

**Heart Failure and Acute Myocardial Infarction Patients' and Caregivers'
Perceptions of Reasons for 30-Day Readmissions in the Community Hospital Setting**

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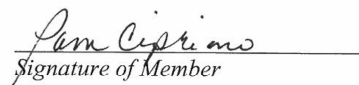
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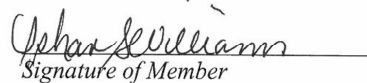
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Abstract

Hospital readmissions are often attributed to failed transitions of care. A gap in the literature exists in understanding readmissions from the patients' and caregivers' perspectives, particularly in the community hospital setting. The purpose of this study was to describe the experience of 30-day readmissions in heart failure and myocardial infarction patients, their root causes, and ways to prevent them from the perspective of patients and their caregivers in a community hospital setting. A phenomenological qualitative study was conducted. Data were collected through semi-structured interviews guided by the Health Belief Model. Colaizzi's seven-step method was used to analyze the data and describe the essential structures of the readmission phenomenon. Six key themes emerged: a need for symptom relief, unmet learning needs, failure to address the primary health concern during the index admission, a lack of patient adherence, challenging treatment regimens, and lack of caregiver inclusion. The Health Belief Model provided the theoretical foundation for exploring patient factors related to readmissions. Perceptions of cardiac patient and their caregivers on the reasons for readmission and the means to prevent them are relevant for shaping effective care transitions. Clinicians need to understand each patient's context for self-care and tailor interventions accordingly.

Keywords: readmissions, heart failure, myocardial infarction, qualitative research, perceptions

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Section I: Introduction

The burgeoning healthcare costs associated with cardiovascular disease and the significant impact on the quality of life of those affected places it in the forefront of major public health concerns. The disease remains the leading cause of death for both men and women in the United States (US), accounting for 33.6% of all deaths in 2007 (Heidenreich et al., 2011). Together coronary heart disease and heart failure (HF) are the reason for 57% of all cardiovascular deaths. Currently, 83 million American adults have one or more forms of the disease, and 4 million of those live with some level of disability as a result (National Center for Chronic Disease Prevention and Health Promotion, Division for Heart Disease and Stroke Prevention, Center for Disease Control, 2011).

A major objective of the Healthy People 2020 initiative is to “improve cardiovascular health and quality of life through prevention, detection, and treatment of risk factors for heart attack and stroke; early identification and treatment of heart attacks and strokes; and prevention of repeat cardiovascular events” (DHHS, 2011, Heart Disease and Stroke Section, para 1). Known risk factors for heart disease include comorbid conditions, intrinsic variables, lifestyle choices, and health disparities (Roger et al., 2011). Comorbid conditions such as hypertension, diabetes mellitus, and obesity are major determinants of cardiovascular risk (Roger, et al., 2011). Genetics and family history are also contributing factors. Behavioral risk factors include an unhealthy diet high in calories, saturated fat, and sodium; a lack of physical exercise; tobacco use; and heavy alcohol consumption (Roger et al., 2011). As in other chronic diseases, there are significant racial disparities in the prevalence and treatment of cardiovascular disease, particularly among African Americans. Despite a 16% higher incidence of hypertension

and a 29% higher age-adjusted mortality rate than Caucasians, African Americans are less likely to receive standard treatments such as β -blockers and invasive cardiovascular procedures (Jones-Burton & Saunders, 2006).

Within the realm of heart disease, health behavior modification is the keystone to reducing risk and managing the disease. The Healthy People 2020 initiative outlines specific objectives for the reduction of cardiovascular risk factors related to lifestyle choices and adherence to medical therapies (HHS, Healthy People 2020, 2011). Behaviors required for managing heart failure (Riegel et al., 2009) and coronary heart disease (Smith et al., 2011) are well documented and include such self-care behaviors as medication adherence, symptom management, diet modification, daily exercise, and smoking cessation.

Adherence to prescribed treatments is less than optimal in patients with acute myocardial infarction (AMI) and heart failure (HF). Adherence is defined as the “active, voluntary, and collaborative involvement of the patient in a mutually acceptable course of behavior to produce a therapeutic result” (Delamater, 2006, p.72). In a comprehensive literature review Evangelista and Shinnick (2008) found the following adherence rates for specific health behaviors in HF patients: monitoring daily weights, 20%-80%; exercise, 9%-53%; following sodium restrictions, 20%-71%; and taking prescribed medications, 50-96%. A 2007 study on adherence with cardio-protective medications following hospitalization for AMI found that more than 1 in 5 patients discontinued one or more of these medications within the first year, resulting in a significantly higher mortality risk (Ho et al., 2007).

The financial burden of cardiovascular disease is overwhelming. In 2007 the annual cost of heart disease was over \$177.5 billion and all cardiovascular diseases combined represented 15% of all U.S. healthcare expenditures (Roger et al., 2011). With a rapidly aging population, 40.5% of the U.S. population is projected to have some form of cardiovascular disease by 2030. Related medical costs are expected to reach \$818.1 billion in the next twenty years (Heidenreich et al., 2011).

Hospitalizations are a large driver of healthcare costs. CMS spends over \$100 billion dollars on hospitalizations including readmissions annually (CMS, 2012a). In 2004 their costs for readmissions alone was \$17.4 billion (Jencks, Williams, & Coleman, 2009). Heart disease in the form of HF and acute MIs accounts for the majority of the readmissions (Elixhauser & Steiner, 2013). From 2007 to 2009 the 30-day readmission rates among Medicare beneficiaries after hospitalization for HF and AMI were 24.8% and 19.9%, respectively (Dharmarajan et al., 2012). There is evidence that a significant portion of readmissions are avoidable (van Walraven, Bennett, Jennings, Austin, & Forster, 2011). Provisions in the Patient Protection and Affordable Care Act allow for significant penalties for hospitals with excess ratios of actual to expected readmissions. Outliers are being held accountable with penalties up to 3% of their Medicare reimbursement by fiscal year 2015 (CMS, 2012b). These penalties, in place since October 1, 2012, have motivated hospitals to place reducing readmissions at the top of their performance improvement agendas.

Understanding the root causes of hospital readmission is important to the work of reducing readmission rates. Poorly planned transitions from hospital to home have been implicated as a root cause (Coleman, Parry, Chalmers, & Min, 2006; Kripalani, Jackson,

Schnipper, & Coleman, 2007). There is an abundance of literature on interventional models designed to enhance these transitions in the cardiac population; however, the majority of interventions aimed at reducing readmissions have not been designed with the patient and caregiver experience in mind. In fact, most appear to be generic in nature. Use of health behavior theory in the design of these interventions is limited, despite their dependency on patients' health behaviors. Furthermore, research on patient factors as a determinant of readmission is very limited. This gap in the literature raises the questions whether the role of patient factors such as underlying health beliefs, capacities for self-care, social support systems, access to care, and other barriers that might preclude treatment adherence have been underappreciated as a root cause of readmission. Recently the American Academy of Nursing identified patient engagement and activation a "health reform imperative and improvement opportunity for nursing" (Pelletier & Stichler, 2013, p.51). Discerning the cardiac patients' and caregivers' perspectives as to the reasons for 30-day hospital readmission and how they could be prevented can serve as the foundation for patient engagement and inform nursing interventions to support patient activation.

The purpose of the present study was to explore HF and AMI patients' and caregivers' experience with hospital readmission within 30-days of discharge from a community hospital. Discerning the reasons for readmission and how to prevent them from this perspective has the potential to shape effective transitions from hospital to home and promote patient and family engagement in their care. The study endeavored to answer the following questions:

- 1) What are the reasons for 30-day readmissions from the perspective of patients with a discharge diagnosis of HF or AMI in the community hospital setting?

- 2) What can be done to prevent the next readmission from the patient's perspective?
- 3) What do the family caregivers of these patients perceive to be the reasons for 30-day readmissions?
- 4) What can be done to prevent the next readmission from the caregiver's perspective?

Conceptual Model

Hospital readmission rates are often viewed as a proxy for the quality of care provided (Ashton & Wray, 1996; Benbassat & Taragin, 2000). An earlier meta-analysis of 16 studies examining actual inpatient care processes concluded the risk of early readmission is increased by 55% when care is substandard (Ashton, Deljunco, Soucek, Wray, & Mansyur, 1997). This conclusion is corroborated by a more recent systematic review by van Walraven et al., which demonstrated that 27% of hospital readmissions are avoidable (2011).

In 1996 the readmission phenomenon was depicted by Ashton and Wray in their *Conceptual framework for the association between premature discharge and early readmission* (see Figure A1, Appendix A). Central to their framework is a proposed causal relationship between premature discharge and unplanned readmission. The model's underlying assumption is that a premature discharge indicates substandard inpatient care processes. Ashton and Wray (1996) considered several other variables that could impact this relationship. Only two variables, outpatient care processes and reimbursement schemas are delineated in Figure 1. Other variables detailed in the manuscript include clinical factors such as comorbidities, functional status, and severity of illness; demographic factors such as age, gender, race or ethnicity, marital status,

socioeconomic status, living arrangements, location of residence; and geographic regions; disease progression with or without optimal therapy; and patient noncompliance with the treatment plan. Ashton and Wray (1996) acknowledged that only a portion of readmissions are attributable to discharge failures.

For nearly two decades this remained the primary model cited in the literature. Recently, Kangovi and Grande (2011) proposed an updated *Determinants of Readmission Model*, depicting additional factors that impact hospital readmissions, such as access to healthcare services and health policy (see Figure A2, Appendix A). These models are not materially different as they both look at the effectiveness of the care delivery system across the continuum, health policy, and certain patient factors such as health status and sociodemographics.

Both Ashton and Wray's 1996 and Kangovi and Grande's 2011 conceptual models lack an in-depth examination of the patient factors. The *Holistic Determinants of Readmissions Model* (HDRM) is proposed by this author (see Figure A3, Appendix A). It addresses the patient factors domain more comprehensively, adding demographic factors and the behavioral constructs found in the Health Belief Model (Edberg, 2007). Additionally, the revised model reflects shifting reimbursement structures within the health policy domain. Growing expectations for access to care and quality outcomes have been accommodated in the model. The HDRM provides the framework for discussion of the literature which includes three major domains: health policy, healthcare services, and patient factors.

Section II: Review of the Literature

A systematic review of the literature was conducted to explore the phenomenon of readmissions in patients with HF and AMI and the design of nursing interventions most effective during transitions of care. The following questions were asked:

1. What is known about the phenomenon of readmissions in patients with coronary heart disease?
2. For patients with heart failure (HF) or acute myocardial infarction (AMI), what is the effectiveness of structured nursing interventions in the prevention of hospital readmissions?

The literature was searched from January 2007 through October 2012 using the CINAHL, Ovid MEDLINE, and full Cochrane Library of electronic databases. The key words of *heart failure* or *AMI* and *patient readmission* or *rehospitalizations* were combined with descriptors of nursing interventions aimed at preparing the patient for discharge while in the hospital or designed to provide post-discharge transitional support. These terms included *transitions of care*, *care transitions*, *self-care*, *self-monitoring*, *hospital to home*, *nursing case or care management*, *nursing disease management*, *nurse coaches*, and *nurse navigators*. Inclusion criteria included English only abstracts, research articles, adult populations (ages 19 and older), and a date range from January 2007 through October of 2012. Quasi-experimental, qualitative, and descriptive studies were included. Systematic reviews and meta-analyses were included if a majority of the studies analyzed described nursing interventions for the cardiac population and readmission rate was an outcome. Exclusion criteria were interventions described as *cardiac rehabilitation*, pilot studies, interventions where the patient was not discharged to

home, and studies that did not use readmission rates as a primary or secondary outcome measure. Thirty-one articles met the final criteria and were read and analyzed for this review. A flow diagram of the studies can be found in Figure A4 (See Appendix A).

The studies in this review were categorized into the three domains of the HDRM: health policy, patient factors, and health services. The health services research studies were further organized according to the type of intervention: education, home care, multidisciplinary, case management and telemonitoring. Further study details can be found in Appendix B.

Health Policy Domain

Only one study included in the review falls within the health policy domain of the HDRM (Soran et al., 2010). Soran's descriptive study is a cost-benefit analysis of the original Heart Failure Home Care Trial (HFHC). The HFHC was a multicenter, randomized, controlled trial comparing the use of an interactive computer based HF monitoring system (n=160) versus standard HF care which included clinician education, enhanced patient education and follow-up (Soran et al., 2008). The primary end point of the original HFHC trial was a composite of cardiovascular death or rehospitalization for HF within 6 months of enrollment. The incidence of the primary outcome was lower in the intervention group when compared to usual care (28.8% vs. 21.2%); however, the difference was not statistically significant. Findings of the secondary descriptive study revealed that the average Medicare costs of patients randomized to the intervention were significantly higher, thus there was no cost benefit to the monitoring intervention (Soran et al., 2010).

Patient Factors Domain

Three studies fall into the patient domain of the HDRM. They investigated the relationship of patient factors and readmissions (Annema et al., 2009; Hodges, 2009; Roe-Prior, 2007). In a mixed methods substudy of the Coordinating Study Evaluating Outcomes of Advising and Counseling in Heart Failure (COACH), a large ($N = 1023$), multisite, randomized controlled trial in the Netherlands, Annema et al. (2009) compared the perceived reasons for 173 readmissions from the perspectives of patients, their caregivers, cardiologists, and nurses. A list of preset conditions was used to gather the opinions of the nurses and cardiologists on an *event registration form*. They were also asked if and how the readmissions could have been prevented. Qualitative interviews were used to seek the opinions of the patient and caregivers on the reason for readmission. All groups agreed that 23-31% of readmissions were avoidable. Although worsening of HF and comorbidities were the top two reasons for readmissions identified by all four groups, patients and caregivers disagreed with healthcare providers on the underlying cause. Patients and providers agreed that the top means to prevent readmission was improvement in patient adherence. Patients found adherence to fluid restrictions particularly challenging. Adequate professional help was the top prevention strategy identified by the caregiver group. The authors concluded the findings broadened the understanding of reasons for readmissions so that more relevant interventions can be formulated (Annema et al., 2009).

The measures of perceptions of *life purpose* and *health related quality of life* and their relationship to readmission rates were the focus of a mixed descriptive, correlational mixed method study by Hodges (2009). Hospitalized HF patients in Texas were studied.

Overall participants had scores reflecting a moderate sense of life purpose and experienced low to moderate difficulty with their HF symptom management. Life purpose scores did not show a relationship with readmissions. Health related quality of life (HRQOL) was measured and a positive, significant, relationship between HRQOL scores and hospital readmissions was found. During the qualitative phase of the study unstructured interviews were conducted with 20 participants. Psychosocial well-being, physiologic well-being, hope/optimism, and spirituality were four themes that emerged. The investigator found that patients with more readmissions, a low sense of life purpose, and high HRQOL score provided less positive comments regarding the four qualitative *a priori* themes.

Roe-Prior (2007) studied the relationships between patient sociodemographics (such as age, gender, living situation, marital status, education and income) and readmissions in 103 elderly HF patients. Only an unmarried marital status was a significant predictor of all-cause readmission ($p = .021$). Low income approached significance as a predictive variable ($p = .059$) in the multiple regression testing.

The review of studies in the patient factors domain demonstrate how little is known about patient factors that contribute to the phenomenon of readmission in cardiac patients. There is incongruence between patients', caregivers', and healthcare providers' perceptions on the factors that cause readmissions. Unmarried HF patients and those patients with HRQOL scores reflecting difficulties in managing their disease are at a higher risk of readmission. A comprehensive understanding of the linkages between patient factors and hospital readmissions in cardiac patients is missing from the literature.

Health Services Domain

Twenty-seven of the included studies investigated the impact of the provision of health services on readmissions as depicted in the revised conceptual model (Figure 3). The manuscripts in the health services domain were reviewed according to the following intervention types: education, home care, multidisciplinary, case management, and telemonitoring. Six systematic reviews or meta-analyses are included. One examined the effectiveness of educational interventions (Brown et al., 2011), two reviewed the impact of telephonic monitoring (Inglis et al., 2010; Stolic et al., 2010) and the remaining three looked at multiple types of non-pharmacologic interventions.

Educational interventions. Patient education is frequently used alone or in combination with other interventions in helping cardiac patients manage their disease. Two original manuscripts and one meta-analysis described interventions that were primarily educational in nature.

In a randomized controlled trial in Spain, Aguado et al. (2010) evaluated a single home-based educational intervention in a sample of 106 patients with a mean age of 77.5 years. The intervention was a two-hour home visit conducted within a week of discharge by a specialty-trained nurse. The nurse assessed the patient's knowledge, health habits, and behaviors susceptible to change. Based on the assessment, guidelines were used to determine which education and self-management strategies were delivered to the patient. During the 24-month follow-up period, the researcher found significantly fewer emergency department visits, unplanned readmissions, and lower costs in the intervention group compared to the usual care group.

Kommuri et al. (2012) tested an hour-long education program delivered to HF patients by a nurse educator prior to discharge. Of the 265 patients who participated in

the study, the mean age was 67 years and 39% were female. The education session covered the basic principles of HF, diet and medication instructions, and self-care behaviors. Written instructions were provided. After six months those randomized to the education intervention demonstrated significantly higher HF knowledge as measured by a tool developed by the researchers, for which the validity and reliability was not presented. The investigators reported that those patients who did not die or experience hospitalizations during the six month follow-up period had significantly increased their HF knowledge.

Brown et al. (2011) conducted a meta-analysis of 13 studies for which the primary intervention was an education program (combined $N = 68,556$). Though no strong evidence of an effect was demonstrated on all-cause mortality, cardiac morbidity, or hospitalization, the authors concluded that the summary effect size of education on mortality (25% risk reduction) and morbidity (17 - 42% risk reduction) was clinically important. Four of six studies in this review reported on hospitalizations. Pooling the results of four of these studies was possible and weak evidence of a reduction in rehospitalization with education was found, RR: 0.83, 95% CIs [0.65, 1.07], $p = 0.16$.

Home care interventions. Two studies focused on time-limited home care interventions. Kwok et al. (2008) conducted a randomized controlled trial ($N = 105$) to evaluate a nurse supported hospital discharge program for HF patients at two hospitals in Hong Kong, China. The nurse visited the patient prior to discharge from the hospital and provided health counseling on drug compliance, diet, and symptom management. The in-hospital education session was followed with a home visit within seven days of discharge. Visits continued once a week for the next four weeks and then monthly for

five months. The nurse worked with a cardiologist and geriatrician to manage the patient. There was no significant difference in the readmission rates in the treatment group versus the control group.

In Shelley and Vollmar's quasi-experimental study ($N = 32$) HF patients discharged from a 230-bed hospital in Boston were visited by a nurse within 48 hours of discharge (2010). Based on the nursing assessment at the first visit, the patient was placed in a group that received telephone advice every 1-2 weeks or a tailored home visit plan. Patient contacts continued for 12 months. The design of this study was subject to considerable bias. The investigators reported that a 99% patient compliance rate was achieved with patients taking medications, performance of daily weight checks, and dietary restrictions. A reduction in readmission rates for the HF participants from 14% to 0.01% was reported.

Multidisciplinary interventions. Three studies tested a multidisciplinary approach to care of HF patients. A HF clinic in Italy was the setting for the treatment intervention in the Del Sindaco et al. (2007) trial. Of the 173 patients in the sample, the mean age was 70 years and 48% were female. The intervention group was treated according to the European Society of Cardiology Guidelines. Components included a first visit to the clinic within 7-14 days of discharge, continuing patient education, therapy optimization, enhanced communication with healthcare providers, and early attention to signs and symptoms of a worsening condition. The nurses periodically called intervention patients to check on them. Clinic visit frequency was tapered over a 24 month period. At 2-years a 36% reduction in all-cause death and HF hospital admissions in the intervention

group was found. Compared to baseline, patients in this group reported significant improvements in functional status, quality of life, and beta-blocker prescription rates.

Mendoza et al. (2009) tested a *hospital at home* model in Spain. Elderly patients ($N=80$) presenting with decompensated HF at the emergency room of a university hospital were randomly assigned to usual care (admitted to the hospital) or an intervention (early discharge from the emergency department followed by an urgent or scheduled home visit). The care team consisted of a nurse and an internal medicine physician. Home visits were made daily by the nurse and every other day by the physician. In-home laboratory tests and electrocardiograms were performed as needed. Mortality and readmissions rates due to HF, functional status, quality of life (QOL) scores, and total costs of care during the follow-up period were found to be similar between usual care and the hospital at home model.

Tibaldi et al. (2009) conducted a similar study ($N = 101$) in an urban academic medical center in Italy. In addition to nurses and physicians, practitioners from other disciplines (geriatricians, social workers and physical therapists) also made visits to the patient's home where sophisticated therapies were delivered. Despite the additional services provided in this multidisciplinary model, the mortality and readmission rates were found to be no different between the intervention and control groups. Intervention patients experienced some improvement in depression, nutritional status and QOL scores which may reflect the additional support services provided. The difference in total cost for patients treated at home (\$2,604) and for patients treated at the hospital (\$3028) was found to be significant ($p < .001$).

Case management interventions. Case management models for caring for

chronically ill patients are common. Angermann et al. (2012) conducted a clinical trial of 715 patients (29% female; mean age of 69 years) discharged from 9 hospitals in Germany following cardiac decompensation. Teaching provided to patients and their families by a HF nurse began in the hospital and included self-monitoring of heart rate and blood pressure. Written educational materials were provided. Nurses conducted telephone monitoring post-discharge from a physician supervised call center. A structured survey was used to conduct calls weekly for the first month. The frequency of the calls over the next five months of the intervention varied according to patient need. No significant difference in any all-cause or HF readmission outcomes was demonstrated at six months. There was a significant difference in the combined outcome of readmission and death for HF ($p = 0.02$) and a significant reduction (38%) in the intervention group's all-cause mortality risk ($p = 0.03$). Patients in the intervention group also had significant improvements in New York Heart Association functional class and the physical functioning and health component scales of the QOL (SF-36) survey.

Copeland et al. (2010) conducted a single site study of 453 patients discharged from a Veteran's Administration (VA) hospital. Of the 453 patients in the sample, the majority was male, 22% were Hispanic, and 97% were African American. The mean age was 70 years. HF patients in the intervention group were treated with a self-management plan based on their prescribed treatment. A nurse conducted telephone surveillance at a frequency determined by a risk stratification algorithm. No significant differences between groups were found in any all-cause or HF readmission outcomes at 30 days or 12 months. Compliance with daily weight checks and exercise were improved based on

self-reports in the intervention group. Total costs were found to be significantly higher in the intervention group as compared to usual care in this trial.

Wakefield et al. (2008) also conducted a randomized controlled trial in a VA tertiary care center. One hundred forty-eight patients (mean age = 69 years; 94% Caucasian; 99% male) were recruited during hospitalization for an acute HF exacerbation. This intervention had two arms: group A was monitored via telephone, group B by videophone. Intervention patients were contacted by a nurse three times the first week post-discharge, and weekly for 11 weeks thereafter. Various strategies to improve patient compliance with prescribed treatment plans were employed including skill training, self-monitoring strategies (e.g. keeping a daily diary), and self-efficacy enhancement strategies (e.g. community support groups, feedback; and realistic goal setting). No significant differences were found across the three study groups for time to first readmission, proportion of patients readmitted at 12 months, HF or all-cause readmission rates. When the intervention groups were combined, there was a significant difference in time to first readmission ($p = 0.02$), risk of all cause readmissions ($p = .04$), and proportion of patients admitted within 12 months ($p = 0.02$) compared to usual care.

In 2009 Wakefield et al. conducted a substudy of the original interventional trial. This secondary analysis examined the intervention's impact on HF patients' disease knowledge, perception of self-efficacy, medication adherence, and satisfaction with care. No significant differences were found between the intervention groups separately or combined on any of the aforementioned outcomes when compared to usual care.

Jaarsma et al. (2008) tested a nurse-led case management program at 17 hospital sites in the Netherlands. Patients ($N = 1023$) were recruited while hospitalized with HF.

They had a mean age of 71 years and were 38% female. This study had two interventional arms with one group of patients being seen by a HF nurse prior to discharge followed by a series of frequent visits to a HF clinic. The other arm of the intervention added weekly telephone contacts, a home visit with a nurse, and two calls and two home visits from a physical therapist, dietician, and social worker. No significant differences were found in the time to first composite event of death and readmission, numbers of days lost to hospitalization or death, and the proportion of patients experiencing multiple readmissions over the 18 month follow up period.

