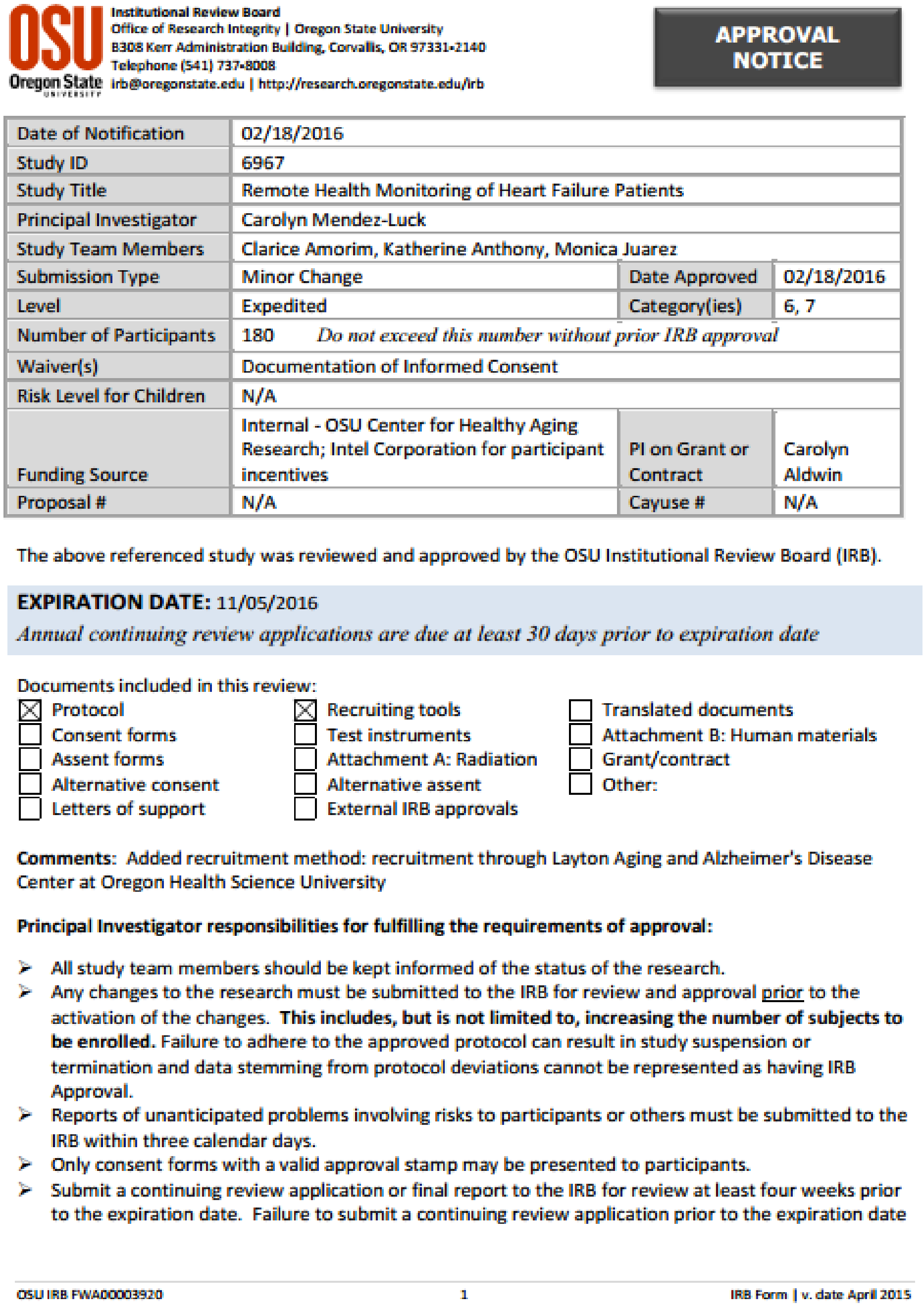
☒ Protocol
☐ Consent forms
☐ Assent forms
☐ Alternative consent
☐ Letters of support
☐ Recruiting tools
☐ Test instruments
☐ Attachment A: Radiation
☐ Alternative assent
☐ External IRB approvals
☐ Translated documents
☐ Attachment B: Human materials
☐ Grant/contract
☐ Other:

Comments:

Principal Investigator responsibilities for fulfilling the requirements of approval:

- All study team members should be kept informed of the status of the research.
- Any changes to the research must be submitted to the IRB for review and approval prior to the activation of the changes. **This includes, but is not limited to, increasing the number of subjects to be enrolled.** Failure to adhere to the approved protocol can result in study suspension or termination and data stemming from protocol deviations cannot be represented as having IRB Approval.
- Reports of unanticipated problems involving risks to participants or others must be submitted to the IRB within three calendar days.
- Only consent forms with a valid approval stamp may be presented to participants.

OSU IRB FWA00003920 1 IRB Form | v. date April 2015



OSU Oregon State University
Institutional Review Board
Office of Research Integrity | Oregon State University
B308 Kerr Administration Building, Corvallis, OR 97331-2140
Telephone (541) 737-8008
irb@oregonstate.edu | http://research.oregonstate.edu/irb

APPROVAL NOTICE

Date of Notification	02/18/2016		
Study ID	6967		
Study Title	Remote Health Monitoring of Heart Failure Patients		
Principal Investigator	Carolyn Mendez-Luck		
Study Team Members	Clarice Amorim, Katherine Anthony, Monica Juarez		
Submission Type	Minor Change	Date Approved	02/18/2016
Level	Expedited	Category(ies)	6, 7
Number of Participants	180 *Do not exceed this number without prior IRB approval*		
Waiver(s)	Documentation of Informed Consent		
Risk Level for Children	N/A		
Funding Source	Internal - OSU Center for Healthy Aging Research; Intel Corporation for participant incentives	PI on Grant or Contract	Carolyn Aldwin
Proposal #	N/A	Cayuse #	N/A

The above referenced study was reviewed and approved by the OSU Institutional Review Board (IRB).

EXPIRATION DATE: 11/05/2016
Annual continuing review applications are due at least 30 days prior to expiration date

Documents included in this review:

☒ Protocol
☐ Consent forms
☐ Assent forms
☐ Alternative consent
☐ Letters of support
☒ Recruiting tools
☐ Test instruments
☐ Attachment A: Radiation
☐ Alternative assent
☐ External IRB approvals
☐ Translated documents
☐ Attachment B: Human materials
☐ Grant/contract
☐ Other:

Comments: Added recruitment method: recruitment through Layton Aging and Alzheimer's Disease Center at Oregon Health Science University

Principal Investigator responsibilities for fulfilling the requirements of approval:

- All study team members should be kept informed of the status of the research.
- Any changes to the research must be submitted to the IRB for review and approval prior to the activation of the changes. **This includes, but is not limited to, increasing the number of subjects to be enrolled.** Failure to adhere to the approved protocol can result in study suspension or termination and data stemming from protocol deviations cannot be represented as having IRB Approval.
- Reports of unanticipated problems involving risks to participants or others must be submitted to the IRB within three calendar days.
- Only consent forms with a valid approval stamp may be presented to participants.
- Submit a continuing review application or final report to the IRB for review at least four weeks prior to the expiration date. Failure to submit a continuing review application prior to the expiration date