A final nurse-led case management intervention by Krantz et al. (2008) was conducted at an integrated delivery system that serves as a safety net provider in Denver, Colorado. The HF population studied ($N = 174$) was extremely vulnerable consisting of 80% uninsured, 72% minority, and 80% unemployed or disabled patients. Patients in the intervention were prescribed a common beta-blocker medication and provided nurse surveillance after hospitalization. The nurse care manager visited the patient once during hospitalization, at home within 2 weeks post-hospitalization, and at 2-week intervals thereafter until the patient's condition stabilized. An 84% reduction in the total number of HF readmissions was found in the intervention group. There was improvement in the mean NYHA class and a higher usage of beta blocker medications in the intervention group. These results were significant, but should be interpreted with caution since enrollment in the study fell short of the sample size predetermined by the power analysis.

A descriptive study in the case management category examined the characteristics of case management interventions. Oliva (2010) evaluated RN nurse case manager activity type, timing, and time spent per patient per month in an exploratory substudy of

HF patients from a large, 5-year, multicenter, randomized controlled trial known as the Medicare Coordinated Care Demonstration. HF patients in the intervention group ($n = 1551$) received an average of 60 minutes of case management time per month. Twenty standardized nursing intervention categories were identified, and case manager intervention times were mapped to each category. Results were correlated with admission rates. Patients who were not readmitted during the study period received “slightly more” time ($p < .05$) in all 20 nursing intervention categories than those patients who were readmitted.

Telemonitoring interventions. Telemonitoring has become a common disease management intervention used with patients with coronary artery disease and in particular HF. There are six manuscripts that describe individual trials of telemonitoring. Two meta-analyses are also included in this intervention category.

Chaudhry et al. (2010) in a large randomized controlled trial conducted in 33 cardiology practices across the United States ($N = 1653$) used remote physiologic monitoring and an automated telephone response system for daily home monitoring of HF patients. Enrollees had a mean age of 61 years, 42% were female and 39% were African-American. Patients were prompted to answer a series of questions related to their health status. Transmitted physiologic and survey data were reviewed daily Monday through Friday by nurse coordinators. Patients in this study had been hospitalized within the previous 30 days for HF decompensation. No effect was found within 180 days on the primary combined endpoint of readmissions or deaths.

In a smaller single site trial, Antonicelli et al. (2008) used a specialized team to monitor HF patients. The study population consisted of 57 patients of which the majority

(58%) was male, and the mean age was 78.2 years. The intervention consisted of weekly phone calls from the team to inquire about symptoms and physiologic measures. Weekly electrocardiograms were transmitted. Treatment changes were made accordingly. Patients and home caregivers underwent a training course during the hospitalization period to learn the home study protocol and ensure correct use of equipment. At 12 months, Antonicelli et al. (2008) found a significantly lower occurrence of the primary combined endpoint of mortality and readmissions in the intervention group ($p = .006$). When the combined endpoints were separately considered, patients in the home telemonitoring group still had a significantly lower rate of hospital readmission versus the control group; however, there were no differences in mortality rates. The treatment group had significantly better health perception scores over baseline as compared to the control group. In the 2010 secondary analysis of this study, Antonicelli et al. found a significant difference in the mean use of beta-blockers in the treatment group.

In a 2008 Canadian study conducted in a large academic heart institute, Woodend et al. studied a sample of 249 patients with HF or angina. The mean age of the sample was 66 years and 75% were male. Nurses began monitoring patients 48 hours after discharge through daily phone line transmission of weight, blood pressure, and periodic transmission of electrocardiograms. Videoconferences were held at least weekly with patients to assess their progress and conduct self-care education. The education component took place over the first eight weeks of the trial. After one year, there was a 45% reduction in the number of admissions for patients with angina who received the intervention compared with those receiving usual care, but not in HF patients. Patients in this group reported higher levels of treatment satisfaction than those receiving usual care,

had better exertion capacity at one year, and scored significantly better on QOL surveys than usual care patients at all three follow-up periods.

Soran et al. (2008) conducted a telemonitoring study in a minority population ($N=315$) where non-Hispanic white men were excluded. The study population had a mean age of 76 years and was 65% female. Telecommunication equipment was used to transmit daily weights and information from an automated telephone survey on HF symptoms. Heart failure trained nurses reviewed the data daily and contacted the patient to verify any changes. Weight gain exceeding a pre-specified amount or concerning symptoms were reported to the patient's primary care physician by the nurse. Information routinely provided to the physicians was used to schedule patient visits and change therapies. Soran et al. (2008) found advanced home based monitoring of HF patients with an interactive program had no statistically significant effect on cardiovascular deaths and readmission rates within 6 months after discharge.

A two-armed telemonitoring intervention versus usual care was used with patients recently discharged from the hospital or diagnosed with acute or worsening HF in a 2011 French trial ($N=138$) by Kurtz et al. The study population had a mean age of 68 years and was 78% male. In one interventional arm of the study, patients were seen at a HF clinic by a multi-disciplinary team consisting of physicians, nurses and dietitians. Five to six, 45-minute face-to-face consultations were provided in a year. Extensive education on treatment plans and medications, symptom monitoring and management, building activity tolerance, and adapting preferred foods to low-sodium versions was conducted. The second interventional arm was designed for those patients who had a telephone and a scale at home, but lacked a relationship with a primary care practitioner. These patients

were followed for 12 months using an automated telephone response system to answer questions on weight, dyspnea, and general health. Stable patients were asked to repeat their call in a week, while patients with worsening symptoms repeated the call in three days. Those patients with a suspected exacerbation proceeded to a medical visit, while those with a high risk of hospitalization were connected directly to the clinic provider. Otherwise, patients in this arm had three planned visits to the clinic during a year. Kurtz, et al. (2011) found a significant reduction in the primary endpoint (cardiovascular death and hospitalization for HF only) in the telemonitoring group compared to standard care. No difference was found between the two interventional arms of the study. When the endpoints were separated the significant difference was found to be in the hospitalization rates, not in mortality.

In an Italian study ($N = 460$) conducted at five cardiac rehabilitation centers, Giordano et al. (2009) used a two-part intervention: *telemonitoring* and *teleassistance*. Telemonitoring included scheduled phone appointments with nurses at either weekly or 15-day intervals depending on their NYHA functional class. Teleassistance occurred when patients contacted the call center as needed in the presence of symptoms. At the end of either type of call, the nurse would set up a follow-up phone appointment, a clinic appointment, or contact the physician directly when a patient was unstable. Weekly care conferences by a multidisciplinary team were held to review the patients. At 12 months Giordano et al. (2009) found significance in the intervention group as compared to usual care on the primary outcome of cardiac readmissions, and secondary outcomes of all-cause readmissions and costs of care, but not for cardiac mortality.

A variety of intervention protocols were used within these studies in terms of interventional components, dose, frequency, physiological measures monitored, type of technology, and follow-up period making true comparison across the studies challenging. Four of the six trials (Antonicelli et al., 2008; Giordano et al., 2009; Kurtz et al., 2011; Woodend et al., 2008) demonstrated significant differences between the intervention groups and control groups on readmission outcomes, however, two of the larger studies in this group did not find the intervention effective (Chaudhry et al., 2010; Soran et al., 2008). In both of these larger studies with no effect, the interaction with the patient was through an automated telephone response system and not direct human contact.

Stolic et al. (2010) performed an integrative review of the literature that included 24 manuscripts ($N=8330$) addressing the effectiveness of structured nurse-led telephone interventions for patients with coronary heart disease. This review also showed mixed results. Only seven of the 24 included studies used readmission rates and/or mortality as an outcome. Of these studies, two with a combined sample size of 1876 patients demonstrated statistically significant differences in readmission rates in the intervention group, and one of those also demonstrated improved mortality rates in the targeted HF population. The other 5 studies did not demonstrate a significant difference between groups. The author believed small sample size and a lack of rigor in research design of many of the studies prevented a detection of an effect of the intervention.

In a Cochrane Review, Inglis et al. (2010) assessed the effects of HF management programs using primarily telemonitoring interventions ($N = 2710$) and/or structured telephone support interventions ($N = 5613$) in a meta-analysis. The criteria of electronic transfer of physiologic data differentiated telemonitoring interventions from structured

telephone support in this review. Telemonitoring interventions that included home visits or more than usual clinic follow up visits were excluded. The summary results of 25 trials published since 2006 found that risk of all-cause mortality was significantly reduced with telemonitoring and positively, but not significantly reduced with structured telephone support. Both types of interventions significantly reduced HF related readmissions. Other effects realized were reduced healthcare costs, improved prescribing of evidence-based medications, patient HF knowledge, self-care behaviors, and NYHA functional class.

Comprehensive reviews of health services using multiple interventions. Three publications not previously discussed are meta-analyses not limited to a specific intervention type. The investigators included all non-pharmacological programs in their inclusion criteria.

Raman et al. (2008) conducted a meta-analysis combining 49 trials ($N = 10,572$) published since 1990 to determine which supportive post-discharge interventions affected the outcome of readmissions. Interventions that utilized increased clinic visits, home visits, and multidisciplinary care were found to reduce the risk of readmissions. The author noted that these primary interventions were often combined with secondary components with telephone follow-up being the most common. Telephone follow up alone had no significant effect on all cause readmissions between comparison groups. Those interventions initiated in the inpatient setting or involving intermediate to long-term follow-up were associated with significant reductions of all cause readmissions in the intervention groups.

Takeda et al. (2012) also compared the effects of various clinical service interventions on mortality and/or hospital readmissions in patients previously

hospitalized with a HF diagnosis. Takeda et al. (2012) maintained there is now good evidence that case management interventions led by a HF specialist nurse significantly reduces HF related readmissions and all cause readmissions at 12 months. The author concluded that the optimal components of the case management interventions are not clear from the evidence, but telephone follow up by the nurse specialist was a common component. Takeda et al. (2012) further concluded that multidisciplinary interventions may be effective in reducing both HF and all cause readmissions, but there is currently limited evidence supporting interventions whose major component is follow up in a HF clinic.

The differences in delivery methods used in care management programs were also the focus of the Sochalski et al. (2009) systematic review. The authors set out to determine which program types contribute to reductions in hospital readmissions for HF patients. Sochalski et al. (2009) included only studies previously published by the authors of the actual review ($N=10$). This inclusion criterion is unusual. The reviewers concluded that overall, patients participating in one of their programs had 25% fewer all-cause readmissions versus usual care. They further concluded that multidisciplinary team approaches and programs using in-person communication resulted in significantly fewer hospital readmissions, while programs using only telephone contact or a single HF expert did not have an effect. The limitation of this review is its unconventional methodology, which may limit its quality and generalizability of the results.

Application of Health Behavior Theories

Within the realm of heart disease, health behavior modification is crucial to secondary prevention efforts. Many cardiovascular risk factors are considered reversible

and may reduce the risk of mortality (Smith et al., 2011; Wood, 2005). Significant suboptimal adherence rates for healthy behaviors have been reported in the HF and AMI populations (Alm-Rojier et al., 2004; Evangelista & Shinnick, 2008; Ho et al., 2007). Considering the abundance of evidence that speaks to the modifiable risk factors and the suboptimal adherence to prescribed therapies it is surprising that only one manuscript in this review explicitly stated that the intervention tested was grounded in health promotion theory and practice (Oliva, 2010). Three additional manuscripts applied the construct of behavioral theory known as self-efficacy to their design (Aguado et al., 2010; Jaarsma et al., 2008; Wakefield et al., 2009).

Bandura first introduced the concept of self-efficacy, “the conviction that one can successfully execute the behavior required to produce the outcome.” in 1977. Since then it has become a major component of health behavior and health promotion models (Edberg, 2007). Two of the studies focusing on enhancing the patient’s self-efficacy had significant results on reducing readmissions (Aguado et al., 2010; Wakefield et al., 2009). Despite the number of interventions aimed at promoting self-care and self-management in the cardiac population, interventions solidly grounded in health behavior theory are limited. The limited research in the application of behavioral theory in the self-care literature regarding HF patients has been previously noted (Riegel et al., 2009).

Summary of the Evidence

The literature was reviewed to determine the current understanding of the phenomenon of hospital readmissions and which structured nursing interventions designed to improve care transitions from hospital to home are most effective in patients with cardiac disease. The proposed Holistic Determinants of Readmissions Model was

used to organize the review of the literature. Three domains: health policy, patient factors, and healthcare services served to organize the review.

The review of the literature on readmissions of HF and AMI patients revealed that patient factors were the focus of less than 10% of the manuscripts, an indication that more research is needed in this area. It is particularly noteworthy that in the study that examined perceived reasons for readmissions, patients and their caregivers disagreed with healthcare providers on the underlying cause in 66% of the cases (Annema et al., 2009). It appears from these results that providers may not explore the root cause of the care transition failure from the patient's perspective.

As this review demonstrated, an extensive body of evidence evaluating the effectiveness of nursing interventions to improve outcomes in HF following hospitalization for an acute exacerbation has been generated in recent years. A considerable gap in the recent literature was also identified for nursing interventions designed to improve readmission outcomes in patients discharged from the hospital after an AMI. No single study focused on this population. This finding was unexpected considering AMI patients are at high risk for 30-day readmissions and are a target for improvement by CMS in terms of process of care measures and readmission rates (CMS, 2012c).

Despite the number of interventions aimed at promoting self-care and self-management in the cardiac population, there is a paucity of interventions solidly grounded in behavioral or health promotion theory. There was limited use of behavioral models in the interventional designs even though the objective of many of the interventions was to improve the patient and caregivers ability to provide self-care and

self-management. Factors such as health literacy, health knowledge and beliefs, self-efficacy, and health behavior have not been adequately addressed in the literature evaluating interventions aimed at reducing readmissions in the cardiac population. Application of behavioral models in examining patient factors related to readmissions and designing interventions to improve self-care is needed.

In the Annema et al. (2009) study, improved treatment adherence was identified by all parties (patients, caregivers, nurses, and physicians) as a factor that could significantly improve readmission rates. Adherence is defined as the “active, voluntary, and collaborative involvement of the patient in a mutually acceptable course of behavior to produce a therapeutic result” (Delamater, 2006, p.72). It is unclear from the literature whether this type of patient and family engagement was integral to the interventional studies’ designs or whether the treatment was mutually acceptable. The majority of interventions appeared to be generic in their approach.

The primary focus for preventing readmissions in patients with HF and AMI has been on improving the effectiveness of the health care services provided to this population. Contributing failures within the health system have been well documented and include ineffective medication reconciliation processes, inadequate communication among hospital personnel and community based providers, suboptimal patient education, and poor planning for transitions from the hospital to the next care setting (Andersen et al., 2006; Berenson, Paulus, & Kalman, 2012; Greenwald, Denham, & Jack, 2007). The majority of interventions aimed at reducing readmissions have been designed and implemented without a comprehensive examination of the patient and caregiver experience. Patient and family centered approaches are needed moving forward.

Results of the literature review raise the question whether patient factors as a determinant of readmission have been truly appreciated. Capacity for self-care, underlying health beliefs, and other barriers may preclude HF and AMI patients from carrying out the prescribed plan of care. This perspective is lacking in the literature and may limit the efficacy of existing interventions.

Purpose of the Study

The purpose of the present study was to explore HF and AMI patients' and their caregivers' experience with hospital readmission within 30-days of discharge from a community hospital. Discerning the reasons for readmission and how to prevent them from this perspective has the potential to shape effective transitions from hospital to home and promote patient and family engagement in their care. The study endeavored to answer the following questions:

Research Questions

The following research questions were addressed in this project:

- What are the reasons for 30-day readmissions from the perspectives of patients and their family caregivers discharged from a community hospital with a diagnosis of HF or AMI?
- What can be done to prevent the next readmission from the patients' and their family caregivers' perspectives?

Section III: Methods

A descriptive, phenomenological qualitative study using the data collection method of semi-structured interviews was conducted to describe patient and caregiver perceptions of their experiences with readmissions and to identify root causes of the

phenomenon from the *emic* or insider's view (Holloway & Wheeler, 2010). A purposive, convenience sample was recruited from the target population. Colaizzi's (1978) seven-stage process detailed below was the approach applied to analyzing the data. The intent of the method is to capture the true essence of the *lived experience* of patients and caregivers with regard to readmissions.

Research Design

A qualitative design using a descriptive, phenomenological method was chosen to explore the experience of patients and their caregivers readmitted to the hospital within 30 days following discharge with a diagnosis of AMI or HF. The rationale for the use of this method lies in the philosophical underpinnings of the phenomenological approach. Phenomenological philosophy is tied to the epistemological question of "how we know" and the ontological question of "what is being" and our knowledge of the nature of reality or "how things really are" (Holloway & Wheeler, 2010). Husserl, the 19th century German philosopher credited with developing phenomenology, describes it as "the science of essence of consciousness" (as cited in Wojnar & Swanson, 2007, p.173). According to Holloway and Wheeler (2010) phenomenology is a philosophy "which explores the meaning of individuals' lived experience through their own description" (p.341). Balls (2009) emphasizes that phenomenology supports the re-examination of a taken-for-granted experience. The perspectives of HF and acute MI patients and their caregivers in regards to the readmission phenomenon have been underappreciated. This methodology allowed the researcher to develop an in-depth understanding of their "lived experience."

Streubert and Carpenter (2011) suggest three questions be answered when

determining whether the phenomenological approach is an appropriate method for a research study. The first question asks if there is a need for further clarity on the chosen phenomenon. As pointed out in the section on gaps in the literature little is known about patients' and caregivers' perceptions concerning reasons for readmission and what might be done to prevent them. The second question asks if the shared "lived experiences" will be the best data source for the phenomenon under investigation. Clearly to gain knowledge of the patient's experience around readmissions, the source for this data needed to be the patients and caregivers. The final question asks the investigator to consider whether the available time and resources can support the methodology and whether the investigator's personal style and abilities are congruent with the methodology. Available resources, time, and the investigator's personal style were considered in selecting this approach and were assessed to be suitable to support the methodology.

The descriptive phenomenological approach involves the exploration, analysis, and description of an observable occurrence that places emphasis on the richness of what is being experienced. In this approach the investigator is obligated to "bracket" or actively and consciously suspend all biases and beliefs regarding the phenomenon of interest (Streubert and Carpenter, 2011). A source of bias brought to this study by the investigator was the knowledge of health promotion and behavioral theory and extensive knowledge of interventions aimed at reducing readmissions. In addition, the investigator was an active participant in institutional efforts in reducing readmissions.

Purpose of the Study

The purpose of the present study was to explore HF and AMI patients' and caregivers' experience with hospital readmission within 30-days of discharge from a community hospital. Discerning the reasons for readmission and how to prevent them from this perspective has the potential to shape effective transitions from hospital to home and promote patient and family engagement in their care. In keeping with the exploratory nature of this study a predictive hypothesis cannot be specified (Wood & Ross-Kerr, 2011). The study endeavored to answer the following questions:

The research questions are as follows:

1. What are the reasons for 30-day readmissions from the perspective of patients with a discharge diagnosis of HF or AMI in the community hospital setting?
2. What can be done to prevent the next readmission from the patient's perspective?
3. What do the family caregivers of these patients perceive to be the reasons for 30-day readmissions?
4. What can be done to prevent the next readmission from the caregiver's perspective?

Definition of Terms

Index admission. Any eligible admission to an acute care hospital assessed in the measure for the outcome whether readmitted to an acute care facility or not within 30 days (CMS & Joint Commission [JC], 2012c).

All cause readmission. An admission to an acute care hospital within 30 days of discharge from an acute care hospital for any cause with the exception of specific *planned* readmissions for the AMI measure (CMS & JC, 2012c).

Planned readmission. An intentional readmission within 30 days of discharge from an acute care hospital that is a scheduled part of the patient's plan of care. Planned readmissions are not counted as a readmission. For the patients with AMI, a return to the hospital may be scheduled for revascularization procedures and are excluded from the readmission count. These procedures include percutaneous transluminal coronary angioplasty (PTCA) on a second vessel or a second location in the same vessel, or coronary artery bypass graft (CABG) surgery after AMI and a period of recovery outside the hospital (CMS & JC, 2012c).

Primary discharge diagnosis. The International Classifications of Diseases and Related Conditions, Ninth Revision, Clinical Modification (ICD-9-CM) code of the principal reason for hospitalization (CMS & JC, 2012c).

Heart failure. A principal diagnosis of HF using the ICD-9-CM codes: 402.01, 402.11, 402.91, 404.01, 404.03, 404.11, 404.13, 404.91, 404.93, and 428.xx (CMS & JC, 2012c).

Acute myocardial infarction. A principal diagnosis of AMI using the following ICD-9-CM codes: 410.0n–410.9n, where n equals 0 or 1 (CMS & JC, 2012c).

Caregiver. For the purposes of this study caregiver will be defined as a family member, friend or significant other identified by the patient as the primary person who supports them in personal care and managing their disease at home. This definition does not include professional health care providers or community health workers.

Setting

The setting for this study was the inpatient medical-surgical nursing units of Martha Jefferson Hospital, a 176 bed non-profit, community hospital in Charlottesville,

Virginia. The hospital serves a 7 county area in central Virginia with a population close to 250,000. The hospital has been an ANCC designated Magnet® facility since 2006. Major services lines include cancer, neurosciences, cardiology including coronary interventions and electrophysiology procedures, orthopedics, and a family birthing center.

In 2012 the facility had 11,049 discharges and 52,633 emergency room visits. The average daily inpatient census of this facility is 98.3 and the average length of stay is 3.26. In 2011, the 30-day readmission rate for Medicare patients with HF hospitalized at Martha Jefferson was 25.6% compared to the nationally reported rate of 24.7%. The 30-day readmission rate for Medicare patients with AMI was 20.5% compared to the nationally reported rate of 19.7%.

Martha Jefferson has been part of Sentara Healthcare, a fully integrated delivery system in Virginia and North Carolina. Sentara's mission is as follows: *We improve health every day* (Sentara Healthcare, 2013). Since the fall of 2012, Sentara has been targeting the diagnoses of Heart Failure, Sepsis, and Pneumonia for reductions in length of stay and mortality and readmission rates. The study site included three 24-bed medical-surgical units and a 30-bed telemetry unit at the facility where all inpatient rooms were private with space provided for family members and/or personal caregivers to spend the night. The facility has patient-directed visitation which allows visitors 24/7 access to the patient with their permission. In 2012 the average daily census ranged from 18.7 – 19.8 patients on the 24-bed units and 23.0 patients on the 30-bed telemetry unit. Staff is scheduled for 12 hour shifts. Typical staffing on the units includes a 1:5 RN to patient ratio on the 7am-7pm shift and 1: 5-6 ratios on the 7pm-7am shift. Support staff

coverage includes 8 hours of a unit secretary per day and a nursing assistant for every 10 - 12 patients.

Interview Process

In-depth semi-structured interviews broadly guided by components of the Health Belief Model (HBM) as described by Edberg (2007) were conducted. The health belief model is an applicable theory in understanding behaviors known to affect outcomes in patients with cardiac disease. In 1974, Becker extended the application of the HBM from its origins in public health to behaviors in response to diagnosed illnesses and an individual's adherence to medical treatment plans. Results from various settings and with different patient populations support the HBM premise that individuals will take health actions to ward off or control illness if they consider themselves susceptible to the condition and if they believe it will result in serious consequences for them. Individuals must believe that they are capable of carrying out the required health actions (self-efficacy), the actions will produce the benefit of reducing their susceptibility to the illness or its severity, and the benefits outweigh any perceived barriers they must overcome to carry out the behavior (Strecher, Champion & Rosenstock, 1997).

Each interview started with the questions "what do you think brought you (or the patient) back to the hospital this time?" and "what might have prevented you (or the patient) from coming to the hospital again?" Interview questions explored beliefs and knowledge concerning the patient's heart disease, health behaviors, ability to carry out prescribed behaviors, and perceived barriers to performing them.

Separate patient and caregiver guides (see Appendices C & D) containing a script to open the interview, topic areas, high-level interview questions, and prompts were used

to ensure the investigators' focus on the areas of interest for this study (Holloway & Wheeler, 2010). In keeping with the phenomenological method a high level of flexibility was maintained in conducting the interviews to ensure a true portrayal of the participants' experiences including their feelings and the meanings they gave to their actions (Holloway & Wheeler, 2010). As recommended in the literature, as themes emerged the interview questions were updated to allow further inquiry into the structure of the phenomenon (Holloway & Wheeler, 2010). The duration of interviews ranged from 13 to 73 minutes.

Description of Sample

A purposive, convenience sample was recruited from the target population of patients readmitted within 30 days of an index admission for HF and/or acute MI. A purposive sample involving participants who share particular characteristics or experiences was desirable to provide rich data pertinent to the research question (Holloway & Wheeler, 2010; Tong, Sainsbury, & Craig, 2007). Consistent with the tradition of qualitative research, the sample size was not predetermined, but guided by the ongoing data analysis. As themes emerged, further inquiry and validation of themes were pursued (Holloway & Wheeler, 2010; Strauss & Corbin, 1998). Participants were recruited and interviewed until informational redundancy was apparent as described by or Sandelowski (1995). The saturation point was considered reached when no new themes were being generated from the interviews (Shi, 2008; Strauss & Corbin, 1998). The sample size was considered adequate when the structures of the phenomenon and their meanings became clear as suggested by Wojnar and Swanson (2007) when conducting qualitative research.

Inclusion criteria

Patient participants meeting the following criteria were recruited to the study:

- 1) over 18 years of age
- 2) a prior discharge diagnosis of congestive HF or AMI
- 3) readmitted within 30 days to medical-surgical or telemetry unit or is later transferred to the medical-surgical or telemetry unit from intensive care.

Caregiver participants meeting the following criteria were recruited to the study:

- 1) identified by the patient as their primary caregiver
- 2) Spend time in the patient's home environment at least once a week
- 3) Frequently checks on the patient by phone or in person
- 4) Identified by the patient as the person they depend on to help with care

Exclusion criteria

Patients with the following characteristics excluded from the study:

- 1) non-English speaking
- 2) diagnoses of aphasia, cognitive impairment, or severe clinical depression
- 3) Actively dying
- 4) discharge disposition on the index admission was to a long term acute care facility, a skilled nursing facility, inpatient rehabilitation center, or residential hospice facility
- 5) readmitted to another institution within 30 days of the index admission at the study site
- 6) readmission meets the CMS criteria for a planned admission.

Caregivers with the following characteristics were excluded from the study:

- 1) they were not identified by the patient as the primary caregiver
- 2) they were not given permission to participate by the caregiver
- 3) they do not speak English
- 4) they are paid caregivers or voluntary community health workers

Procedures

The data collection period was from November 2013 through April 2014. Each day a standard report generated from the electronic medical record system was used to track readmissions of patients. Eligible patients and caregivers were approached. Following receiving informed consent of the patient (see Appendix E) and/or caregiver (see Appendix F) a mutually agreeable time was set for the interviews. Select demographic data were collected through the electronic medical record and during the interview. Patient interviews were conducted in the patients' rooms to ensure ample time and privacy. Interviews with caregivers were conducted in a private office within the setting without the patient present to enable them to express their perceptions freely. Interviews were audio-recorded and transcribed by a contracted professional transcriptionist.

Audio files, transcripts and demographic data files were de-identified through the use of alphanumeric codes to protect participant confidentiality. All electronic files were stored securely. Only one file was used to store patient identity information, and it was stored separately in a password protected manner by the primary investigator.

Measures

Demographic data including gender, education level, age, payor class, zip code, ejection fraction, discharge diagnosis on index admission, primary diagnosis on

readmission, major comorbid conditions, and the total number of medications recorded on the readmission history were collected on the patient sample from the electronic medical record and during the course of the interview. Data were collected on the caregivers during the interviews and included age, gender, relationship to the patient, and education level. As this is a qualitative study, results included the major themes that emerged from the patient and caregiver interviews.

Reliability

In qualitative research reliability has been alternatively described as the trustworthiness (Holloway & Wheeler, 2010; Roberts, Priest, & Traynor, 2006). Several methods recommended in the literature were taken during the course of the study to establish trustworthiness of the results. Consultation was received during the design, data collection, and data analysis phases from a doctoral prepared researcher experienced in qualitative inquiry (Holloway & Wheeler, 2010; Roberts et al., 2006). Data collection was limited to the principal investigator and a research assistant who held regular research meetings to ensure consistency in data collection (Roberts et al., 2006), establish an audit trail (Fleming, Gaidys, & Robb, 2003), and determine additional paths of inquiry needed as informed by the ongoing data analysis. Field notes and memos were used to document such things as general impressions, nonverbal cues observed in the participants, insights on the investigator's performance during the interview process, and questions the interviews generated for the investigators. Field notes are known to assist in understanding and synthesizing data (Holloway & Wheeler, 2010). As recommended the interviews were audiotaped to ensure accuracy and professionally transcribed by a third party (Roberts et al., 2006; Tong, Sainsbury, & Craig, 2007). Triangulation of the two

data sources (patients and caregivers) was sought to strengthen the design (Holloway & Wheeler, 2010; Roberts et al., 2006). Follow-up contacts by phone and mail were made with participants to ensure the data gleaned from transcripts accurately reflected their experiences (Elliott et al., 2011; Fleming, Gaidys & Robb, 2003). The results were reviewed for legitimacy by a primary care physician experienced in the patient-centered medical home model and who has practical expertise in reducing readmissions. In addition, two doctoral prepared nurses experienced in conducting and/or reviewing qualitative research were provided a sample of transcripts along with the findings to further assess the authenticity of the results (Holloway & Wheeler, 2010; Roberts et al., 2006). And finally, computerized data analysis software was used to reduce bias and allow for robust manipulation of the data (Roberts et al., 2006).

Data Analysis

Data analysis began after the first interview and continually guided future data collection as emerging ideas and concepts were recognized. The interview guide went through 3 iterations as data unfolded and additional questions engendered by the data analysis were added. Colaizzi's seven-stage process as described by Holloway and Wheeler (2010) was the approach applied to analyzing the data. All interview scripts were read to acquire a feeling for them. Then each interview transcript was revisited, significant statements were extracted, and meanings of the statements were formulated. These meanings were organized into themes and then validated with the original interview transcripts. Any discrepancies within and between themes were reconciled by expanding a theme, reassigning data to other themes, or adding a new theme until a good "fit" was achieved. In the final step, themes were integrated into a description of the

structure of the phenomenon of readmissions from the insider's view, i.e. that of patients and their caregivers. The software program N'Vivo, version 10 was used to assist in the analysis.

Protection of Human Subjects

The study protocol was submitted and reviewed for the protection of human subjects by the Martha Jefferson Hospital Institutional Review Board (see G1, Appendix G). Approval was sought and approved to extend the study period to a later date (see G2, Appendix G). An exemption was obtained from the University of Virginia Health Sciences Research Board (see G3 Appendix G, *Determination of UVA Agent Form*). The study protocol was followed and no adverse effects occurred. This project was funded in part by a research fellowship grant provided by the Martha Jefferson Foundation. The sponsor had no role in the design and conduct of the study or the preparation and approval of this manuscript.

Strengths and Weaknesses of the Design

Strengths of the study include the significance of the topic for nursing practice and the rich data collected concerning patient factors contributing to readmissions. The investigators were able to pursue lines of inquiry as the interview unfolded creating new insights and details of the participants' experiences with managing heart disease at home and interfacing with the healthcare system. Interviews methods often result in a higher data yield than other forms of data collection (Wood & Ross-Kerr, 2011). The face to face nature of the interviews allowed the investigators to note the affective aspects of the responses. The ability to clarify responses to the questions directly with the participant can increase the likelihood that quality data is collected (Wood & Ross-Kerr, 2011). In-

depth interviews are a low cost method of data collection (Shi, 2007). The data were collected and analyzed using accepted methods to ensure trustworthiness which strengthened the design.

Weaknesses of the design included the usual risks inherent in semi-structured interviews. There was a risk of introducing the investigator's own bias based on previous experiences related to the phenomenon of readmissions. Bias on the part of the investigator in formulating questions during the semi-structured interview may have influenced the results (Streubert and Carpenter, 2011; Shi, 2007); however, attempts were made through field memos and research meetings to minimize potential bias. Audiotaping of the interviews may have caused participants to be uneasy and limit their responses. Findings are limited to the sample respondent population and are not generalizable to other populations; however, the findings of this study provide insights into the patient factors that may be determinants of readmission. These findings could be incorporated into future interventions and allow for further evaluation of their effectiveness.

Products of the Capstone

The formal products of this Capstone project will include:

- 1) The results of the qualitative analysis
- 2) A manuscript summarizing the Capstone suitable for publication in the

Journal of Cardiovascular Nursing (See Appendix J)

Section IV: Findings

The following research questions were addressed in this project:

- What are the reasons for 30-day readmissions from the perspectives of patients and their family caregivers discharged from a community hospital with a diagnosis of HF or AMI?
- What can be done to prevent the next readmission from the patients' and their family caregivers' perspectives?

These questions were pursued through in-depth semi-structured interviews guided by the HBM model. Interview questions explored beliefs concerning the patient's heart disease, current health behaviors, and perceived barriers to performing them. Behavior modifying factors of health knowledge and self-efficacy were also explored. The mean duration of interviews was 33 minutes. A total of 466 minutes of interview data was collected and 11,237 lines were transcribed.

A total of 10 patients and four caregivers were interviewed. All four caregivers interviewed were female and all were spouse to the patient. Three patients were readmitted following an index admission for AMI and seven patients were readmitted following an index admission for HF. Days to readmission varied from zero (same day) readmission to 28 days. Patient ages ranged from 29 to 90 years. Education levels of the patients varied tremendously ranging from an eighth grade level education to the graduate level. Ejection fractions were collected and ranged from (10-60 %). All patients had a primary care physician and all except one saw their primary care physician on a regular basis. All patients had health insurance: seven had Medicare as the primary payor, one

patient had both Medicare and Medicaid, and two patients had commercial insurance.

Demographics of the participants can be found in Table 1 (see Appendix H).

Data saturation was reached in the study. Consistent with the literature, the saturation point was considered reached when no new themes were being generated from the interviews (Shi, 2008; Strauss & Corbin, 1998) and the structures of the readmission phenomenon from the patients' and caregivers' perspective were clear and their meanings were visible (Wojnar & Swanson, 2007).

Several themes emerged from the data. Triangulation of themes occurred between the caregivers' perceptions and patients' perceptions on five themes: worsening of condition/need for symptom relief, unmet learning needs, failure to address the health issue during the index admission, patient non-adherence with the treatment plan, and challenging treatment regimens. An additional theme emerged from the caregivers perspectives: lack of caregiver inclusion.

Worsening of condition/need for symptom relief

Several patients and caregivers pointed to the worsening of the patient's condition or the need for symptom relief as the primary reason for readmission to the hospital. The most common symptoms were shortness of breath and chest pain. Other symptoms included fluid accumulation (swelling), leg pain, syncope, and bleeding. Frequently participants did not see a connection between the readmission and how the patient's care was managed at home. Many stated they "did not know" or could not identify any actions they could have taken to prevent the need for readmission. An 81-year-old male patient with an ejection fraction of 30% had been home for 28 days. He relayed this story of gradual decline:

When I got home I was feeling alright, walking around and all. But then gradually my physical therapist took me outside, so I could walk. My distance is getting shorter. So I told my wife, I said, 'Something's not right. I'm not getting better.' I said, 'I get very short of breath.' So she said, 'Well, we're going back to the hospital and check you in. So that's what we did. (quote from patient 1a)

Patient 8a, an African American gentleman with HF and an ejection fraction of 30%, had been home for 11 days. When asked what had brought him back to the hospital he stated, "my legs. I've been having problems with my legs.... Swelling. Fluid and everything." He conveyed the extreme discomfort he had been experiencing prior to admission. When asked if there was anything that could have prevented his readmission he replied. "No... I had to come. I couldn't take it no longer. I can't sleep.... I been up all night just walking the floor."

Some participants felt hospital readmission was inevitable due to the severity of the patient's condition. One caregiver reported:

...he's in congestive heart failure and that's bad. He doesn't have much of a heart left. And then with his heart racing like it was. So we just live day-to-day. (quote from caregiver 2b)

Unmet Learning Needs

When participants were asked about instructions they received regarding care at home, most reported that they felt prepared; however, with more specific questioning, the theme of unmet learning needs emerged. All patients acknowledged that they had received discharge instructions although some had difficulty recognizing them as such. Others had difficulty recalling or incorporating their instructions when they got home.

Patients and caregivers in the study identified the need for more detailed and tailored instructions to fully implement their treatment recommendations once home in order to prevent readmission. The greatest reported deficits involved implementing a low salt and/or heart healthy diet, weight monitoring, and activity level.

All HF participants had been told to restrict their sodium intake, but there appeared to be an extended learning curve regarding the salt content in foods as demonstrated by the following example of an African American patient (8a) with a ninth grade education discussing his low-salt diet:

I had no idea just from your canned food,... like chicken noodle soup. I used to just get that all the time. That's full of salt. And those little dinners, I was shocked at that.... Yeah, I believe they could have told me back when I first started coming up here. I think it might have really helped.

A caregiver participant, the spouse of a patient readmitted following an AMI, was looking for more information regarding dietary recommendations,

Now I'm sure there are probably some specifics related to his condition. The only thing I know is to reduce caffeine, but aside from that I don't know of anything specific other than I know just generally healthy food, more fruits, vegetables, grains, and so forth. (quote from caregiver 3b)

There were indications that the application of the information to their everyday experience was not well understood. For example, patient 4a, a 72- year -old, African-American woman with an eighth grade education, described her condition as “decongestional heart failure.” She had just been diagnosed with HF on her previous admission and understood her condition to be “very” serious. When asked what she had

to do differently every day to take care of her congestive heart failure she replied “nothing that I know of.”

The following excerpt is from an interview with a 90-year-old, Caucasian gentleman, readmitted post-AMI with a 12th grade education. When first asked by the researcher, he denied receiving any instructions; however, when asked if he was given any papers with information regarding his care he made the following comments:

Yeah, they give you beautiful pictures of the heart. Now who in the hell cares about some pictures, right? Tell me “Eat this, don’t eat that, don’t do this.”

Because a person my age, I don’t care about this report, that report... (quote from patient 5a)

He further relayed that he was given a folder with “all kinds of literature and brochures,” but he did not look at it because it was “page after page after page” and “you need a pair of magnifying glasses to read it.” He threw the folder out without reading it.

Another post AMI patient (3a) knew that he had received discharge instructions, but simply could not recall them. He stated that he did not have time to read them but had planned to do so during his readmission. At readmission, he had an outstanding question about how long he needed to continue taking his beta blocker.

HF patients and their caregivers understood they were to obtain daily weights, but experienced confusion around what a change in weight really meant in regard to the patient’s condition. Neither patients nor caregivers conveyed that they routinely monitored for symptoms such as dyspnea on exertion or ankle swelling. There was also a tendency for patients and caregivers to complete the task of weighing, but keep the information to themselves until they visited the doctor or the home health nurse arrived.

Significant weight gain did not always cue the patient to action. One caregiver relayed the following story:

The nurse, when she comes, she'll put him on the scale – he weighs originally 140 lbs. On that Wednesday, she came and he weighed 158 lbs. She called the doctor. So she calls me back that night and the doctor said for me to double on his Lasix in the morning and at night. So that's what I did. (quote from caregiver 9b)

Another patient's wife had remaining questions concerning the patient's weight and expressed it in this excerpt:

I still can't understand that, three pounds in a day or five pounds in a week. I guess if you don't lose it by the end of the week and it's totaled to five. But I'm hoping that he starts putting on some weight though. I mean, how am I going to know if it's from water. (quote from caregiver 1b)

According to this caregiver, her husband had come back the hospital "because his body had filled up with fluid." She stated he had "ten pounds of fluid." When asked how she knew it was time to bring him to the hospital she relayed that he couldn't breathe despite turning his home oxygen up to 5 liters. She relayed that when the rescue squad arrived he was put him on 15 liters of oxygen.

In general it appeared that patients had not been provided clear instructions regarding activity level and exercise and some misperceptions were apparent. Patient 4a expressed that the most important thing she needed to do for herself was getting her rest and that she needed to be "more careful." She had the perception that she shouldn't exercise. The youngest patient participant in the study was most concerned about the lack of specific guidance he received regarding a safe activity level. He had a 10% ejection

fraction and had been readmitted with chest pain. He reported that there was some further heart damage because he had exerted himself too much. He expressed his learning need in these words:

I would have liked to know more about level of activity, but I know....that's kind of a rough estimate, but I think there could have been better guidance there. At what point do I want to push more?...They did a very good job from a diet standpoint....but I'm not exactly sure at what point should I be doing what type of exercise. (quote from patient 6a)

These data demonstrate that despite receiving care instructions in the hospital setting during the index admission, a deeper understanding was needed to apply the information in the real-world environment. The unmet learning needs left uncertainties among participants in managing the patient's care in the home setting.

Failure to address the health issue during the index admission

Some participants including both patients and caregivers shared their perception that the readmission was due to a failure by the healthcare team to find or effectively treat the problem that brought the patient to the hospital the first time. Many felt they were left without an answer regarding what had caused the patient's symptoms or the deterioration in the patient's condition.

One 64-year-old male patient with an index admission of HF had multiple comorbid conditions including diabetes and severe chronic obstructive pulmonary disease. His wife, who functions as his primary caregiver at home, provided her thoughts regarding the link between her husband's earlier admission, and two subsequent readmissions:

...it was pneumonia the first time, but when he came back in this second time, they said it was pneumonia, but I think that had to be something else going on because we came in right before Christmas and stayed eight days. We went home for Christmas, and then we was [sic] back in here before New Year's and we stayed here twelve days...So it had to be something more than just pneumonia that was the problem. (quote from caregiver 9b)

Patient 8a described his frustration following a series of admissions. He conveyed that he did not have the answers or relief he needed. He stated, "I come, stay one day, they'll send me home, then the next couple days I'm back again. I've just been in here a week before and now right back here again." Later in the interview he relayed, "When I came this time I told them, 'You all just keep me until you find something,' because I got tired of coming in and going back home." He reported that he did not feel physically "ready to go" at the time of his last discharge and that the same symptoms (leg swelling and pain) brought him back to the hospital for his most recent admission. He stated, "I had to come back. They goofed something up." When asked how the hospital could have been more helpful to him on his index admission he simply stated, "If they pay attention to me when you tell them how you feel."

A caregiver (3b) stated she did not feel certain that her husband was "ready to go" home because he had to "stop three times just getting down to the lobby because of shortness of breath and pain." Her husband was readmitted the same day due to a syncopal episode, and since she was not provided with a clear explanation for the episode she was left with concerns about the patient's impending discharge from the hospital:

You know, one doctor would say one thing and then another doctor would something completely different and then a whole new doctor would come...And we're leaving with the impression of nobody really knows what's wrong with him... and therefore, we don't know what to do.

In each of these cases the patients or caregivers did not feel their voices were heard to their satisfaction. They expressed frustration that the "real" problem wasn't solved the first time, and some even indicated they "knew" they would be readmitted as a result.

Lack of patient adherence

Four patients reported a lack of adherence to one or more elements of their prescribed treatment plan. In only 2 of the cases, however, did participants link their lack of adherence to their need for readmission. Medications, diet, smoking cessation, and activity level were the common areas of non-adherence identified by participants.

Despite the number of medications patients in the study were prescribed, eight patients reported they adhered to their prescribed medications. Most patients or caregivers kept all of their medications in one prominent spot as a reminder (e.g. kitchen table or bedroom dresser) and most loaded a pillbox by day of week and time of day. Many had a caregiver who filled the box for them or had been assisted by a home health nurse in mapping out their medication schedule. Three other patients conveyed they had not persisted in taking certain prescribed medications or did not get the prescriptions filled. Reasons stated for these choices were an intolerance of the medication and the expense. One patient admitted to consciously skipping doses of medications on occasion. Another patient (5a), a 90-year-old gentleman post AMI, described his medication

routine as once a day. In a follow-up question he was asked if there were medications he was supposed to take more than once a day. He replied, "There are but I've never done it that way. I figure, 'screw you. I'm going to take it only once.' " He saw prescription costs as a significant barrier to continuing with his medications. At points in the past he had stopped taking all of his medications.

Patient 10a reported frequent problems with adhering to his treatment plan and made a direct connection to his readmission. He stated, "...it's my fault. You know, there are some things I could do to make it better. I'm not the perfect patient." He relayed that even though he knew his treatment regime was "a matter of life and death," he did not really see it that way in "a day-to-day setting." He described his behavioral pattern:

And then all of a sudden I'll say, 'Well I'll be alright tonight. One more night is not going to hurt anything.' It's about like when you quit smoking and start again, 'One cigarette is not going to hurt anything.' And that's the mentality that screws you up because you have that, 'It's just one,' or what not. But then I miss my 100 units on a Monday night. Then Tuesday night is like 'eh.' ... and then you missed the 100 again Tuesday night. So it kind of steamrolls ...

This same patient had a fluid restriction of one liter per day. He described barriers to adherence such as his "mouth always feeling full of cotton" and being so thirsty that if he let himself he could easily "drink a 55 gallon drum of water." He reported that he had quit smoking 8 months earlier and could see the benefits in his health status from this significant change, but described it as "throwing a bucket of water in the ocean." He considered it too little too late and questioned the benefit of further changes.

Patient 7a, a post-AMI patient, directly connected his actions and his need for readmission. Four days prior to his readmission (26 days post discharge) the patient had been cutting wood for his wood burning stove. "...He told me to take it easy, which I didn't do. As a result, I'm back in for a second visit." He was asked if he had enough instruction before he left the hospital and he said, "Oh, no question. I thought the amount of time I gave myself was enough and it wasn't." When asked if the hospital could have been more helpful in giving a timeframe for activity he replied, "No, I think they did the right thing. I just jumped the gun on it is all." His failure to "take it easy" appeared to be influenced by the barrier of not having help at home to chop the wood he needed to keep his home heated. He admitted that adjusting to his activity limitations would be challenging, but that "somebody else will have to cut the wood now."

In the case of patient 3a, he was able to speak about how his own choices caused his index hospitalization for an acute MI. He talked about the severity of his current illness and made a connection back to a previous medical episode:

The heart?... yeah, pretty serious stuff. I mean I know when I had my bypass [the doctor] said 'Go have fun; you've got 45 years back.' I'm obviously not doing that right; I'm not doing something right because I'm here again.

He discussed his lack of initiative and "willpower" to quit smoking, adhere to a healthier diet, and engage in regular exercise. He talked about his habit of eating sweets and having to have something in his stomach before he went to bed as "probably more in my head than in my stomach." In discussing the instructions he received regarding smoking cessation, he elaborated with this statement, "honestly yeah, I usually tune it out when they say the word *stop*." He made this remark despite his personal health goal to be

“completely cigarette free.” He reported that stress would be the barrier to reaching this goal. He explained his plan:

...so I am going to have to try and curb it somehow. I'm not sure yet though. I will think about it over the next couple of days. I just seem to fall into these high stress situations.

This patient's statements reflected a lack of self-efficacy in making the needed behavior changes. The patient's wife, caregiver 3b, shared his belief and worried he would “have another heart attack and die.” She described his personality as having a “glass half empty” approach.” She described his needs:

Now if he has what he needs...that I don't know because all of it is really in your mind. And personally, I'm the kind of person... I do well with that. I'm able to make changes and to accomplish things just because I take the time to do it. He's not from what I know about him, he doesn't have that same skill. ... I believe he needs some guidance or support, but outside of me, because sometimes when I say it, it's not effective and it's perceived as something other than being helpful.

She felt her husband would need additional resources to achieve his goals. She learned about the hospital's cardiac rehabilitation program during his readmission and planned on researching the program further once home.

Challenging treatment regimens

Several patients had significant co-morbid diagnoses aside from their primary cardiac disease including hypertension, diabetes, renal disease, congestive obstructive pulmonary disease and obesity. In addition two patients were being treated for depression and another patient relayed that he had suffered from chronic anxiety for years. Such comments as “but there is so much wrong with me that I really can’t concentrate on one thing, because if I do I’m turning my back on everything else” and “there’s a combination of things that are close together so it is hard to figure out” are evidence of the complexity of the patients’ condition and treatment regimens. One gentleman readmitted with acute coronary syndrome described his attempts to follow his diet instructions this way:

...With the high blood pressure and the diabetes and cholesterol and everything else, it’s hard to have a set diet. It’s just trying to mix the batch the best I can to have a little of this even though it’s not good for this. And then I’ll have a little of this even though it’s not good for this. It’s a whole lot more on figuring out how to mix and match than it is just to go ahead and eat and get it over with. (quote from patient 7a)

Caregivers and patients alike described the confusion these complex regimens created and perceived it as a barrier to successfully managing care, particularly when multiple physicians were involved. Examples of uncoordinated care among providers were shared with the investigator. Caregiver 9B paints the following picture:

Like I told the doctor, you see this doctor, you see that doctor. This doctor tells you one thing, that doctor tells you something else. My husband, he’s got let’s see, four doctors: diabetes doctor, heart doctor, our family doctor, and his lung

doctor. And none of them agree with them. He goes to one; well this one put him on that. That one will put him on this. So they got me running in circles just to try to keep his meds up.

Discharge instructions during their index admission were targeted at their heart disease. At the time of discharge, the comorbid conditions were not discussed in most cases. Putting it all together in a cohesive plan was a need expressed by patients.

Lack of caregiver inclusion

Unique to the caregiver group was an emerging theme that they were not included at an appropriate level in discharge planning and education. Two of the four caregivers interviewed expressed this concern. They felt it had a negative impact on the ability for the husband-wife dyad to manage the patient's care at home. Their statements were very powerful and provided a perspective not heard in the patient interviews. Two examples follow. The first is an excerpt from a spouse of a patient readmitted following an AMI:

So I think sometimes the doctors feel like if they talk to the patient they're giving them the information. In my particular instance my husband, sometimes talking to him is like playing telephone because I don't always get the accurate version or accurate information...So I think that would be helpful for someone to say "Okay, he's going home. Here's what we suggest. If you have any questions here's who you call." (quote from caregiver 3b)

She felt that no one knew she existed and felt lucky if she happened to be there when the doctor came. She suggested an exit interview be conducted with the family member who's going to be the primary caregiver to be certain they knew the plan, what resources they had and who to call if there were problems after discharge. The second

account comes from caregiver 9b. She had managed her husband's care of several comorbid conditions for a number of years and was a strong advocate. She relayed that despite her husband's wishes to the contrary, staff in the hospital still addressed all of their conversations to him and often provided instructions when she was not there:

...like I told them, he don't understand and ... half the times he's out of it and he don't know what he's talking about. So when they talk to him, he don't understand it. *So you talk to me* [emphasis added]. That's the way I want it, but they'll still tell him if I'm not there.... but he don't know what they talking about.

The caregivers believed their involvement was critical due to the inability of the patient to understand and integrate the information received into their care at home.

Section V: Discussion

The purpose of this study was to explore patient factors as a component of the readmission phenomenon. Patients readmitted within 30-days after discharge from inpatient treatment for heart disease (HF or AMI) were interviewed and their voices were heard. This work builds on the limited qualitative research focusing on the perceptions of readmitted cardiac patients and their caregivers and is the first study to focus on a defined cardiac patient population readmitted within 30-days in a community setting. Six key themes emerged from the study data: worsening of their condition/need for symptom relief, unmet learning needs, a perceived failure of the healthcare team to address their health issue during the index admission, a lack of patient adherence, challenging treatment regimens, and a lack of caregiver inclusion in discharge education and treatment planning. The results provide a deeper understanding of patients' and

caregivers' lived experiences with readmission to the hospital and their capacity to care for themselves or their loved one at home.

Patients and caregivers conveyed that worsening of their health status with a need for symptom relief was a primary reason for readmission to the hospital setting. This finding was expected and is consistent with the findings of others (Annema et al., 2009; Patel et al., 2007). Qualitative research specific to the perceptions of post-AMI patients on this aspect of the readmission phenomenon was not found in the literature.

The anguish with which some patients and caregivers in this study described the symptoms leading to readmission was striking. The three post-MI patients in the study responded immediately to the acute onset of symptoms by calling 911. They perceived their symptoms (chest pain, syncope, bleeding) put them at great risk and sought professional help immediately. In the HF patients it appeared more gradual progression of their symptoms (fluid accumulation, weight gain, and shortness of breath) were not recognized and only when symptoms became more life-threatening (dyspnea at rest) were they seen as cues to taking action. Some patients and caregivers in the current study relayed that hospital readmissions were inevitable due to the severity of the patient's condition. These beliefs may be indicative of a knowledge deficit or a low self-efficacy in their perceived ability to manage the condition and prevent readmission. These findings build on previous qualitative studies investigating patients' knowledge and beliefs about HF and their self-care routines. Horowitz, Rein, & Leventhal (2004) found that HF participants operated on an acute vs. chronic model when it came to self-care. As a consequence, they did not routinely manage symptoms, which resulted in seemingly preventable exacerbations. HF symptom recognition and response was the topic of a

study by Jurgens et al. in 2009. These investigators found the majority (54%) of HF patients believed they had little to no control over their symptoms. Patel et al. (2007) found that 11% percent of patients actually postponed seeking medical attention because they felt their situation was hopeless which is consistent with some HF patients in the current study.

Surprisingly, participants in the current study did not identify seeking help earlier as a measure that could have prevented the readmission. Thirty four % of patients in the Patel et al. (2007) study reported they had wanted to seek care earlier, but simply had not. In the Annema et al. (2009) study, 13% of patients and 12% of caregivers felt seeking help earlier could have prevented the readmission. Patel et al. (2007) reported a barrier to seeking help earlier for some patients was lack of primary care access. Several patients in the current study had professional home health services involved. Primary care access was not a barrier as 90% of the patients had seen their physician within two weeks of their discharge. In fact some were sent to the hospital following a phone call or visit to the primary care physician office. This is consistent with previous findings where access to primary care is associated with a higher readmission rate in the general population (Kangovi et al., 2012). In combination, these previous works and the current study have important implications for assisting HF patients and their caregivers to prevent readmissions. Enhancing their skills in symptom monitoring and management, and using subtler changes from baseline as cues for specific interventions at home may improve their perceived self-efficacy in preventing a readmission to the hospital. This has been noted in previous studies of HF patients regarding self-care (Kyoung et al., 2014; Riegel et al., 2009).

Several patients and caregivers identified unmet learning needs when discussing the instructions they received and how prepared they felt in caring for themselves at home. Surprisingly, in the study by Annema et al. (2009) knowledge deficit was not a reason for readmission identified by patients or caregivers; however, it was perceived as a reason for readmission by the participating cardiologists and the HF nurses in a portion of the cases. Strunin, Stone, and Jack conducted a qualitative study in 2007 to understand the phenomenon of frequent rehospitalization from the patient's perspective in a generic population. A lack of understanding about their medical condition or care procedures to be followed was not evident in this urban population of primarily low income patients. In a 2012 study of all 30-day readmissions in a large urban setting, Kangovi et al. found a lack of preparedness at discharge as the reason cited by 11.8 % of the study participants.

The investigators recognized that some unmet learning needs described by patients were related to participants' inability to receive, recall, and understand the discharge information. Consideration of the risks of health literacy (Dennison et al., 2011; DHHS, Office of Disease Prevention and Health Promotion, 2007; Mitchell, Sadikova, Jack, & Paasche-Orlow, 2012) and cognitive deficits in cardiac patients (Gharacholou et al., 2011; Gure et al., 2012; Kim, Pressler & Groh, 2013; Riegel et al., 2013) is warranted in light of these incidental findings. Both are important patient factors in considering the readmission phenomenon as they can adversely impact a patient's capacity for self-care (Walsh et al., 2012).

Patients and caregivers in the current study identified the need for more detailed and tailored instructions to fully implement their treatment recommendations. Areas noted by patients included medications, diet, weight monitoring, and activity level. These

findings corroborate previous studies with the aim of understanding self-care behaviors in both the HF and AMI populations (Clark et al., 2014; Decker et al., 2007; Hanssen, Nordrehaug & Hanestad, 2005; Ho et al., 2007; Horowitz et al., 2004; Riegel & Carlson, 2002; Riegel et al., 2012; van der Wal et al., 2006). A qualitative study examining patients' information needs in acute MI patients revealed that healthcare providers consistently failed to meet both in-hospital and post-discharge information needs (Hanssen, Nordrehaug & Hanestad, 2005). Decker et al. (2007) found AMI patients post discharge wanted information specific to personal characteristics and situations. Their need for detail increased over time as they took a more active role in their self-care. Knowledge deficits were perceived as barriers to managing the patients' care in the current study. This further corroborates a 2014 systematic review by Clark et al., 2014 examining the determinants of HF self-care. Knowledge and skills represent modifying behavioral factors in the HBM that can assist patients in carrying out the prescribed treatment (Edberg, 2007).

Discharge education and instructions in the hospital setting tend to be broad and generic. Marked decline in hospital length of stays limit the time that can be devoted to education by the healthcare team. As noted in the position statement of the American College of Cardiology Fellows' Health Policy Statement on Patient-Centered Care in Cardiovascular Medicine, education is an ongoing process that can be built upon over time and must be individually and culturally appropriate (Walsh et al., 2012). While education can begin in the hospital it must continue beyond its walls where it can be more tailored to the patients' psychosocial, cultural and environmental context.

An unexpected finding was the perception of some patients and caregivers that the reason for the patient's subsequent readmission was the failure of medical providers to address the health issue during the index admission, a finding not previously cited in the literature. This needs to be interpreted with caution, however, since the perspective of the medical providers is not part of the dataset. This theme is significant since patients and caregivers did not feel listened to, perceived they left without answers, and then were readmitted. We know that valuable information for diagnosing and care planning can be missed if there is not good two-way communication between the healthcare team and the patient and family (McDonald, Bryce, & Graber, 2013). Two-way communication has been shown to improve clinical reasoning as well (McDonald et al., 2013). The patient safety literature is full of examples of serious consequences to patients when the healthcare team did not attend to the patient or family member concerns during a hospitalization. Some patients and caregivers in the current study left without a clear understanding of symptom management, a barrier to self-care. This is an important finding since as previously noted symptom management is the primary reason for patients with cardiovascular disease to seek care in the acute care setting (Annema et al., 2009; Patel et al., 2007).

Only 2 of 11 study patients linked a lack of adherence to prescribed interventions to their readmission. In the Annema et al. (2009) study, non-adherence to prescribed interventions (diet, medication and fluid restrictions) was identified by 25% of the HF patients and 26% of the caregivers as a reason for readmission. The current study adds more data regarding specific behavioral factors, which may be helpful in selecting more tailored interventions. One patient in the current study attributed his readmission to his

lack of adherence to his prescribed activity level. Annema et al. (2009) reported that 3% of patients and 7% of caregivers felt readmission was due to an “imbalance of activity and rest,” while activity compliance was not a factor in the study by Kangovi et al. (2012). The second patient in the current study that connected his readmission to his non-adherence experienced challenges with certain medications and his severe fluid restriction. Adherence to medications as a reason for readmission was reported by Kangovi et al. (2012) in 5.7% of patients; however, problems with adherence to fluid restrictions were not.

The HBM is helpful in understanding the non-adherence behavior in these two cases. In the case of the AMI patient it is important to note his previous AMI was three years earlier after which he had a percutaneous intervention (PCI). Altered perceptions of the seriousness of his disease may explain this patient's decision to engage in the physically demanding activity of cutting wood within a month after discharge. A 2009 qualitative study by Astin et al. found a mismatch in illness perceptions among patients receiving PCI. Participants often had difficulty understanding the severity of their condition, which sometimes resulted in unwise activity levels which is consistent with the actions of the patient in the current study. The patient experiencing difficulties with adherence to medication and fluid restriction expressed a sense of reduced susceptibility to the consequences of his day-to-day behaviors. He also described the barriers of annoying side effects and severe adverse effects of his prescribed medications and severe thirst as contributors to his non-adherence. He desired external cues to action to facilitate his health behaviors.

Surprisingly, no patients in this study had been prescribed fluid restrictions to control their heart failure symptoms. Fluid restrictions were expected to be a significant adherence issue for readmitted HF patients based on previous research as in the study by Annema et al. (2009). This finding may be explained by more recent heart failure guidelines such as the 2013 AHA/ACC guidelines, which recommend that fluid restriction be driven by the clinical picture (Yancy et al., 2013).

Five participants (both patients and caregivers) in the current study believed improved adherence to prescribed health behaviors (diet, medications, smoking cessation and exercise) could prevent the next readmission. In the 2009 Annema et al. study 33% of HF patients and 18% of caregivers felt that improved adherence with medications, diet and fluid restrictions would protect against readmissions. Strunin et al.(2007) found adherence to be a major issue with nearly 50% of the participants describing circumstances that prevented them from following medical advice they had been given. Self-reported adherence to prescribed medications in 8 of 11 patients in the current study is comparable to the finding of Kangovi et al. (2012) where overall medication compliance was 80.3%. Annema et al. (2009) did not report medication compliance separately. Barriers to medication adherence identified in the current study included cost, medication intolerance, worrisome or annoying side effects and a denial of perceived risk (susceptibility) in the day-to-day. These barriers are consistent with the qualitative findings of others in regard to medication adherence in cardiac patients (Decker et al., 2007; Garavalia et al., 2009; Happ, Naylor, & Roe-Prior, 1997; Kangovi et al., 2012).

The noted barriers to adherence to a heart healthy diet (Condon & McCarthy, 2006) or a salt restricted diet (van der Wal et al., 2006), exercise, and smoking cessation

were also consistent with previous findings in the literature (Hanssen, Nordrehaug & Hanestad, 2005). The HBM proposes that the benefits of the behavioral change must exceed the barriers in order for uptake of the changes to occur (Edberg, 2007). A focus on the patients' and caregivers' understanding of the benefits of these therapies and addressing their perceived barriers would be important in these cases.

As the results of the current study demonstrate, the complexity of a patient's treatment regimen is a perceived barrier by patients and caregivers to successful home management. Patients' and caregivers' expressions of confusion appear to represent a decline in self-efficacy as the complexity of the treatment plan grows. Sources of complexity described by patients included co-morbid conditions and a lack of coordination among physicians from different specialties. The results of the current study support the findings of Annema et al. (2009), where 38% of patients and 37% of caregivers reported other diseases as a reason for readmission. They also corroborate the findings of Patel et al. (2007) where 57% of patients put off seeking care because they had attributed their symptoms to something other than HF. Comorbid conditions as a risk factor in readmissions has been previously established (Braunstein et al., 2003; Dunlay et al., 2012; Patel et al., 2007; Tsuyuki et al., 2001). The current study provides insight into how the interactions between these disease states are perceived by patients and caregivers and the additional challenges it creates for self-management. The experience of patients trying to reconcile contradictory specialist recommendations documents the fragmentation of our healthcare system. Recognizing the burden navigating between specialists creates for patients and their caregivers is an area for further consideration in preventing readmissions.

The need for inclusion by the caregivers is an important finding to consider. Annema et al. (2009) found the perceptions of caregivers on the reason for readmission differed from patients in 60% of the cases, and perceptions of caregivers and patients taken together differed from the perspective of the healthcare providers 76% of the time. The researchers suggest that a full picture of the reasons for readmission from both the patient and caregiver is needed to ensure interventions prescribed by the healthcare team are relevant to the HF patient's situation. The results of this study build on this recommendation by demonstrating the caregivers' expressed need to be included in care planning and education. Researchers in both the 2012 Kangovi et al. and the 2007 Strunin et al. studies found that the lack of social support in lower socioeconomic populations is a significant contributor to readmission. The limited research on the presence of social support has shown to improve outcomes in cardiac patients including rehospitalization and mortality (Luttik, Jaarsma, Moser, Sanderma, & van Veldhuisen, 2005). In the current study capable caregivers were present, but not consistently included in transition planning. A recent review found that family caregivers have been largely ignored and engaging them deserves higher priority in most transitional care programs (Gibson, Kelly, & Kaplan, 2012). While patients' rights to autonomy, privacy, and confidentiality must be respected, ensuring their desired social support (i.e. caregivers) are informed and included in the decision making is important.

In summary, the HBM was a useful theoretical framework to guide this research. The findings provide important insights into the perspectives of HF and AMI patients and their caregivers on the readmission phenomenon. Understanding the patients' and caregivers' beliefs about the perceived threat of their illness on a day-to-day basis and

whether they view the condition as acute or chronic may interfere with effective self-care and lead to preventable readmissions. Patients and caregivers need more detailed and tailored instructions as part of transitional care in order to implement effective self-management strategies at home. The lack of inclusion of caregivers, uncoordinated care, complex treatment regimens, and ineffective communication were described as barriers to preventing readmissions. Recognition that every patient's situation is unique will assist the healthcare team in enhancing care transitions and preventing readmissions.

Nursing Practice Implications

The findings in this qualitative study have several implications for nursing practice. In general tools to assess the knowledge and beliefs of both patients and caregivers about the patient's condition including perceived threats of the illness and the barriers and benefits of treatment would be helpful in determining where intervention is needed. These tools already exist for HF and AMI patients (Katz et al., 2009; Sethares & Elliot, 2004; van der Wal et al., 2006) and could be used more broadly as individual patient assessment tools to tailor interventions. Equipping patient and caregivers with self-management strategies to respond to subtle changes is essential. Improved assessment of patients' cognitive functioning and health literacy levels of both patients and caregivers is necessary so that educational materials and methods are delivered at the appropriate level (Cloonan et al., 2013). In addition, continuing education and support for behavioral changes post discharge is warranted (Riegel et al., 2009). The perceptions by patients and caregivers that the healthcare team failed to take care of the patients' needs at the index admission indicate the need for further engagement of the patient and their caregivers. Nurse leaders must work to ensure transition planning in the hospital is

patient and family centered and their context for self-care is understood. Ensuring the complexities of a patients' treatment regimen is considered by all providers is imperative and as others have suggested interventions aimed at readmission may need to have a broader focus (Kangovi et al., 2012).

Nursing Research Implications

The findings of this study support the need for continuing research on effective interventions to impact the outcome of readmissions. Focus groups with families and caregivers would be a logical progression in this research. Further research on the impact of low health literacy and cognitive deficits on readmissions is warranted. Currently most interventions appear to be one size fits all. The results of the current study demonstrate opportunities still exist for more effective interventions related to fluid balance, symptom recognition and self-management. The use of simulation techniques with HF patients to enhance this learning would be an exciting area to pursue. As part of their performance improvement efforts many hospitals have already begun the process of focused interviews with patients readmitted within 30-days, however, a validated tool that incorporates constructs of behavioral theory has yet to emerge. Research on the use of a structured "exit" interviews that include patients, caregivers, and the healthcare team along the continuum of care using technologies such as web meetings and video conferencing would also be a natural progression of this work.

Limitations

There are important limitations to note. The study was limited to one community hospital so the findings may be unique to this setting. As in most qualitative studies convenience sampling was used. The disproportionate share of men and participants with

some form of health insurance and good access to primary care may have affected the results. Barriers to adherence were thoroughly explored in this study, but benefits of adherence to therapies were not systematically pursued which may have provided richer data on this topic. The small numbers of caregivers recruited is another limitation of the study. A significant decline in the readmission rate occurred between the time this study was conceived and participants were recruited. The population studied may represent those readmissions which are more challenging to prevent.

Conclusion

Reduction of readmissions in acute care hospitals is an imperative for US hospitals and is an important outcome for patients, their families, and the healthcare system. The HBM was used as a theoretical guide to explore the perspectives of AMI and HF patients' and caregivers' on the phenomenon of readmissions. Consideration of patient factors beyond sociodemographics is relevant to engaging patients and caregivers in shaping effective transition plans. Interventions to prevent readmissions in HF and AMI patients should consider the patient factors of comorbid conditions, health knowledge, self-efficacy, and beliefs regarding barriers in carrying out the prescribed treatment plan. Clinicians need to understand each patient's context for self-care and tailor interventions accordingly to reduce their risk of readmission. Nurses across the continuum of care are in a unique position to "hear their voices."

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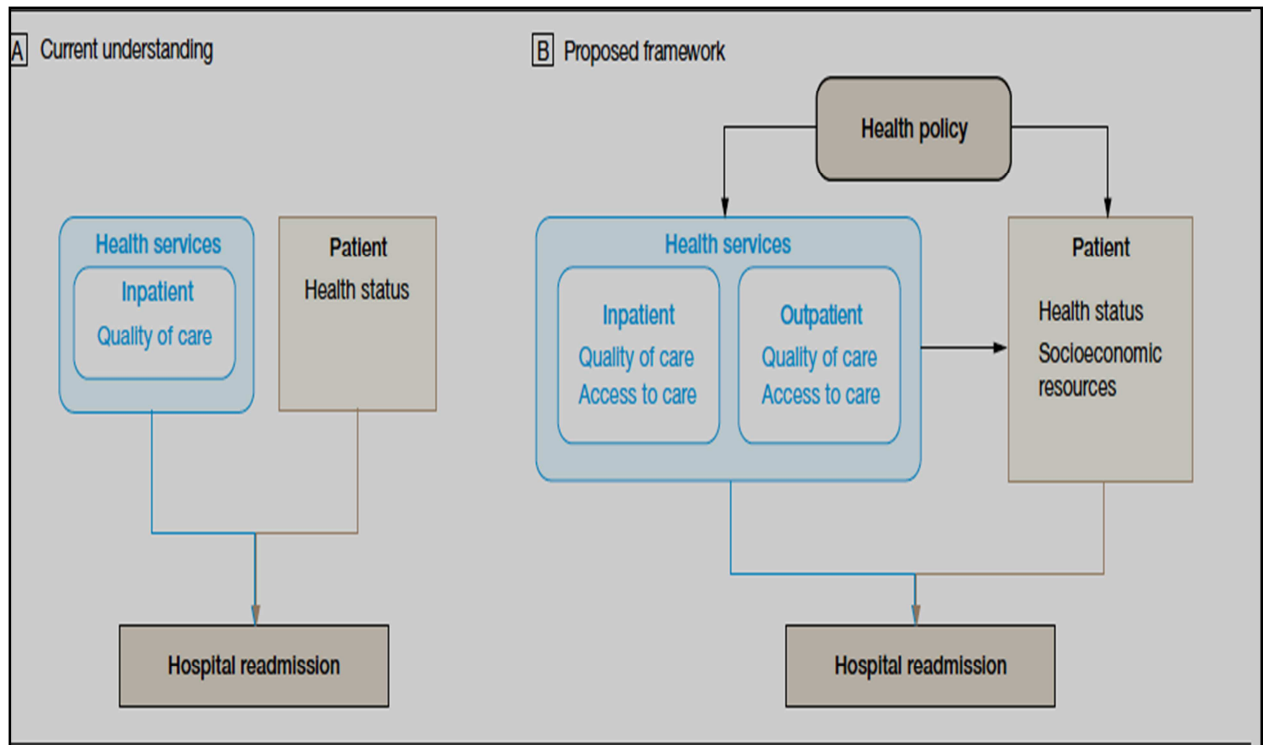
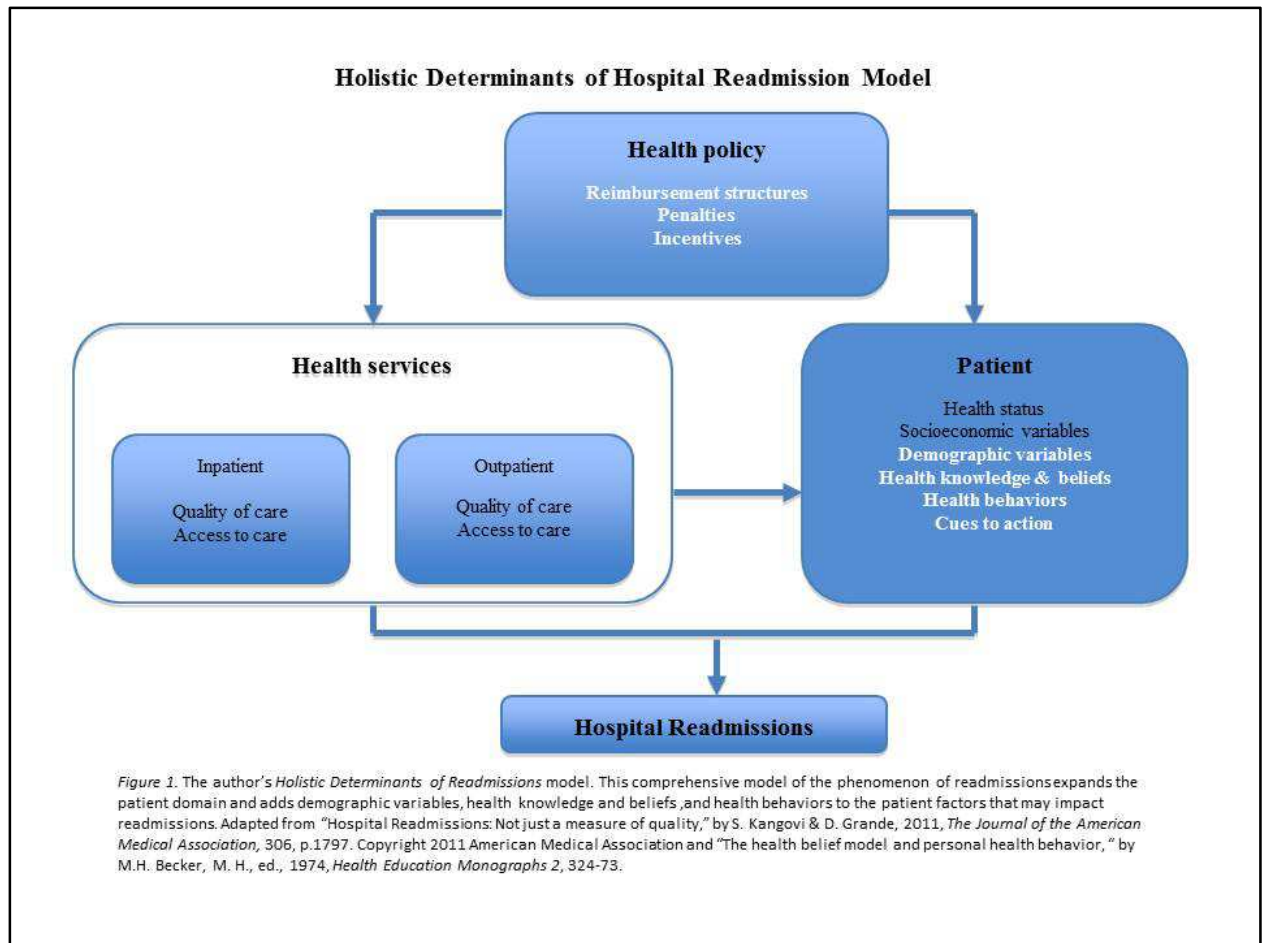


Figure A2. Kangovi's (2011) *Determinants of Hospital Readmission* model. Kangovi's expansion of Ashton & Wray's (1996) conceptual framework. Kangovi included health policy as a major component and added access to care as a health services factor and illustrated socioeconomic resources as a patient factor contributing to readmissions.

Reprinted from "Hospital Readmissions: Not just a measure of quality," by S. Kangovi & D. Grande, 2011, *The Journal of the American Medical Association*, 306, p.1797.

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*Figure A3. The author's Holistic Determinants of Readmissions model. This comprehensive model of the phenomenon of readmissions expands the patient domain and adds demographic variables, health beliefs and health behaviors to the patient factors that may impact readmissions. Adapted from "Hospital Readmissions: Not just a measure of quality," by S. Kangovi & D. Grande, 2011, *The Journal of the American Medical Association*, 306, p.1797. Copyright 2011 American Medical Association and "The health belief model and personal health behavior," by M.H. Becker, M. H., ed., 1974, *Health Education Monographs* 2, 324-73.*

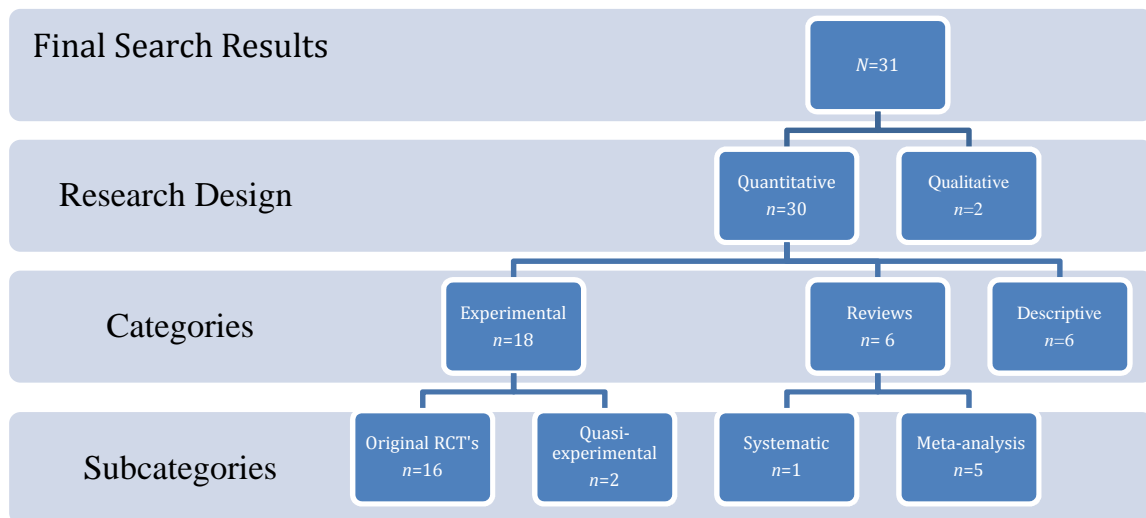


Figure A4. Research design categorization of articles meeting inclusion criteria.

Appendix B**A. Studies on health policy**

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Soran, 2010	Secondary Analysis of multicenter “Heart Failure Home Care (HFHC)” trial	To assess the impact of a home based disease management program that included a HF monitoring system on the clinical and economic outcomes of Medicare beneficiaries representing the elderly, women, and non-Caucasian males	HF patients ($N = 315$) discharged from the University of Pittsburgh Medical Center in Pennsylvania, Case Western University Hospital in Ohio, and Mount Sinai Medical Center in Florida. Mean age = 76, 65% female. Non-Hispanic white males were not enrolled.	The 6-month mean Medicare costs were estimated to be \$17,837 and \$13,886 for the intervention and usual care groups, respectively. Overall medical costs were significantly higher for those receiving the intervention than those receiving usual care. The model accounted for an estimated 9% of the variation in costs.

B. Studies related to patient factors

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Annema, 2009	A descriptive sub study of a multicenter RCT on the effects of education on HF outcomes	To gain insight into reasons for HF readmission from the perspective of patients, caregivers, cardiologists, and HF nurses; to examine similarities and differences in perspectives on the reason for an HF readmission; and to describe possibilities to prevent an HF readmission from different perspectives.	1023 patients from 17 Dutch hospitals were included in the original study. Information on the reasons for readmission in the opinion of patients, caregivers, cardiologists, and HF nurses was gathered on (46%) of the readmissions ($N = 173$).	The agreement on the possible prevention of the readmission was 72% between patients and their caregivers and 78% between health care providers. Patients described improvement of adherence (33%), in particular to fluid restrictions, as the most important intervention to prevent readmission.

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Hodges 2009	A descriptive, mixed qualitative and quantitative correlation study	To explore individual perceptions of <i>life purpose (LP)</i> <i>health related quality of life (HRQOL)</i> , and hospital readmissions among older adults with HF in order to provide a foundation for the development of safe and effective holistic intervention strategies to decrease readmissions.	41 male and female participants aged 60 years and old from San Antonio, Texas, recruited from cardiology offices and HF clinics.	There was a positive significant and moderate relationship between LP and HRQOL and a positive, significant, and moderate relationship between HRQOL and hospital readmissions. Psychosocial well-being, physiologic well-being, hope/optimism, and spirituality were the 4 most frequently mentioned themes identified during the patient interviews.
Roe-Prior 2007	Descriptive secondary analysis correlating sociodemographics with healthcare utilization	The purpose of this study was to perform a secondary analysis of data collected in an earlier study (Roe-Prior, 2004) to determine if sociodemographic factors, such as age, gender, race, living situation, marital status, education, and income were related to post-discharge service utilization in the elderly hospitalized with an acute exacerbation of HF.	Elders hospitalized with HF in two Philadelphia (urban) hospitals and a similar group of admitted to two Scranton, Pennsylvania ($N = 103$).	Sociodemographic factors are less important than severity of illness factors in predicting post-discharge service use, but do have a positive predictive value. All -cause readmission was predicted by being single and low-income approached significance. None of the factors were predictive of HF related readmissions. Community “dwellers” were more likely to use the emergency room for acute care than urban patients, and patients who used the ED for acute care tended to be less educated. Black/Asian race was correlated significantly to the use of unscheduled physician visits.

C. Studies related to health services: Experimental studies

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Angermann, 2012	RCT, multicenter trial	To determine if <i>HeartNet Care</i> would have a more a favorable impact on time to death or readmission than usual care. <i>HeartNet Care</i> was a coordinated nurse-led intervention that included an in-hospital HF nurse specialist to teach self-monitoring, structured post-discharge telephone support by trained nurses, medication titration in collaboration with the PCP, and needs adjusted specialist care. Contacts were weekly the first month and then tailored to NYHA class and individual needs thereafter. Usual care was standard discharge planning, treatment plans, discharge letters, and follow-up with PCP's or cardiologists within 7–14 days.	Patients were recruited at 9 hospitals in Bavaria and Baden-Württemberg discharged from the hospital following acute decompensated HF ($N = 363$). NYHA class II – IV, 40% III-IV; Mean age = 68.6; 29% female. Patients were followed for 6 months.	The combined primary endpoint of mortality and readmissions was neutral. HNC patients improved NYHA class ($P=0.05$), physical functioning ($P=0.03$), and physical health component ($P=0.03$). There was a 38% reduction in all- cause mortality in the intervention group, but no significant difference with primary outcomes of readmission. Quantitative assessment of patient requirements suggested that besides telemonitoring individualized care considering noncardiac problems should be integrated in efforts to achieve more sustainable improvement in HF outcomes.
Antonicelli 2008; 2010	Single site RCT	To explore whether, the addition of home telemonitoring to a team based, integrated HF care system reduces mortality and re-admission rates in elderly HF patients. The secondary aims of the study were to assess the impact of telemonitoring on patients' compliance with prescribed therapies, quality of life and the costs of the intervention as compared to usual care.	HF patients admitted to the Italian National Research Center on Aging Hospital ($N = 57$). Mean age of 78.2; 58% men; NYHA class II ($n = 33$), class III ($n = 21$) and class IV ($n = 3$). 12 month follow-up.	Home-based telemonitoring-with integrated management resulted in a significant reduction in the combined rate of HF mortality and hospital readmission. The intervention group had significantly better health perception scores as compared to patients in the control group. Positive results need to be confirmed by studies including a larger sample and a longer follow-up period.

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Aquado, 2010	Single study RCT	To evaluate the effectiveness of a single nurse performed, 2 hour, home-based, educational intervention for patients admitted with HF.	A 400-bed urban teaching hospital in Barcleona, Spain ($N = 106$). Mean age = 77; NYHA class II – IV; left ventricular ejection fraction < 45%. Patients were followed for 24 months.	The intervention group had significantly less emergency room visits ($p = .000$), fewer unplanned readmissions ($p = .000$), and lower costs ($p = .001$). This was a single study with a homogenous and well-educated population, so generalizability is limited.
Copeland , 2010	Single-site RCT	To assess the effect of a telephone interventions focusing on education and behavior management to improve quality of life among patients with HF.	A Veterans Health Administration hospital. Patients with HF ($N = 453$); mean age of 70; 22% Hispanic; 7% African American; all but 5 patients were male. Patients were followed for 1 year.	No significant differences on the primary clinical outcomes of readmissions, 30-day all cause readmissions, HF readmissions were found. The intervention group had better compliance scores on 2 out of 4 self-care recommendations. Costs were significantly higher in the intervention group. Nursing case management models can add cost and increase utilization.
Chaudhry, 2010	Multisite RCT	To determine whether an interactive, voice-response, non-physiologic telemonitoring would reduce the combined end point of all cause readmissions or deaths among patients recently hospitalized for HF versus usual care.	33 cardiology practices across the United States ($N = 1653$). Mean age = 61 years; 42% female; 39% African-American; 94.2% NYHA class II-IV. Patients were followed for 6 months	No significant differences were found between the two groups for either the primary endpoints of all cause readmissions or deaths or the secondary endpoints of HF hospitalizations, numbers of days hospitalized and number of hospitalizations. The intervention was ineffective.

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Del Sindaco 2007	RCT	To determine the long-term efficacy of a hybrid home-based, and hospital clinic-based interdisciplinary HF disease management program involving cardiologists, primary care physicians and nurses, combining pre and post-discharge care including nurse telephone follow-up and primary care visits.	HF patient seen at 2 HF clinics in Rome, Italy ($N = 173$). Mean age, 77; 48% women; 61.8% NYHA class III - IV; 75 % with ejection fractions of $< 40\%$. Patients were followed for 2 years.	At the 2-year follow-up, the intervention group had a 36% reduced risk of death or readmission for HF and a number needed to treat of 3.8. The program was associated with a 42% relative risk reduction of an unplanned hospital admission due to HF. All-cause mortality and cardiovascular mortality did not have significant reductions when examined independently. The intervention group reported significant improvements in functional status, quality of life and b-blocker prescription rate. The hybrid disease management program was effective in improving outcomes.
Giordano 2009	Multicenter RCT	To determine whether a home-based telemanagement and teleassistance (HBT) programme in HF patients decreased hospital readmissions and hospital costs in comparison with the usual care (UC).	Patients hospitalized with diagnosis of HF at 5 cardiac rehab centers in Italy discharged on optimal drug therapy. ($N = 460$). Mean age 57; 16% female in HBT and 14 % in UC group. NYHA class III - IV 56% in HBT group and 35% in UC group. Follow-up was 1 year.	A significant positive difference was found in the HBT group for all cause hospital readmissions ($p = 0.03$), with the number needed to treat being 4 to prevent one readmissions, and for HF readmissions ($p = 0.0001$). HBT patients experienced a 31% decline ($p < 0.001$) in hemodynamic instability, and significantly lower costs. Home telemanagement in HF patients has the potential to improve access, outcomes and reduce costs. A larger study is needed to validate the results.

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Jaarsma 2008	2- armed multisite RCT called the Coordinating Study Evaluating Outcomes of Advising and Counseling in Heart Failure (COACH)	To examine the effects of two arms of a nurse-led disease management program in a sufficiently large population with an assumed relatively high event rate. Intervention A included a visit by the HF nurse in hospital, additional visits at the HF clinic where patients were educated by protocol with behavioral strategies to improve adherence. Intervention B added more intensive contacts and support with weekly contact with the nurse in the first month and then monthly. Additional contacts were made such as home visits from other ancillary disciplines.	Patients hospitalized for HF at 17 hospital sites in all four regions of Netherland ($N = 1023$). Mean age = 71 years; 62% male; 50% of patients had mild HF and 50% had moderate to severe HF. Patients were followed for 18 months.	No difference was found for the primary composite end point of death and hospitalization between both the moderate or intensive intervention group and the group receiving usual care. There was no significant difference in the median number of days lost to death or hospitalization between groups. There was also no difference between groups with respect to the proportion of patients who had multiple HF readmissions. These results do not support the concept that adding nurse- led management program to standard care of a cardiologist reduces the combined end point of death or rehospitalization because of HF.
Kommuri 2012	Single site RCT	To examine the effect of a 1 hour nurse-led discharge education session on performance on HF knowledge assessments (HFKQ) and clinical events of death or rehospitalization.	Patients hospitalized with HF at the University of Michigan ($N = 265$). Mean age 67; 39% female; 78% Caucasian. Patients were followed for 6 months.	Patients randomized to the nurse education intervention ($n = 113$) demonstrated significantly higher total HFKQ score increases compared to patients receiving the standard discharge process ($p = 0.007$). Patients experiencing death or rehospitalization in the subsequent 6 months were found to have significantly lower HFKQ scores ($p = 0.002$) compared to patients without a clinical event.

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Krantz 2008	Single –site RCT	To determine whether patients receiving carvedilol 3.125 mg twice daily starting before hospital discharge coupled with nurse surveillance and counseling after hospitalization had better clinical outcomes as compared to usual care.	Patients hospitalized at a Denver hospital with a primary diagnosis of acute decompensated HF ($N = 174$). Patients were 80% uninsured, 72% minorities, and 80% unemployed or disabled. Patients were followed for 6 months.	The intervention group improved significantly in NYHA class, had significantly higher b-blocker utilization and an 84% reductions in the total number of HF readmissions compared with usual care ($p=.02$).
Kurtz 2011	Quasi-experimental	To assess the effect on cardiovascular death or re-hospitalization for HF of three different clinical management strategies: standard HFcare, management in a HF clinic and in-home monitoring through telephonic automated prompts (Telecard) and escalation protocols.	Patients recently discharged from hospital or diagnosed with acute or worsening HF up to three months before at Rouen University Hospital in France ($N = 138$). 78% male with a mean age of 68. 12 month follow-up.	A significant reduction in the combined primary endpoint in the telemonitoring group compared to standard care, but no difference between the HF clinic and telemonitoring groups. The risk reduction for the primary endpoint (CV death and hospitalization for HF) was 28% and 32% in the Telecard and HF clinic groups respectively. Outcomes in isolation showed only a difference in hospitalization rate, not cardiac mortality.

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Kwok, 2008	Single-site RCT	To evaluate the effectiveness of a community nurse-supported hospital discharge program in preventing hospital readmissions, improving functional status and handicap of older patients with chronic HF, and reducing costs of care.	Patients hospitalized with HF over 60 years age in a major teaching hospital in Hong Kong ($N = 105$). 45 % male. 6 month follow-up.	No significant difference in readmission rates, but the number of readmissions tended to be lower in the intervention group. There was no significant difference in costs of care, functional status or mortality rates.
Mendoza 2009	Single –site RCT	To assess the effectiveness of a <i>Hospital at Home</i> model (H@H), a multidisciplinary team home care intervention, compared with in-hospital care on the combined outcome of mortality, HF re-admission, or other cardiovascular event (such as stroke, acute coronary syndrome, and need for coronary revascularization), and the evolution of functional status and quality of life. A secondary aim was to compare the health expenditures between groups.	Patients > 65 years identified in the emergency department with acute HF at an academic hospital in Spain ($N = 80$). NYHA class II – III; Mean age = 80. Patients were followed for 12 months.	There were no significant differences in mortality, cardiovascular events or readmissions due to HF, functional status, or HRQOL. Costs in the H@H were significantly less than the usual care group ($P < 0.001$). The Hospital at Home model was equally effective as usual care, but delivered at less cost.

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Soran 2008	RCT, multicenter trial	To assess the impact of a computer-driven telephonic home-based disease management program on the clinical and economic outcomes of Medicare beneficiaries.	Elderly woman and non-Caucasian male Medicare beneficiaries with HF admitted to hospitals in Pittsburgh, Miami, and Chicago ($N = 315$). NYHA class II-III. Mean age = 76 years; women, 65%. Non-Hispanic white men were not enrolled. Patients were followed for 6 months.	No difference between intervention and control group on clinical outcomes of readmissions, cardiac mortality and hospital length of stay for HF. The investigator speculated that there was no difference because the control group received the same enhanced education and a scale as did the intervention group.
Shelley, 2010	Quasi - experimental with a pre- post test	To evaluate the effectiveness of home visits combined with telephone follow-ups and to determine how rates of compliance vary as a function of the number of home nursing visits a participant received.	Patients discharged with HF from a Boston Magnet hospital ($N = 32$). 69% females; Mean age = 77 years. Patients were followed for 12 months.	Readmission rate for the HF participants involved in the outpatient HF program was reduced from 14% to 0.01%. Significance of these results was not presented. This study had significant design challenges.

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Tibaldi, 2009	A single-site RCT	To evaluate the feasibility and effectiveness of a physician-led hospital-at home service for selected elderly patients with acute decompensation of HF.	Patients 75 years or older admitted for HF decompensation at an Italian academic hospital ($N = 101$). NYHA III-IV only; 35 % NYHA class IV; Mean age = 81; 52% men. Patients were followed for 6 months.	No significant differences in the length of stay in the ED, 6 month mortality, and number of hospital admissions. The mean time to first admission was longer for the intervention group ($p = 0.02$), and this group also experienced significant improvements in depression, nutritional status, and quality-of-life scores. Costs of the hospital at home service were significantly less than usual care ($p < .001$).
Wakefield 2008; 2009	2- armed RCT	To evaluate the efficacy of two telehealth-facilitated post-discharge support programs (one telephone and one videophone) in reducing resource use in patients with HF vs. usual care.	107-bed VA tertiary care referral center. Patients hospitalized for HF exacerbation ($N = 148$). NYHA II 28%; III-65%; IV-7%; Mean age = 69; 94% Caucasian, 99% male. 12 month follow-up.	No difference was demonstrated across the three groups for HF readmissions, mortality or time to first readmission. No difference was detected in the HRQOL score, self-efficacy, perception of care or medication knowledge. There was a significantly lower all-cause readmission rate of combined intervention subjects ($p = .04$) and time to first admission ($p = .02$).

Lead Author	Design	Purpose	Sample and Setting	Findings and Recommendations
Woodend, 2008	Single-site RCT	To determine whether telehome monitoring of patients with cardiac disease at high risk of readmission would reduce hospital readmissions, improve functional status, and improve quality of life over usual care	Patients with HF or angina at University of Ottawa Heart Institute, a 1200 bed teaching facility ($N = 249$). NYHA \geq class II; Mean age = 66; 75% male. 12 month follow-up.	At one year a significant reduction in the number of readmissions for angina patients in the intervention group, but not HF patients. No reduction in angina or HF patient's number of days spent in the hospital. No significant differences between groups in the number of emergency department cardiology, primary care or home care visits at any interval. The combined intervention group had significantly higher HRQOL and care satisfaction scores over time, and better exertional capacity.

D. Studies related to health services: Descriptive studies

Lead Author	Design	Purpose	Setting and Sample	Findings and Recommendations
Oliva, 2010	Descriptive, exploratory sub-study of a multicenter 5-year RCT.	Patients in the treatment arm of the study ($N=1551$). Comorbidity mean = 4.5 conditions; mean age = 75 years. No NYHA class. Two-thirds live in rural zip codes.	To determine if RN case manager activity type, timing, and time in minutes/hours is associated with readmission frequency in older adult patients with a primary diagnosis of HF. A Medicare Coordinated Care Demonstration (MCCD) site in Illinois.	Patients experiencing 2 or more inpatient admissions received slightly less case management time ($p < .05$) than patients with either 1 or no admissions during the study period. The most frequent activities the nurse case managers engaged in were in the following standardized categories: Assessment, Identify Needs, Explain Disease/Self-Care, Monitor and Explain Medications.

E. Studies related to health services: Systematic reviews and meta-analysis

Lead Author	PICO question	Eligibility Criteria	Summary measures	Summary of evidence	Limitations
Brown, 2011 Sample $N = 68,556$ Mean age = 61.9 years. 82% Caucasian 58% male Studies: 13 since 1990	1. To assess the effects of patient education on mortality, morbidity, HRQOL, and costs in patients with CHD 2. To explore predictors of the effects of patient education with respect to index cardiac event.	Inclusions: RCTs; primary intervention was education; minimum of 6-month follow-up; published in 1990 or later; adults with CHD. Exclusions: HF, heart valve surgery, heart transplant, device implants; studies with exercise or psychiatric interventions	<ul style="list-style-type: none"> total mortality cardiovascular mortality non-cardiovascular mortality total cardiovascular (CV) events fatal and/or non-fatal myocardial infarction other CV events 	No strong evidence of an effect of education on all-cause mortality, cardiac morbidity, revascularization or hospitalization. No consistent difference in HRQOL, however, a number of studies demonstrated statistically significant differences in HRQOL domains in favor of intervention. Five studies looked at costs and none found to be cost-effective. Conclusion: Summative effects of education on mortality (25% RR) and morbidity (17-42% RR) are clinically important.	The event rate was low; and therefore, the meta-analysis lacked sufficient statistical power to make definitive conclusions on the impact of educational interventions. Bias was introduced as groups often received additional interventions.

Lead Author	PICO question	Eligibility Criteria	Summary measures	Summary of evidence	Limitations
<p>Inglis, 2010</p> <p>Sample Telephone support N = 5613 Tele-monitoring N = 2710 Adults > 18 with HF Mean age: 44.5 to 78 years. 64% males</p> <p>Studies: 25 since 2006</p>	<p>1. To update the systematic review and meta-analysis previously completed in 2007.</p> <p>2. To assess the effects of telemonitoring and/or structured telephone support program.</p>	<p>Inclusions: RCTs Primary interventions: structured telephone support or telemonitoring.</p> <p>Exclusions: intervention or usual care could not include a home visit or more than the usual (four to six weeks) clinic follow-up.</p>	<ul style="list-style-type: none"> all-cause mortality. all-cause and HF-related hospitalizations other outcomes included length of stay; quality of life, acceptability of the intervention to the patient; and cost. 	<p>Structured telephone support and telemonitoring programs for patients with HF reduced the risk of all-cause mortality by 12% and reduced the risk of HF hospitalization by more than one fifth and may reduce all-cause hospitalizations from 8% to 9%. Confirms the efficacy of structured telephone support or telemonitoring as a component of multidisciplinary HF management. Structured telephone support and telemonitoring reduced healthcare costs, were accepted by patients, improved prescribing of evidence-based pharmacotherapies, improved patient HF knowledge, self-care behaviors, and NYHA functional class.</p>	<p>Unable to stratify the effect of the interventions by age, sex, functional class.</p>

Lead Author	PICO question	Eligibility Criteria	Summary measures	Summary of evidence	Limitations
Raman, 2008 Sample: <i>N</i> = 4,795 Studies: 49 since 1990	1. What is the effectiveness of interventions to support post-discharge care to the outcome of readmissions in HF patients 2. What is the relationship of various parameters to the outcome – such as length of follow up; concurrent discharge planning; place, components and frequency of interventions; patient characteristics	Inclusions: English language RCT's, studies published 1990 –July 2007 Exclusions: patients not discharged to home, studies with less than 10 patients per arm of the study	<ul style="list-style-type: none"> • all cause mortality • length of stay • costs • quality of life • combined endpoint consisting of mortality and hospitalization. 	Interventions that utilized increased clinic visits, home visits, and multidisciplinary care reduced the risk of readmissions. Studies with intermediate to long-term follow-up, interventions initiated in the inpatient setting, and patient ages greater than 75 years were associated with significant reduction of all cause readmissions in the intervention group. Telephone only support did not reach significance. There was no distinct combination of program components associated with improved clinical outcomes. Evidence was sparse for interventions beginning in the outpatient clinics.	Studies had several different combinations of intervention components, resulting in considerable heterogeneity. Difficult to ascertain the effects of individual components.

Lead author	PICO question	Eligibility Criteria	Summary measures	Summary of evidence/ Conclusions	Limitations
Sochalski, 2009 Sample: <i>N</i> = 2038 Studies: 10 from 1990-2004	Do the delivery methods used in care management programs for HF contribute to differences in hospital readmissions?	Inclusions: RCT's on diseases management programs for HF conducted by the authors from 1990 - 2004	<ul style="list-style-type: none"> • hospital readmissions • readmission days per month for each person 	Program patients had 25 percent fewer all-cause readmissions and 30 percent fewer all cause readmission days (significant reductions). Multidisciplinary team approaches resulted in significantly fewer hospital readmissions and readmission days- 2.9 percent and a 6.4 percent reduction respectively. In-person communication led to significant reductions in both hospital readmissions and readmissions days per month 2.5 percent and 5.7 percent, respectively. No difference with only telephone contact. A single HF expert telephone communication did not produce significant results.	Data limitations prevented assessing the cost implications associated with the programs. Only used HF programs so not generalizable. All models of care may not have been represented. AHA Taxonomy may not have captured all of the heterogenic factors that exist among models. Limited to (RCT's).. may be biased due to inclusion of author studies only

Lead author	PICO question	Eligibility Criteria	Summary measures	Summary of evidence/ Conclusions	Limitations
<p>Stolic, 2010</p> <p>Sample: <i>N</i> = 8330</p> <p>Studies: 24 from 1980–2009</p>	To perform a review of the research literature addressing the effectiveness of nurse-led telephone interventions for people with coronary heart disease	<p>Inclusions: studies with telephone interventions related to people with cardiac disease in the post discharge period; nurse delivered; published between 1980–2009 and hypothesis tested.</p> <p>Exclusions: not in English; not cardiac recovery monitoring interventions.</p>	<p>Varied across studies but included:</p> <ul style="list-style-type: none"> • risk factors • knowledge • functional status • psychological status • self - management and efficacy • complications • hospital consumption • patient satisfaction 	The results suggest that people with cardiac disease showed some benefits from nurse-led/delivered telephone interventions. This review has established that there is not sufficient evidence of the benefits. More quality research into this area is needed.	Limitations inherent in the design of some of the included studies do not permit an assessment that nurse-led telephone follow-up calls are beneficial. The author was not always clear in distinguishing “positive” results from “significant.” The 9 studies in this review that did not detect positive findings had similarities including reduced study rigor and sub optimal design, non-expert nurses providing the intervention and fewer numbers of calls.

Lead author	PICO question	Eligibility Criteria	Summary measures	Summary of evidence/ Conclusions	Limitations
Takeda, 2012 Sample: <i>N</i> = 5942 Studies: 25 from 1980–2009	Primary: To compare the effects of different clinical service interventions (not primarily educational) versus 'usual care' on death and/or hospital readmissions in patients who have previously been admitted with a diagnosis of HF. Secondary: To compare the effects on hospital bed days and HRQOL	Inclusions: RCTs with at least six months follow up; adults >18 with at least one HF hospital admission; case management, HF clinic or multidisciplinary models that were inpatient, outpatient or community based. Exclusions: patients with cardiac disorders other than HF; educational, solely exercise, and cardiac rehab interventions; generic interventions to reduce readmissions not solely aimed at HF patients and those that were solely telemonitoring and/or telephone interventions.	<ul style="list-style-type: none"> • total deaths • HF deaths • all cardiac deaths • non cardiac deaths • all-cause mortality • all cause readmissions • readmissions due to HF • all cardiac cause readmissions • non cardiac readmissions • unplanned readmissions • elective readmissions • total LOS • length of time between index discharge and readmission • event free survival • HRQOL 	For HF patients previously admitted to hospital for HF there is now good evidence that case management interventions led by a HF specialist nurse significantly reduces HF related readmissions after 12 months follow up, all cause readmissions and although not significantly, all-cause mortality. The optimal components of these case management type interventions are not clear from the evidence but telephone follow up by the nurse specialist was a common component. Multidisciplinary interventions may be effective in reducing both HF and all cause readmissions. There is currently limited evidence to support interventions whose major component is follow up in a HF clinic.	The generalizability of the findings of the studies has slightly improved since the earlier version of this review but only half of the studies reported the proportion of eligible patients who were actually randomized.

CHD- Coronary heart disease; CV –Cardiovascular; ED – Emergency department; HF - Heart failure; HRQOL - Health related quality of life; LOS- Length of stay; MD - Medical doctor, NYHA- New York Heart Association; RCT - Randomized control trial; RN - Registered nurse; RR- Risk reduction; VA- Veterans Administration

Appendix C

Patient Interview Guide version 4

Script

Mr/Ms. _____ Thank you for speaking with me concerning your experience with coming back to the hospital. I really want this to be a conversation about your experience. There are no right or wrong answers to the questions I am about to ask. I am not looking for a certain answer. Instead, I am trying to learn about the details of your experience to gain a better understanding of your particular situation. Please answer the questions in your own words and in as detailed a manner as possible.

Please be reminded that all of your responses will be audio-recorded so I can really listen during the interview and have an accurate record of your answers to which I can refer back to later. The audio recording will be held in the strictest confidence and handled in a secure manner. No information will be revealed without your expressed permission. I also want to remind you that your participation is completely voluntary and you may withdraw from the study at any time including before we start or during the interview. You can also refuse to answer any question that I pose and we will move on to the next question. I also want to remind you that your participation or lack of participation will not affect your care at the hospital now or in the future.

Also please let me know if you need a break or need to stop. Do you have any further questions? Are you ready to begin?

Questions

These are the type of questions that will be asked the patient. Additional or different questions may be asked depending on where the interview leads.

General

1. What do you think brought you back to the hospital this time?
 - a. Tell me what happened in the last couple of days
 - b. What might have prevented you from coming to the hospital again?
2. If you could have done anything differently at home related to taking care of yourself what would that be?
3. What can you remember about your last visit to the hospital?
 - a. What was the experience like for you?
 - b. If you could change anything about your experience in the hospital last time related to your readiness to go home what would that be?
4. How can the hospital be more helpful in your care?
 - a. Tell me more about that

Health

5. What is most important to you at this point in your life regarding your health?
 - a. Can you tell me more about that?
6. What goals do you have for yourself this year, i.e. what would make you the happiest if you were to look back this time next year and thought I am glad I did that?
 - a. Is there anything that would prevent you from doing that?
7. What do you think might keep you healthier?

- a. Is there anything that prevents you from doing that?

Illness/Illnesses

- 8. What can you tell me about your present illness/illnesses?
- 9. What this experience similar or different to what brought you to the hospital last time?
 - a. Can you tell me more about that?
- 10. How did you know you needed to come back to the hospital?
 - a. What was that like for you?
- 11. What is it like to live with your illness/illnesses day-to-day?
 - a. How does it affect you (emotionally, physically)?
- 12. What do you think caused your illness?
- 13. What do you worry about regarding your illness?
- 14. How serious do you feel your illness is?

Care

- 15. What do you do each day to care of your illness?
 - a. What is that like for you?
- 16. How well do you feel you are able to care for yourself?
 - a. What concerns do you have in taking care of yourself at home?
 - b. How do you feel you care at home has been going?

Discharge Instructions

- 17. How prepared did you feel to take care of yourself after discharge?
 - a. How were you involved in the planning for your discharge?
- 18. What instructions were you given about your care at home?

- a. How helpful were the instructions you received?
19. Were you able to follow the instructions?
- a. How do you feel you do with following the instructions?
 - b. Which ones, if any, do you find any of the instructions hard to follow?
20. What questions do you still have about your care?

Medications

21. Tell me about your medications.
- a. What are they for?
22. Which new prescriptions were prescribed at the last hospitalization?
- a. Were there any prescriptions you did not get filled?
 - i. If yes, why not?
23. Do you ever have any trouble taking your medications as instructed?
- a. Do any of your medications cause problems for you?
 - i. If so what are the problems?
 - ii. How have you managed that?
24. Are there any medications you have stopped taking or decided not to take anymore?
- a. Tell me more about that.
 - i. Does the patient have any trouble refilling the medications?
25. Are there any medications you are taking differently than first instructed since discharge?
- a. Tell me more about that.
26. How do you keep up with taking your medications?

- a. Do you ever miss a dose?
 - b. What do you do when that happens?
27. What is it like for you to take these medications?
28. What questions do you still have about your medications?

Diet

29. What instructions were you given about your diet?
- a. Are you able to follow your instructions?
 - b. How does it fit with your lifestyle?
 - c. Do you have any concerns or difficulties with your diet?
30. What instructions were you given about the amount of liquids you should have?
- a. How well are you able to follow these instructions?
 - b. Any concerns or difficulties?
31. What instructions were you given about weighing yourself?
- a. How often do you weigh yourself?
 - b. Do you experience any difficulties with weighing yourself?
 - c. Do you have a scale?
 - i. Can you see the scale?
 - d. What do you do with your weight information?
32. What might have been more helpful to you regarding your diet instructions?
- a. What are they?

Exercise

33. What level of activity were you told you could have?
- a. How are you doing with that?

- 34. What is it like for you to get around?
- 35. What instructions were you given about regular exercise?
 - a. What is like for you to exercise?
 - b. What might keep you from exercising?
- 36. What might be helpful in supporting your exercise/activity level?

Other instructions

- 37. What other instructions were you given?
 - a. Any other restrictions (smoking, activity, etc.)?
- 38. What is that like for you?
 - a. Are you having any difficulties with these instructions?
- 39. What might be helpful to you in following these instructions?

Doctor

- 40. Do you have a regular doctor you see outside the hospital?
 - a. What kind of doctor is he/she?
- 41. Did you see your doctor(s) after your last discharge?
 - a. How long after your discharge was the appointment?
 - b. Did you have an appointment prior to discharge and were you able to go?
 - i. If not, why not?
- 42. How do you get to your appointments?
 - a. Any difficulties?
- 43. What is your experience like when you go to your doctor(s) visit(s)?
 - a. What is the relationship like with your doctor?
 - b. Anything you would like to see happen differently at the doctor's office?

- c. How could the doctor or office staff be more helpful to you?

Family/Support Available

- 44. Who usually helps you at home?
 - a. Anyone else?
- 45. Tell me what your illness is like for your family and friends?
- 46. What does your family know about your illness?
- 47. What does your family know about your care?
- 48. What other resources were you offered such as home care, telemonitoring?
 - a. Did you accept these resources?
 - i. Why or why not?
 - b. What has been your experience with these resources?
 - i. Are they still in place?
- 49. Have you found any other resources that are helpful to you (church, friends, other agencies)?
- 50. What other resources might be helpful to you?

Advanced Directive

- 51. Have you thought about your wishes for your ongoing medical care?
 - a. If not, why not?
 - b. If yes, what are your wishes?
- 52. Have you made your wishes known concerning your medical care?
 - a. Have you written down your choices for what you would or would not want?
 - b. Have you chosen a person to be your decision maker if you are too sick to

talk to your doctor?

c. If not, why not?

53. Has your doctor or anyone else asked you about an advanced directive?

54. Have you completed an advanced directive?

a. If not, why not?

Other

55. Is there anything else that I haven't touched on that you think would be important for me to know about your experience with your readmission to the hospital or your care at home?

Appendix D

Caregiver Interview Guide version 4

Script

Mr/Ms. _____ Thank you for agreeing to speak with me concerning your experience with your loved one coming back to the hospital. I really want this to be a conversation about your experience. There are no right or wrong answers to the questions I am about to ask. I am not looking for a certain answer. Instead I am trying to learn about the details of your experience to gain a better understanding of your particular situation. Please answer the questions in your own words and in as detailed a manner as possible.

Please be reminded that all of your responses will be audiorecorded so I can really listen during the interview and have an accurate record of your answers. The audiorecording will be held in the strictest confidence and handled in a secure manner. No information will be revealed without your expressed permission. I also want to remind you that your participation is completely voluntary and you may withdraw from the study at any time including before we start or during this interview. You can also refuse to answer any question that I pose and we will move on to the next question. I also want to remind you that your participation or lack of participation will not affect your or your loved one's care at the hospital now or in the future.

Also please let me know if you need a break or need to stop. Do you have any further questions? Are you ready to begin?

Questions

These are the type of questions that will be asked the patient. More questions may be asked depending on where the interview leads.

General

1. What do you think brought the patient back to the hospital this time?
 - a. Tell me what happened in the last couple of days
 - b. What might have prevented you from coming to the hospital again?
2. If you could have done anything differently at home related to taking care of the patient what would that be?
3. What can you remember about the patient's last visit to the hospital?
 - a. What was that experience like for you?
 - b. If you could change anything about your experience in the hospital last time related to your readiness to take your loved one home what would that be?
4. How can the hospital be more helpful to you in taking care of the patient?
 - a. Tell me more about that

Health

5. What is most important to you regarding the patient's health?
 - a. Can you tell me more about that?
6. What goals do you have for your loved one this year, i.e. what would make you feel good if you were to look back this time next year and thought I am glad that happened the way it did?
 - a. Is there anything that would prevent that from happening?

7. What do you think is most important to the patient?
8. What do you think would keep the patient healthier?
 - a. Is there anything that would prevent that from happening?

Illness/Illnesses

9. What can you tell me about the patient's present illness/illnesses?
10. Was this experience of coming to the hospital similar or different to what brought the patient to the hospital last time?
 - a. Can you tell me more about that?
11. How did you know your loved one needed to come back to the hospital?
 - a. What was the experience like for the patient?
 - b. What was the experience like for you?
12. What is it like for you to live with the patient's illness day-to-day?
 - a. How does it affect you (emotionally, physically)?
13. What do you think caused the patient's illness?
14. What do you worry about regarding the patient's illness?
15. How serious do you think the patient's illness is?

Care

16. What do you do to help care for the patient?
 - a. What is that like for you?
17. How well do you feel you are able to assist in the patient's care?
 - a. What concerns do you have in taking care of the patient at home?
 - b. How do you feel the patient's care at home has been going?
 - c.

Discharge Instructions

18. How prepared did you feel to take care of the patient after discharge?
 - a. How were you involved with planning for the discharge?
19. What instructions were you given about the patient's care at home?
 - a. How helpful were the instructions you received?
20. Was the patient and/or you able to help carry out the instructions?
 - a. How do you feel the patient does with following the recommendations for his/her care?
 - b. Which instructions, if any, did the patient and/or you find hard to follow, if any?
21. What questions do you still have about the patient's care?

Medications

22. Tell me what you know about the patient's medications.
 - a. What are they for?
23. Which new prescriptions were prescribed at the last hospitalization?
 - a. Were there any prescriptions the patient did not get filled the last time he left the hospital?
 - i. If yes, why not
24. Does the patient have any trouble taking the medications as instructed?
 - a. Do any of the medications cause problems for the patient?
 - ii. If so what are the problems?
 - iii. How has the patient managed them?
25. Are there any medications that the patient has stopped taking or decided not to

take anymore?

a. Tell me more about that

i. Does the patient ever have any trouble refilling the medications?

26. Are there any medications that the patient is taking differently than first instructed since his/her discharge?

a. Tell me more about that

27. How do you or the patient keep up with taking the medications?

a. Do you ever miss a dose?

b. What do you do when that happens?

28. What questions do you still have about the patient's medications?

Diet

29. What instructions were you given about the patient's diet?

a. Is the patient and/or you able to follow the instructions?

b. How do these instructions fit into the patient's lifestyle?

c. Do you have any concerns or difficulties with the patient's diet?

30. What instructions were given about the amount of liquids the patient should have?

a. Is the patient able to follow these instructions?

b. Are there any concerns or difficulties?

31. What instructions were given about the patient weighing him/herself?

a. How often does the patient weigh him/herself?

b. Does the patient have any difficulties in weighing him/herself?

c. Does the patient have a scale

i. Can the patient see the scale without difficulty

- d. What do you do with the patient's weight information?
- 32. What might have been more helpful to you regarding your diet instructions?
 - a. What are they?

Exercise

- 33. What level of activity were you told the patient could have?
 - a. How is the patient doing with that?
- 34. What is it like for you to get around with the patient?
- 35. What instructions were you given about regular exercise?
 - a. What is like for the patient to exercise?
 - b. Is there anything that keeps the patient from exercising?
- 36. What do you do to support the patient's activity level?

Other instructions

- 37. What other instructions were you and the patient provided that we haven't discussed?
 - a. Any other restrictions (smoking, activity, etc.)?
 - b. Is the patient having any difficulties with these instructions?
- 38. What is that like for you in assisting the patient with these instructions?
- 39. What might be helpful in assisting the patient in following these instructions?

Doctor

- 40. Does the patient have a regular doctor he/she sees outside of the hospital?
 - a. What kind of doctor is he/she?
- 41. Do you remember if the patient saw his/her doctor(s) after the last discharge?
 - a. How long after the discharge was it?

- b. Did the patient have an appointment and were you able to go?
- 42. How does the patient get to the appointments?
 - a. Any difficulties?
- 43. What is your experience like when you go to your doctor(s) visits?
 - a. What is the relationship like between the doctor and the patient?
 - b. Anything you would like to see happen differently at the doctor's office?
 - c. How could the doctor or office staff be more helpful to you?

Family/Support Available

- 44. Tell me what it is like for family to live with your loved one's illness.
- 45. Does the patient have other caregivers, besides you?
 - a. If so, what is the involvement with the patient?
- 46. What other resources were offered to the patient such as home care, telemonitoring?
 - a. Did the patient accept these resources?
 - i. Why or why not?
 - b. What has been your experience with these resources?
 - i. Are they still in place?
- 47. Have you found any other resources to help in the patient's care? (church, friends, other agencies?)
- 48. What other resources might be helpful in caring for the patient?

Advanced Directive

- 49. Have you talked to the patient about his/her wishes for medical care if they were too sick to talk to the doctor?

- a. (If yes), what are the patient's wishes?
- b. How do you feel about the patient's wishes?
- c. If not, why not?
- d. If not, have you thought about what is best for the patient?

50. Has anyone spoken to the patient or you about writing down that patient's medical choices (an advanced directive)?

- a. Has the patient named a medical decision maker if he/she is not able to speak for him/herself?
- b. Does the patient have an advanced directive?

Other

51. Is there anything else that I haven't touched on that you think would be important for me to know about the patient's or your experience with the patient's readmission to the hospital or care at home?

Appendix E

Patient Informed Consent

Informed Consent Form for patients readmitted within 30 days post hospitalization with a discharge diagnosis for Heart Failure and Heart Attack who we are inviting to participate in the research study, titled "Heart Failure and Acute Myocardial Infarction Patients' and Caregivers' Perceptions of Reasons for 30-Day Readmissions in the Community Hospital Setting"

Principal Investigator: Amy Black, MSN, RN, NEA-BC

Research Associate: Faye Satterly, BSN, MFA, RN

Organization: Martha Jefferson Hospital

Sponsor: Martha Jefferson Foundation

Name of Project: Heart Failure and Acute Myocardial Infarction Patients' and Caregivers' Perceptions of Reasons for 30-Day Readmissions in the Community Hospital Setting

NOTE: This Informed Consent Form has two parts:

Part 1: An Information Sheet (to share information about the study with you)

Part 2: Certificate of Consent (for signatures if you choose to participate)

You will be given a signed copy of the full Informed Consent Form

Part I: Information Sheet**Introduction**

Amy Black is a doctoral student at the University of Virginia, School of Nursing. Ms. Black and a research associate, Faye Satterly, will be conducting a research project at Martha Jefferson on what patients and their caregivers think causes some patients discharged from the hospital with a diagnosed heart problem to return to the hospital again within a 30-day period. Today you will receive information about the study and be invited to be part of this research.

You do not have to decide today whether or not you will participate in the study. You may want to talk this over with someone you know before you decide. As the information about the study is being presented, please do not hesitate to ask a question or let the researcher know if you do not understand any of the words or concepts. The goal of this information session is to make sure you understand the research project and what your participation means should you decide to be a part of the study.

Purpose of the research

When patients get readmitted to the hospital shortly after they are discharged it is a burden to the patient and their family. In the United States this happens close to 25 % of the time for patients over 65 years of age. We think that is too often and we want to learn more about why this might be and what we can do to prevent it from happening as often as it does. We want to learn from our patients and their family or other caregivers the reasons they think you had to come back to the hospital within 30 days of being discharged. We want to know what is happening once you get home, what happens

before you come back, and what you think might have helped to prevent you from returning to the hospital.

Type of Research Intervention

This research will involve your participation in a single, private interview with a member of the research team that is anticipated to take 45 minutes. The researchers will also be collecting the following demographic information: medical record number, encounter number, age, gender, marital status, level of education, discharge and readmit dates and diagnoses, other major medical diagnoses, ejection fraction (a measure of heart function), county of residence, type of insurance, and zip code. Some of this information will be asked during the interview and some will be collected from the electronic medical record. No other information will be collected from the medical record.

Participant Selection

You are being invited to participate in this research study because you were recently hospitalized due to a heart problem and then readmitted within 30 days. The family member, friend or other person that usually assists you with your care will also be asked to participate with your consent.

Voluntary Participation

Your participation in this research is entirely voluntary. You are not required to participate. It is entirely your choice. If you chose not to participate the care you receive at Martha Jefferson will continue and nothing will change. Your current and future care at Martha Jefferson will not be affected in any way.

Procedures

We are asking you to help us learn more about the reasons for a patients' return to the hospital within a 30-day time period following discharge for a heart problem. If you consent to participate you will be privately interviewed by the researcher or research associate. If you accept the invitation we will also be asking you who your main caregiver or support person is at home and be seeking your permission to interview them privately as well. We will be asking similar questions of both you and your caregiver. If you chose not to have your caregiver interviewed we will not proceed with your participation in the study.

Examples of topics that participants will be asked to discuss are what is it like to live with your heart problem, what you do to take care of yourself at home, what your discharge instructions were and whether you understood them, what your experience was when you got home from the hospital, what your beliefs are about your health, what your goals are for your health, what you find easy and hard to do when it comes to taking care of yourself, what brought you back to the hospital and what you think could have prevented your readmission.

During the interview, the researcher will sit down with you in your hospital room. If you do not wish to answer any of the questions during the course of the interview, you may say so and the researcher will move on to the next question. Only the researcher will be present unless you would like someone else to be there with you. If someone enters your room the researcher will temporarily stop the interview.

The interview will be audio-recorded, but you will not be identified by name on the recording, only by a code that is a unique combination of letters and numbers. The

information recorded is confidential, and only the researchers and a professional transcriptionist will have access to it. The researcher will also make notes immediately following the interview. The audio recording and notes will be kept secure in a computer file that is password protected. The audio recording, transcripts, and notes will be destroyed after 1 year.

Duration

The interview will take place in one sitting, while you are still a patient here. The interview will take approximately 45 minutes. The interviews will be conducted during the months of October 2013 to January 2014. The data review will continue through March 2014.

Risks

We will be asking you to share with us some personal and confidential information, and you may feel uncomfortable talking about some of the topics or answering some of the questions. You do not have to answer any question or take part in the interview if you do not wish to do so. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview even if the question is asked of you. You can also withdraw from the study at any time which means you can stop the interview anytime if you wish too.

Benefits

There may be no benefit to you directly, but your participation in this study is likely to help us find out more about how to prevent some patients from being readmitted within 30 days following a hospitalization for a heart problem at Martha Jefferson. If the

study is published in a professional journal it may benefit other patients both within and outside of Charlottesville.

If the researcher hears something during the course of the interview that might help your physician or nurse to take better care of you during this hospitalization the researcher can pass that information along with your permission. The researcher will tell you what that might be at the end of the interview.

Reimbursements

You will not be provided any incentive to take part in the research.

Confidentiality

The researcher will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a letter-number code on it instead of your name. Only the researchers will know what your code is and this information will be kept on a log that is stored separately in a secured fashion. It will not be shared with anyone unless requested by the Institutional Review Board for regulatory audit purposes.

Sharing the Results

Results from the study will be presented as common themes that are identified across the participant interviews. Examples might include reasons for readmissions, beliefs about heart problems or treatments and patient's experiences at home. The knowledge developed from this research will be shared in a summary fashion with participants before it is made widely available to the public. Following sharing the summary results with the researcher's doctoral committee at the University of Virginia, they will be shared at professional conferences and submitted to a professional journal for

publication so that other interested healthcare professionals may learn from the research.

There is a possibility some direct quotes from a participant will appear in the publication of the results to help further explain a theme that is identified in the course of the study.

Any quotes that may appear will not be identified with the patient's name and any quotes that risk revealing a patient's identity will not be used.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your care at Martha Jefferson now or in the future.

You may stop participating in the interview at any time without your care being affected.

Who to Contact

If you have any questions, you can ask them now or later. If you wish to ask questions of the researcher later, you may contact:

Amy Black MSN, RN, NEA-BC

Martha Jefferson Hospital

500 Martha Jefferson Drive

Charlottesville, VA. 22911

Email: asblack@sentara.com

Phone: 434-654-7311

This proposal has been reviewed and approved by the Martha Jefferson Institutional Review Board (IRB), which is a committee whose task it is to make sure that research participants are protected from harm.

If you wish to contact the IRB, you may contact:

Joyce Agati Miller, Ph.D.

Martha Jefferson Hospital

500 Martha Jefferson Drive

Email: jamille5@sentara.com

Phone: 434-654-7942

Part II: Certificate of Consent

I have been invited to participate in research about the experience of patients' and their caregivers' discharged from the hospital with the diagnosis of a heart problem that return to the hospital for admission within a 30-day period. I have been asked to participate in a private interview and will be asked a series of questions about my experience at home and prior to returning to the hospital. I will also be asked questions about my condition and my beliefs about what brought me to the hospital and what might have been done to prevent it.

I will also be giving my permission for the investigator to access my personal health record for certain information. I will also be giving my permission to contact my primary support person or caregiver.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant_____

Signature of Participant _____

Date _____

If the consent was read to the patient:

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____

Signature of witness _____

Date _____

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the consent form

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this signed informed consent form has been provided to the participant.

Print Name of Researcher/person taking the consent_____

Signature of Researcher /person taking the consent_____

Date _____

Appendix F**Caregiver Informed Consent**

Informed Consent Form for patients readmitted within 30 days post hospitalization with a discharge diagnosis for Heart Failure and Heart Attack who we are inviting to participate in the research study, titled "Heart Failure and Acute Myocardial Infarction Patients' and Caregivers' Perceptions of Reasons for 30-Day Readmissions in the Community Hospital Setting"

Principal Investigator: Amy Black, MSN, RN, NEA-BC

Research Associate: Faye Satterly, BSN, MFA, RN

Organization: Martha Jefferson Hospital

Sponsor: Martha Jefferson Foundation

Name of Project: Heart Failure and Acute Myocardial Infarction Patients' and Caregivers' Perceptions of Reasons for 30-Day Readmissions in the Community Hospital Setting

NOTE: This Informed Consent Form has two parts:

Part 1: An Information Sheet (to share information about the study with you)

Part 2: Certificate of Consent (for signatures if you choose to participate)

You will be given a signed copy of the full Informed Consent Form.

Part I: Information Sheet**Introduction**

Amy Black is a doctoral student at the University of Virginia, School of Nursing. Ms. Black and a research associate, Faye Satterly, will be conducting a research project at Martha Jefferson on what patients and their caregivers think causes some patients discharged from the hospital with a diagnosed heart problem to return to the hospital again within a 30-day period. Today you will receive information about the study and be invited to be part of this research.

You do not have to decide today whether or not you will participate in the study. You may want to talk this over with someone you know before you decide. As the information about the study is being presented, please do not hesitate to ask a question or let the researcher know if you do not understand any of the words or concepts. The goal of this information session is to make sure you understand the research project and what your participation means should you decide to be a part of the study.

Purpose of the research

When patients get readmitted to the hospital shortly after they are discharged it is a burden to the patient and their family. In the United States this happens close to 25 % of the time for patients over 65 years of age. We think that is too often and we want to learn more about why this might be and what we can do to prevent it from happening as often as it does. We want to learn from our patients and their family or other caregivers the reasons they think the patient had to come back to the hospital within 30 days of being discharged. We want to know what is happening at home after discharge, what happens

before the patient comes back, and what you think might have helped to prevent the patient from returning to the hospital.

Type of Research Intervention

This research will involve your participation in a single, private interview with me that is anticipated to take 45 minutes. I will also be collecting certain demographic information such as age, gender, marital status, and level of education during the interview.

Participant Selection

You are being invited to participate in this research study you are a caregiver of a patient recently hospitalized due to a heart problem and then readmitted within 30 days. The patient has already been asked to participate in the study and has given permission for the research team to contact you for participation.

Voluntary Participation

Your participation in this research is entirely voluntary. You are not required to participate. It is entirely your choice. If you chose not to participate the care the patient currently is receiving or receives in the future or that you may receive at Martha Jefferson in the future will not be affected.

Procedures

We are asking you to help us learn more about the reasons for a patients' return to the hospital within a 30-day time period following discharge for a heart problem. If you accept the invitation to participate you will be privately interviewed with a member of the research team.

We will be asking similar questions of both you and the patient. Examples of topics that participants who are caregivers will be asked to discuss are what is it like to care for the patient's and his/her heart problem, what you know about the discharge instructions provided to the patient, what you do to take care of the patient at home, what your experience was when the patient got home from the hospital, what your beliefs are about the patient's health, what your goals are for the patient, what is easy and hard to do when it comes to assisting the patient in his/her care, what you think brought the patient back to the hospital and what you think could have prevented the patient's readmission.

During the interview, the researcher will sit down with in a comfortable room in the hospital. If you do not wish to answer any of the questions during the course of the interview, you may say so and the researcher will move on to the next question. Only the researcher will be present unless you would like someone else to be there with you.

The interview will be audio-recorded, but you will not be identified by name on the recording, only by a code that is a unique combination of letters and numbers. The information recorded is confidential, and only the researchers and a professional transcriptionist will have access to it. The researcher will also make notes immediately following the interview. The audio recording and notes will be kept secure in a computer file that is password protected. The audio recording, transcripts, and notes will be destroyed after 1 year.

Duration

The interview will take place in one sitting, while the patient is still here. The interview will take approximately 45 minutes. The interviews will be conducted during the months of October 2013 to January 2014. The data review will continue through March 2014.

Risks

We will be asking you to share some personal and confidential information, and you may feel uncomfortable talking about some of the topics or answering some of the questions. You do not have to answer any question or take part in the interview if you do not wish to do so. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview even if the question is asked of you. You can also withdrawal from the study at any time which means you can stop the interview anytime if you wish too.

Benefits

There may be no benefit to you directly, but your participation in this study is likely to help us find out more about how to prevent some patients from being readmitted within 30 days following a hospitalization for a heart problem at Martha Jefferson. If the study is published it may benefit other patients both within and outside of Charlottesville.

Reimbursements

You will not be provided any incentive to take part in the research.

Confidentiality

The researcher will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a letter-number code on it instead of your name. Only the researchers will know what your code is and this information will be kept on a log that is stored separately in a secured fashion. It will not be shared with anyone unless requested by the Institutional Review Board for regulatory audit purposes.

Sharing the Results

Results from the study will be presented as common themes that are identified across the participant interviews. Examples might include reasons for readmissions, beliefs about heart problems or treatments and patient's experiences at home. The knowledge developed from this research will be shared in a summary fashion with participants before it is made widely available to the public. Following sharing the summary results with the researcher's doctoral committee at the University of Virginia, they will be shared at professional conferences and submitted to a professional journal for publication so that other interested healthcare professionals may learn from the research. There is a possibility some direct quotes from a participant will appear in the publication of the results to help further explain a theme that is identified in the course of the study. Any quotes that may appear will not be identified with the patient's name and any quotes that risk revealing a patient's identity will not be used.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect that patient's or your care at Martha Jefferson now or in the future. You may stop participating in the interview at any time without the patient's care being affected.

Who to Contact

If you have any questions, you can ask them now or later. If you wish to ask questions of the researcher later, you may contact:

Amy Black MSN, RN, NEA-BC

Martha Jefferson Hospital

500 Martha Jefferson Drive

Charlottesville, VA. 22911

Email: asblack@sentara.com

Phone: 434-654-7311

This proposal has been reviewed and approved by the Martha Jefferson Institutional Review Board (IRB), which is a committee whose task it is to make sure that research participants are protected from harm.

If you wish to contact the IRB, you may contact:

Joyce Agati Miller, Ph.D.

Martha Jefferson Hospital

500 Martha Jefferson Drive

Email: jamille5@sentara.com

Phone: 434-654-7942

Part II: Certificate of Consent

Informed Consent (continued) Page 8 of 9

I have been invited to participate in research about the experience of patients' and their caregivers' discharged from the hospital with the diagnosis of a heart problem that return to the hospital for admission within a 30-day period. I have been asked to participate in a private interview and will be asked a series of questions about my experience in caring for the patient at home and my experience with the patient prior to returning to the hospital. I will also be asked questions about the patient's condition, care and my beliefs about what brought my family member/friend back to the hospital and what might have been done to prevent it.

I have been informed that the patient has given his/her written consent for me to participate in this interview and discuss his/her case with the researcher.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant _____

Signature of Participant _____

Date _____

If the consent was read to the participant:

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Signature of witness _____

Date _____

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. A copy of this informed consent form has been provided to the participant.

Print Name of Researcher/person taking the consent_____

Signature of Researcher /person taking the consent_____

Date _____

Appendix G

Institutional Review Board Approvals

G1 Martha Jefferson IRB Approval

500 Martha Jefferson Drive Charlottesville, VA 22911	All Departments (434) 654-7000 Hospital (800) 633-6353 Toll Free www.marthajefferson.org	Physician Referral & Program Information (434) 654-7009 (888) 662-6663 Toll Free
---	---	---



INSTITUTIONAL REVIEW BOARD at MARTHA JEFFERSON HOSPITAL
CERTIFICATE OF INITIAL APPROVAL
With Expedited Review of Final Changes Made at the Request of the Full Board

SPONSOR:	Martha Jefferson Foundation
STUDY TITLE:	Heart Failure and Acute Myocardial Infarction Patients' and Caregivers' Perceptions of Reasons for 30-day Readmissions in the Community Hospital Setting
PRINCIPAL INVESTIGATOR:	Amelia Black, MSN, RN, NEA-BC

IRB REVIEW DATE:	10.9.13
IRB REVIEW STATUS:	Full Board Review
DATE OF CHAIR'S EXPEDITED REVIEW AND APPROVAL OF IRB REQUESTED CHANGES:	10.17.13
APPROVAL INCLUDES:	<ul style="list-style-type: none"> Protocol, dated 10.17.13 Consent Form, dated 10.17.13 On page 2 of both the patient consent form and the caregiver consent form, "burden" was changed to "stressor". The interview guides were revised to include more open-ended questions regarding general health, care, and medications to enrich the type of data to be obtained during the interviews. NOTE: As long as the questions added to the interview guide fit reasonably within the original framework of the study, then the investigator can change the questions without IRB review. If the investigator needs to go beyond the original intent of the study or find that the follow-up questions that they are asking change the overall risk to participants in the study, then the investigator would need to submit a modification with a new interview guide that reflects the new direction or increased risk.

VOTE:	7 For 0 Against 0 Abstain
EXPIRATION DATE:	10.8.14 (annual review)

This is to certify that the information contained herein is true and correct as reflected in the records of the Martha Jefferson Hospital Institutional Review Board. **WE CERTIFY THAT MJH IRB IS IN FULL COMPLIANCE WITH HHS RULES AND REGULATIONS.**

 Susan Cabell Mains, MBA Alternate Chair, Institutional Review Board Martha Jefferson Hospital Charlottesville, Virginia 22911	10/17/13 Date
---	------------------

For Use by IRB Office	Initial: 6/04; Revised 10/04
-----------------------	------------------------------

MJH-IRB-Protocol File #: 13-008

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G2 MJH IRB Extension

500 Martha Jefferson Drive
Charlottesville, VA 22911

All Departments
(434) 654-7000 Hospital
(800) 633-6353 Toll Free
www.marthajefferson.org

Physician Referral & Program Information
(434) 654-7009
(888) 652-6663 Toll Free

Martha
Jefferson Hospital

INSTITUTIONAL REVIEW BOARD at MARTHA JEFFERSON HOSPITAL

CERTIFICATE OF APPROVAL**By Expedited Review**

SPONSOR: Martha Jefferson Foundation
STUDY TITLE: Heart Failure and Acute Myocardial Infarction Patients' and
Caregivers' Perceptions of Reasons for 30-day Readmissions in the
Community Hospital Setting

PRINCIPAL INVESTIGATOR: Amelia Black, MSN, RN, NEA-BC

IRB REVIEW DATE: 1.16.14

IRB REVIEW STATUS: Expedited Review (due to non-scientific changes)

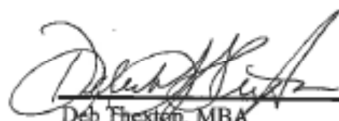
APPROVAL INCLUDES:

- Protocol, dated 12.30.13
- Consent Form, dated 12.30.13
- Amendment #1 includes the extension of the data collection through April 2014.

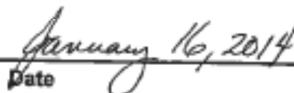
STATUS: Open to enrollment

EXPIRATION DATE: 10.8.14 (annual review)

This is to certify that the information contained herein is true and correct as reflected in the records of the Martha Jefferson Hospital Institutional Review Board. **WE CERTIFY THAT MJH IRB IS IN FULL COMPLIANCE WITH HHS RULES AND REGULATIONS.**



Deb Flexien, MBA
Compliance Officer, Institutional Review Board
Martha Jefferson Hospital
Charlottesville, Virginia 22911


Date

For Use by IRB Office

Initial: 6/04; Revised 10/04

MJH IRB Protocol File #: 13-008

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G3 UVA Determination of Agent Form



DETERMINATION OF UVa AGENT FORM

INFORMATION ABOUT THIS FORM

- This form is to determine if UVa personnel are or are not considered to be working as an Agent* for UVa on this project.
- If it is determined that UVa personnel are considered to be working as an Agent* for UVa the study team will be required to submit an additional submission to the IRB-HSR, unless the project is determined to not involve human subject research. See [Determination of Human Subject Research Form](#)

**Agent- all individuals (including students) performing institutionally designated activities or exercising institutionally delegated authority or responsibility.*

Enter responses electronically. Email the completed form to IRBHRS@virginia.edu for pre-review.

An IRB staff member will reply with any changes to be made.

Name of Individual to be Working on Project:	Amelia S. Black
Email:	asblack@sentara.com
Phone:	4346547311 (office); 4348067597(mobile)
UVa Messenger Mail Box #	none
Project/Protocol Title if Known:	<input type="checkbox"/> Unknown or Title: Heart Failure and Acute Myocardial Infarction Patients' and Caregivers' Perceptions of Reasons for 30-Day Readmissions in the Community Hospital Setting
Explain your role in the project: (200 words or less)	I am the principal investigator in this project which is my capstone work for my Doctorate of Nursing Practice at the University of Virginia School of Nursing.
Explain the reason for traveling to the outside institution.	I am employee at Martha Jefferson Hospital and therefore it is my preference that my study be conducted on the premises of the facility where I am present on a fulltime basis.

Website: <http://www.virginia.edu/vpr/irb/hsr/index.html>

Phone: 434-924-2620 Fax: 434-924-2932 Box 800483

1. Answer the following questions:

- ☐ Yes ☐ No I was involved in the design of this research project.
☐ Yes ☐ No A UVa IRB has approved this research. IRB-HSR # [REDACTED]
☐ Yes ☐ No Funding to conduct this research will come from UVa.
☐ Yes ☐ No The only reason I am traveling to this outside institution is to work on this research.
☐ Yes ☐ No Working on this research is required for my degree program.

2. I confirm that

- ☐ Yes ☐ No I am a student, employee and/or faculty member of the University of Virginia.
☐ Yes ☐ No My work on this project will be overseen by the Principal Investigator and the IRB at the outside institution. This includes completing any training in human subject research protection as required by the outside IRB.
☐ Yes ☐ No I will communicate with the IRB and the Contracts Office, to determine what approvals may be needed, prior to receiving any data from the outside institution.

OR

3. I confirm that :

- ☒ Yes ☐ No I designed this research.
☒ Yes ☐ No I am a student at UVa but am employed by another institution.
☒ Yes ☐ No All subjects will be enrolled at this outside institution.
☒ Yes ☐ No The research will be overseen by their IRB and, if applicable, their HIPAA Privacy Board. This includes completing any training in human subject research protections as required by the outside IRB.
☒ Yes ☐ No There is no funding for this study or if there is funding, it will be handled by the institution at which I am employed.
☒ Yes ☐ No I have notified the outside IRB that an UVa IRB will not be overseeing my work.
 ATTACH COPY OF OUTSIDE IRB APPROVAL.

FOR IRB-HSR OFFICE USE ONLY

☐ UVa personnel are not considered to be working as an Agent for UVa on this project.
 No approvals from the UVa IRB-HSR are required.

☐ UVa personnel are considered to be working as an Agent for UVa on this project.
 Submit a research application to the UVa IRB-HSR.

 Signature of IRB Chair, Director or Designee

 Date

Website: <http://www.virginia.edu/vpr/irb/hsr/index.html>
 Phone: 434-924-2620 Fax: 434-924-2932 Box 800483

Appendix H

Table 1

Participants Sociodemographics

Characteristic	Patient (n=11)	Caregiver (n=4)
Age mean (SD)	67.2 (12.4)	64 (4.7)
Gender, n (%)		
Male	10 (91%)	
Female	1 (9%)	4 (100%)
Race, n (%)		
Black	2 (18%)	0 (0%)
White	9 (82%)	4 (100%)
Education		
Bachelor's or higher	1	1
12 th grade	4	1
Some high school	3	2
8th grade or less	3	
Discharge Diagnosis Index Admission, n (%)		
AMI	(4) 36%	
HF	(7) 64%	
Number of medications at discharge		
6-12	10	
13-19	2	
> 20	1	
Comorbidities, n (%)		
COPD	(4) 36%	
Type II Diabetes	(6) 55%	
HTN	(6) 55%	
Renal Disease	(7) 64%	
Payor Source Primary/Secondary, n (%)		
Medicare	(4) 36%	
Medicare/Commercial	(4) 36%	
Medicare/Medicaid	(1) 9%	
Commercial	(2) 18%	
Days Elapsed to Readmission		
0 - 6	3	
7 - 13	2	
14 - 20	2	
21 - 27	4	

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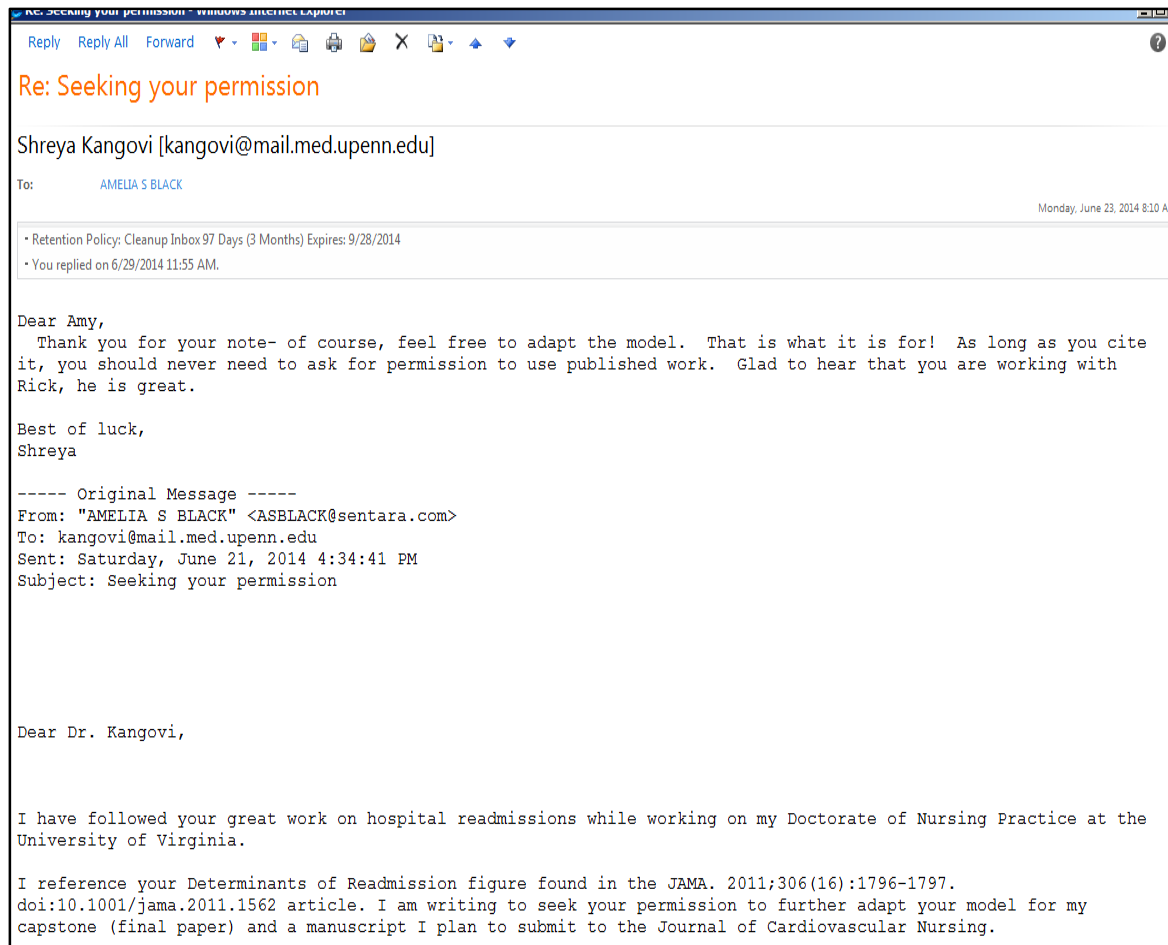
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Journal of Cardiovascular Nursing Author Guide

Purpose of the Journal

The primary objective of *The Journal of Cardiovascular Nursing* (JCN) is to foster expert, evidence-based clinical practice of cardiovascular nurses by publishing outstanding clinically relevant cardiovascular research, and state-of-the art, systematic reviews of the cardiovascular research literature. Issues address the physiological, psychological, and social responses of cardiovascular patients and families in a variety of environments.

Publication Policy

JCN publishes both unsolicited articles (research reports, brief reports, systematic reviews of the literature, instrument development papers, and articles on innovations in practice) on any cardiovascular topic, and invited articles on planned topics. We publish Brief Reports, which are shorter versions of research articles and which can include pilot or preliminary results, negative findings, descriptions of study designs (and which can include baseline participant characteristics), and descriptions of unique clinical trial or intervention study methods.

Authors are encouraged to submit (1) original research articles and brief reports; (2) analytical, systematic reviews that codify existing knowledge; (3) instrument development papers and testing of the psychometric properties of new or existing instruments; (4) clinical articles that synthesize information in a specific area or guide the practice of specialists in the field; and (5) articles describing innovations in practice. The decision to accept or reject an article will be based on the judgment of peer reviewers and the editors.

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Appendix K

Draft Manuscript

Heart Failure and Acute Myocardial Infarction Patients' and Caregivers' Perceptions of Reasons for 30-Day Readmissions in the Community Hospital Setting

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Abstract

Background: Hospital readmissions are often attributed to failed transitions of care. A gap in the literature exists in understanding readmissions from the patients' and caregivers' perspectives, particularly in the community hospital setting. **Objective:** The purpose of this study was to describe the experience of 30-day readmissions in heart failure and myocardial infarction patients, their root causes, and ways to prevent them from the perspective of patients and their caregivers in a community hospital setting. **Methods:** A phenomenological qualitative study was conducted. Data were collected through semi-structured interviews guided by the Health Belief Model.¹ Colaizzi's² seven-step method was used to analyze the data and describe the essential structures of the readmission phenomenon. **Results:** Six key themes emerged: a need for symptom relief, unmet learning needs, failure to address the primary health concern during the index admission, a lack of patient adherence, challenging treatment regimens, and lack of caregiver inclusion. **Conclusion:** The Health Belief Model provided the theoretical foundation for exploring patient factors related to readmissions. Perceptions of cardiac patient and their caregivers on the reasons for readmission and the means to prevent them are relevant for shaping effective care transitions. Clinicians need to understand each patient's context for self-care and tailor interventions accordingly.

Keywords: readmissions, heart failure, myocardial infarction, qualitative research, perceptions

INTRODUCTION

The Hospital Readmission Reduction Program within the Affordable Care Act (ACA) ³ provides an impetus for hospitals to reduce their readmission rates. The purpose of this study was to describe HF and AMI patients' and their caregivers' experience with hospital readmission within 30-days of discharge from a community hospital. This perspective can inform effective care transitions and promote patient and family engagement.

BACKGROUND

In 2004 the Centers for Medicare and Medicaid Services (CMS) spent 17.4 billion dollars on hospital readmissions.⁴ Heart disease in the form of heart failure (HF) and acute myocardial infarction (AMI) accounts for the majority of readmissions.⁵ From 2007 to 2009, 30-day readmission rates among Medicare beneficiaries hospitalized for HF and AMI were 24.8% and 19.9%, respectively.⁶ A portion of hospital readmissions are known to be avoidable.⁷ Provisions in the ACA allow for significant penalties for hospitals with excess readmissions. With up to 3% of their Medicare reimbursement at risk⁸, hospitals have placed reducing readmissions at the top of their performance improvement agendas.

The Holistic Determinants of Readmissions Model (HRDM, Figure 1), adapted from Kangovi and Grande,⁹ addresses the phenomenon of readmissions. The model includes three major domains for consideration: healthcare services, patient factors, and health policy. Hospital readmission rates are often viewed as a proxy for the quality of care provided.¹⁰⁻¹² Patient factors such as demographics, socioeconomic factors, and comorbid conditions and the fee-for-service reimbursement have been implicated as contributing factors.^{9, 10}

The HDRM provides a framework for examination of the recent literature concerning the phenomenon of readmissions in cardiac patients. Few studies¹³⁻¹⁵ related to the phenomenon of readmissions in cardiac patients have focused on patient factors. HF patients of a single marital status¹³ and those with a lower perception of health care related quality of life¹⁴ were found to be more vulnerable to readmission. Only one recent study examined the perceptions of cardiac patients and their caregivers concerning readmissions.¹⁵ Annema et al (2009) found the perceptions of HF patients and caregivers on the reasons for readmission differed significantly from those of healthcare providers. There is an abundance of healthcare service trials aimed at reducing readmissions including educational,^{16,17} homecare,^{18,19} multidisciplinary teams,²⁰⁻²² case management,^{23,24-27} and telemonitoring.^{28,29-33} Recent meta-analyses of each type of intervention have been conducted.³⁴⁻³⁹ No particular type of delivery model was shown to be superior in preventing readmissions although most were superior to usual care. Within the health policy domain a recent study by Soran et al⁴⁰ found no cost-benefit to the original Heart Failure Home Care Trial, a multicenter study comparing the use of an interactive HF monitoring system, to standard HF care.

The Health Belief Model (HBM) is an applicable theory in understanding health behaviors in patients with cardiac disease. The HBM has empirical support and theorizes that individuals will change health behaviors if they feel susceptible to an illness and its consequences, believe they are capable of carrying out the behaviors (self-efficacy), and that the benefits to performing the behaviors outweigh the barriers or costs to performing the behaviors.¹ Behaviors required for managing heart failure⁴¹ and coronary heart disease⁴² are well documented and include medication adherence, symptom

management, diet modification, daily exercise, and smoking cessation. Suboptimal adherence exists in both HF and post MI patients.^{43, 44} Despite the emphasis on promoting self-care and self-management, interventions employing constructs of health behavior theory were limited.^{16,25,26,45}

Research Questions

Knowledge is limited on patient factors influencing readmission. A broader understanding of care transition failures from the cardiac patient's perspective is warranted. The following research questions were addressed in this study:

- What are the reasons for 30-day readmissions from the perspectives of patients and their caregivers discharged from a community hospital with a diagnosis of HF or AMI?
- What can be done to prevent the next readmission from the patients' and their caregivers' perspectives?

METHODS

A qualitative design using a descriptive, phenomenological⁴⁶ method was used to explore the experience of AMI and HF patients and their caregivers readmitted to the hospital within 30-days. Patient and caregiver experiences have underappreciated in the pursuit to understand readmissions in patients with cardiac disease. The descriptive phenomenological method allowed for a deep inquiry into patient factors that may contribute to readmissions.

Setting and Sample

A purposive, convenience sample^{47, 48} of 10 patients and four caregivers were recruited from the target population of patients readmitted within 30 day of an index

admission for HF or AMI at a 176-bed non-profit community hospital in the Mid-Atlantic. The hospital cares for 10,500 inpatients annually and has an average length of stay of 3.3 days. Patients were recruited from the hospital's inpatient medical-surgical and telemetry units. Patients were excluded if they were non-English speaking, under the age of 18 years, readmitted from another care facility, cognitively impaired or receiving comfort care. Caregivers were identified by patients as the person whom they depended on to assist them with their care at home. Those caregivers who were non-English speaking, under the age of 18 years, employed, cognitively impaired, or did not have the patients' permission to participate were excluded.

Consistent with the tradition of qualitative research, the sample size was guided by the ongoing data analysis. Participants were recruited until data saturation was reached. Data saturation was reached when no new themes were being generated⁴⁹⁻⁵¹ and the structures of the phenomenon were clear and their meanings visible.⁴⁶

Data Collection and Analysis

The data collection period was from November 2013 to April 2014. Data were collected through in-depth semi-structured interviews guided by the Health Belief Model.¹ An interview guide was used to ensure the investigators' focus on the study's areas of interest.⁴⁹ The interviews started with the question, "What do you think brought you back to the hospital this time?" The mean duration of the interviews was 33 minutes for a total of 466 minutes.

Data analysis began after the first interview and continually guided future data collection. Colaizzi's seven-stage process as described by Holloway and Wheeler⁴⁷ was used to analyze the data. All interview scripts were read to acquire a feeling for them.

Then each interview transcript was revisited, significant statements extracted, and meanings formulated. Meanings were organized into themes and validated with the original interview transcripts. Discrepancies within and between themes were reconciled until a good “fit” was achieved. In the final step themes were integrated into a description of the structure of the phenomenon of readmissions from the insider’s view, i.e. that of patients and their caregivers. The software program N’Vivo, version 10 was used to manage data.⁵²

Trustworthiness

Several accepted measures^{47, 48, 51, 53} were taken to ensure the trustworthiness of the results. Consultation was received during the design, data collection, and data analysis phases from doctoral prepared researchers. Data collection was limited to the principal investigator and a research assistant who held regular research meetings to ensure consistency in data collection, establish an audit trail, and determine additional paths of inquiry as informed by the ongoing data analysis. Field notes were used throughout the study. Interviews were audiotaped to ensure accuracy and professionally transcribed by a third party. Follow-up contacts by phone and mail were made with participants to ensure data gleaned from the transcripts accurately reflected their experiences. Results were reviewed for legitimacy by a primary care physician experienced in readmission reduction.

Protection of Human Subjects

The study protocol was submitted and reviewed for the protection of human subjects by the Hospital Institutional Review Board and an exemption obtained from the University of Virginia Research Board. The study protocol was followed and no adverse effects occurred.

FINDINGS

Eleven patients are represented in the findings, ten of which were interviewed. In addition, four caregivers were interviewed. Three patients were readmitted following an index admission for MI and seven patients were readmitted following an index admission for HF. Days to readmission varied from zero (same day) to 28 days. Patient ages ranged from 29 to 90 years with a mean of 67.2 years. Six of the eleven patients had less than a 12th grade education. Ejection fractions ranged from 10-60 %. Participant demographics are found in Table 1.

Five congruent themes between the patients' and caregivers' perceptions emerged from the qualitative data: worsening of condition/need for symptom relief, unmet learning needs, failure to address the health issue during the index admission, non-adherence with the treatment plan, and challenging treatment regimens. An additional theme emerged from the caregivers' perspective: lack of caregiver inclusion.

Worsening of Condition/Need for Symptom Relief

Several patients and caregivers pointed to the worsening of the patient's condition or the need for symptom relief as the primary reason for readmission to the hospital. The most common symptoms were shortness of breath and chest pain. Most participants did not see a connection between the readmission and how the patient's care was managed at home. Often they could not identify any actions they could have taken to prevent the need for readmission. Some participants felt hospital readmission was inevitable due to the severity of the patient's condition.

An 81-year-old male patient (1a) with an ejection fraction of 30% had been home for 28 days. He relayed a story of gradual decline finally telling his wife, "Something's

not right. I'm not getting better...I get very short of breath." She took him back to the hospital with the intent of getting him "checked in."

Patient 8a, an African American gentleman with HF and an ejection fraction of 30%, had been home for 11 days with leg pain and swelling. When asked if there was anything that could have prevented his readmission he replied. "No... I had to come. I couldn't take it no longer. I can't sleep...I been up all night just walking the floor."

Unmet Learning Needs

Participants were asked about instructions they received regarding care at home. Most reported they felt prepared; however, with more specific questioning, the theme of unmet learning needs emerged. All patients acknowledged receiving discharge instructions, but some had difficulty recognizing them as such and remembering them. Both patients and caregivers identified the need for more detailed and tailored instructions to implement their treatment recommendations once home. Knowledge deficits included specifics on diet, weight monitoring, and activity level.

There were indications that the application of care instructions to the patients' everyday experience was not well understood. An African American patient (8a) with a ninth grade education did not realize that canned food and prepared dinners were "full of salt." A 72-year-old, African-American woman (patient 4a) with an eighth grade education described her condition as "decongestional heart failure." She understood her condition to be "very" serious; yet, when asked what she had to do differently to care for herself she replied "nothing that I know of."

A 90-year-old, Caucasian gentleman (patient 5a) readmitted post-AMI denied receiving any care instructions, but then admitted to throwing them out. He did not read

them because it was “page after page” and “you need a pair of magnifying glasses to read it.”

Neither patients nor caregivers conveyed they routinely monitored for symptoms such as dyspnea on exertion or ankle swelling. HF patients and their caregivers understood the need for daily weights, but experienced confusion around whether weight changes were significant. There was a tendency for patients and caregivers to weigh the patient daily, but keep the information to themselves until the home health nurse arrived or their doctor visit. Significant weight gain was not always a cue to action as relayed in the following story from caregiver 1b:

I still can't understand that 'three pounds in a day or five pounds in a week'...

I'm hoping that he starts putting on some weight though...how am I going to know if it's from water?

In general it appeared instructions regarding activity level were limited. A HF patient (4a) had the perception she shouldn't exercise, and stated the most important thing she needed to do for herself was “get her rest.” . The youngest patient participant in the study (6a) had a 10% ejection fraction and had been readmitted with chest pain. He reported he suffered further heart damage from exerting himself too much. “At what point do I want to push more?” he asked. “I'm not exactly sure at what point should I be doing what type of exercise.” Despite receiving care instructions during the index admission, a deeper understanding was needed to apply the information in the real-world environment. The unmet learning needs left uncertainties among participants in managing the patient's care in the home setting.

Failure to Address the Health Issue during the Index Admission

Some participants shared the perception the patient's readmission was due to a failure by the healthcare team to effectively treat the initial problem on the index admission. One 64-year-old male HF patient also had severe chronic obstructive pulmonary disease. His wife (caregiver 3b), his primary caregiver at home, provided these thoughts regarding the link between his earlier admission and two subsequent readmissions:

...it was pneumonia the first time, but when he came back in this second time, they said it was pneumonia, but I think that had to be something else going on... it had to be something more than just pneumonia that was the problem.

Patients and caregivers did not feel their voices were heard to their satisfaction and left without answers. They expressed that the "real" problem wasn't solved the first time. For example, on his second readmission patient 8a told his doctors "yall keep me til you find something!" These participants indicated they "knew" a rehospitalization would result.

Lack of Patient Adherence

Four patients reported a lack of adherence to one or more elements of their treatment plan. Two of the four linked their lack of adherence to their need for readmission. Medications, diet, smoking cessation, and activity level were the common areas of non-adherence identified.

Eight out of 11 patients reported adhering to their prescribed medications. Reasons cited were cost, annoying side effects, and severe adverse effects. Three patients had not persisted in taking certain medications or did not get their prescriptions filled. One patient

admitted to consciously skipping doses of medications. Patient 5a was asked if there were medications he was supposed to take more than once a day. He replied, “There are, but I’ve never done it that way. I’m going to take it only once.”

Patient 10a reported frequent problems with adhering to his treatment plan and made a direct connection to his readmission. He stated, “...it’s my fault. You know, there are some things I could do to make it better. I’m not the perfect patient.” He relayed that even though he knew his treatment regimen was “a matter of life and death,” he did not see it that way in “a day-to-day setting.”

Patient 7a, a post-AMI patient, also connected his need for readmission with his non-adherence. Four days prior to his readmission he had been cutting wood for his wood-burning stove. “...He told me to take it easy, which I didn’t do,” he explained. “As a result, I’m back in for a second visit...I thought the amount of time I gave myself was enough and it wasn’t.”

An MI patient (patient 3a) was able to speak about how his own choices affected his health. He discussed his lack of initiative and “willpower.” He identified stress as the barrier to reaching this goal. He explained his plan:

...so I am going to have to try and curb it somehow. I’m not sure yet though. I will think about it over the next couple of days. I just seem to fall into these high stress situations.

This patient’s statements reflected a lack of self-efficacy in making the needed behavior changes.

Challenging Treatment Regimens

Several patients had significant co-morbid diagnoses aside from their primary cardiac disease including hypertension, diabetes, renal disease, congestive obstructive pulmonary disease, and obesity. In addition two patients were being treated for depression and another suffered from chronic anxiety. Such comments as “...there is so much wrong with me that I really can’t concentrate on one thing, because if I do I’m turning my back on everything else” and “there’s a combination of things that are close together so it is hard to figure out” are evidence of the complexity of the patients’ condition and treatment regimens.

Caregivers and patients alike described the confusion these complex regimens created and perceived it as a barrier to successfully managing care. Examples of uncoordinated care among providers were shared. Caregiver 9B paints the following picture:

... This doctor tells you one thing, that doctor tells you something else. My husband, he’s got let’s see, four doctors: diabetes doctor, heart doctor, our family doctor, and his lung doctor. And none of them agree with them...they got me running in circles just to try to keep his meds up.

Having a cohesive plan that addressed more than their heart condition was a need expressed by patients.

Lack of Caregiver Inclusion

An emerging theme unique to the caregiver group was a concern over not feeling included in transition planning. Two of four caregivers expressed this concern and felt it had a negative impact on the ability to manage the patient’s care at home. Their

statements were powerful and provided a perspective not heard in the patient interviews.

An excerpt from a spouse of a readmitted AMI patient (caregiver 3b) is an example:

So I think sometimes the doctors feel like if they talk to the patient they're giving them the information. In my particular instance my husband, sometimes talking to him is like playing telephone...I don't always get the accurate version or accurate information...."

She felt that no one knew she existed unless she happened to be there when the doctor came. She suggested an exit interview be conducted with the primary caregiver to be certain they knew the plan.

Caregiver 9b had managed her husband's care for a number of years and was a strong advocate. She relayed that despite her husband's wishes to the contrary, staff in the hospital addressed all of their conversations to him:

... half the times he's out of it... So when they talk to him, he don't understand it. *So you talk to me* [emphasis added]. That's the way I want it, but they'll still tell him if I'm not there....

The caregivers believed their involvement was critical due to the inability of the patient to understand and integrate the information received into their care at home.

DISCUSSION

The purpose of this study was to explore patient factors as a component of the readmission phenomenon. It is the first study to focus on cardiac patients (HF or AMI) readmitted within 30 days in a community setting. Six key themes emerged from the interview data: worsening of their condition/need for symptom relief, unmet learning needs, perceived failure of the healthcare team to address their health issue during the

index admission, a lack of patient adherence, challenging treatment regimens, and a lack of caregiver inclusion. The results provide a deeper understanding of patients' and caregivers' lived experiences with readmission and their capacity to provide care for the patient at home.

Patients and caregivers conveyed worsening of their condition with a need for symptom relief was a primary reason for readmission. This finding is consistent with the Annema et al¹⁵ study. Worsening of HF and other conditions were the most frequently cited reasons for readmission provided by patients and caregivers. MI patients in the study responded immediately to the acute onset of symptoms by calling 911. HF patients did not recognize progression of their symptoms (fluid accumulation, weight gain, and shortness of breath) as cues for action until they became more life-threatening (dyspnea at rest). These findings build on previous qualitative studies investigating patients' knowledge and beliefs about HF and their self-care routines. Horowitz, Rein, and Leventhal⁵⁴ found HF participants operated on an acute vs. chronic model when it came to self-care. They did not routinely manage symptoms, resulting in seemingly preventable exacerbations. Jurgens et al.⁵⁵ found 54% of HF patients believed they had little to no control over their symptoms, which is consistent with patients in the current study. These results have important implications for assisting HF patients and their caregivers to enhance their skills in symptom monitoring and management. Using subtler changes from baseline as cues for specific interventions at home may improve their perceived self-efficacy in preventing a readmission as noted in previous studies of HF patients regarding self-care.⁴¹

Several patients and caregivers identified their unmet learning needs.

Surprisingly, in the study by Annema et al¹⁵ knowledge deficit was not identified as a reason for readmission by patients or caregivers; but it was perceived as a reason for readmission by the physician and nurse participants in a significant number of the cases. In the 2012 study of all 30-day readmissions in a large urban setting by Kangovi et al⁵⁶ a lack of preparedness at discharge was the reason for readmission cited by 11.8 % of the study participants. Patients and caregivers in the current study identified the need for more detailed and tailored instructions regarding medications, diet, weight monitoring, and activity level. These findings corroborate previous studies with the aim of understanding self-care behaviors in both the HF and AMI populations.^{41, 44,54,57-61} The HBM identifies knowledge and skills as important modifying behavioral factors that can assist patients in carrying their treatment plan.¹ Education can begin in the hospital but must continue beyond its walls where it can be more tailored to the patients' psychosocial, cultural and environmental context.

The investigators recognized that some of the unmet learning needs described were related to participants' inability to receive, recall, and understand the discharge information. This incidental finding whether temporary or permanent represented a significant barrier to adopting prescribed health behaviors. Consideration of health literacy⁶²⁻⁶⁴ and cognitive deficits in cardiac patients is warranted⁶⁵⁻⁶⁸ in light of these incidental findings. Both are important patient factors in considering the readmission phenomenon as they can adversely impact a patient's capacity for self-care.⁶⁹

The perception of some patients and caregivers that the reason for the patient's subsequent readmission was the failure of medical providers to address the health issue

during the index admission was a finding not previously cited in the readmission literature. This theme is significant because patients and caregivers did not feel heard, perceived they left without answers to their concerns, and then were readmitted. Valuable information for diagnosing and care planning can be missed and clinical reasoning adversely affected if two-way communication between the healthcare team and the patient and family is lacking.⁷⁰ This finding is an important consideration in preventing readmissions.

Two study patients linked non-adherence to their readmission as did 25% of HF patients in the Annema et al¹⁵ study. One patient in the current study attributed his readmission to a lack of adherence to his prescribed activity level. Annema et al¹⁵ reported that 3% of patients and 7% of caregivers felt readmission was due to an “imbalance of activity and rest.” Activity compliance was not a factor in the study by Kangovi et al⁵⁶ The second patient in the current study connected his readmission to his non-adherence with medications and his severe fluid restriction. Adherence to medications as a reason for readmission was reported by Kangovi et al⁵⁶ in 5.7% of patients (2012), and problems with adherence to fluid restrictions were reported by Annema et al.¹⁵

The HBM is helpful in understanding the non-adherence behavior in these two cases. A qualitative study by Astin et al⁷¹ found patients receiving PCI often had difficulty understanding the severity of their condition, resulting in unwise activity levels in some. Such altered perceptions may explain the decision of the patient in the current study to engage in the physically demanding activity of cutting wood within a month after discharge. The patient experiencing difficulties with adherence to medication and

fluid restriction expressed a sense of reduced susceptibility to the consequences of his day-to-day behaviors. He desired external cues to action to facilitate his health behaviors, which are seen as important behavior modifiers in the HBM.

Three participants in the current study believed improved adherence to prescribed health behaviors could prevent the next readmission. This finding is consistent with the study by Annema et al¹⁵ where 33% of HF patients and 18% of caregivers felt that improved adherence with medications, diet, and fluid restrictions would protect against readmissions. Strunin et al⁷² found adherence to be a major issue with nearly 50% of the participants describing circumstances that prevented them from following medical advice. Barriers to medication adherence identified in the current study included cost, medication intolerance, worrisome or annoying side effects and a denial of perceived risk (susceptibility) in the day to day. These barriers are consistent with the qualitative findings of others in regard adherence in cardiac patients.^{56, 58,59,61,73-75} The HBM proposes that the benefits of the behavioral change must exceed the barriers in order for uptake of the changes to occur.⁷⁶ Ensuring patients' and caregivers' understanding of the benefits of therapy and addressing their perceived barriers would be important in these cases.

The current study results demonstrate the complexity of a patient's treatment regimen can be a perceived barrier to successful home management. Patients and caregivers expressions of confusion appear to represent a decline in self-efficacy as the complexity of the treatment plan grows. Results of the current study support the findings of Annema et al¹⁵ (2009), where 38% of patients and 37% of caregivers reported other diseases as a reason for readmission and Patel et al⁷⁷ where 57% of patients put off

seeking care because they had attributed symptoms to something other than HF.

Comorbid conditions as a risk factor in readmissions has been previously established.^{77,}

⁷⁸⁻⁸⁰ The current study provides insight into how they create challenges for self-management. Recognizing the burden navigating between specialists creates for patients and their caregivers is an area for further consideration in preventing readmissions.

The need for inclusion by the caregivers is an important finding to consider.

Annema et

Al¹⁵ found the perceptions of caregivers on the reason for readmission differed from patients in 60% of the cases. The researchers suggest a full picture of the reasons for readmission from both the patient and caregiver is needed to ensure interventions prescribed by the healthcare team are relevant to the patient's situation. The results of the current study build on this recommendation by demonstrating the caregivers' expressed need to be included in transition planning to ensure the prescribed care is carried out in the home environment. Lack of social support in lower socioeconomic populations is a significant contributor to readmission^{56,72} and the presence of social support has shown to improve outcomes in cardiac patients including readmission.⁸¹ In the current study, caregivers were present, but not consistently used as a resource. A recent systematic review found family caregivers have been overlooked and engaging them in transitions deserves higher priority.⁸²

In summary, the HBM was a useful theoretical framework to guide this research. The findings provide important insights into the perspectives of HF and AMI patients and their caregivers on the readmission phenomenon. Understanding the patients' and caregivers' beliefs about the perceived threat of their illness on a day-to-day basis and

whether they view the condition as acute or chronic may interfere with effective self-care and lead to preventable readmissions. Low self-efficacy may lead to unmet learning needs. Patients and caregivers need more detailed and tailored instructions as part of transitional care in order to implement effective self-management strategies at home. The lack of inclusion of caregivers, uncoordinated care, complex treatment regimens, and ineffective communication were described as barriers to preventing readmissions. Recognition that every patient's situation is unique will assist the healthcare team in enhancing care transitions and preventing readmissions.

Nursing Practice Implications

Findings in this qualitative study have several implications for nursing practice. Recognizing every patient's unique situation will assist nurses in enhancing care transitions. Using existing tools to assess the knowledge and beliefs of HF and AMI patients^{61, 83, 84} about their condition would be helpful in tailoring interventions. Assessing patients' cognitive functioning and health literacy levels is necessary to ensure appropriate educational materials and methods are provided.⁸⁵ Equipping patient and caregivers with self-management strategies to respond to subtle changes is essential. Perceptions that the healthcare team failed to take care of the problem at the index admission indicate the need for further engagement of the patient and their caregivers. The complexities of a patients' treatment regimen must be considered by all providers, and as others have suggested, interventions aimed at readmission may need to have a broader focus.⁵⁶ Nurse leaders must work to ensure transition planning in the hospital is patient and family centered and their context for self-care is understood.

Nursing Research Implications

Findings of this study support the need for continuing research on effective interventions to impact the outcome of readmissions in the cardiac population. Focus groups with patients and caregivers would be a logical progression in this research. Further exploration of the impact of low health literacy and cognitive deficits on readmissions is warranted. Opportunities still exist for more effective interventions related to fluid balance, symptom recognition and self-management. Many hospitals have begun the practice of focused interviews with readmitted patients; however, a validated tool incorporating constructs of behavioral theory is needed. Testing the impact of structured “exit” interviews using web meetings and video conferencing would also be a natural progression of this work.

Limitations

There are important limitations to note. The study was limited to one community hospital so findings may be unique to this setting. As in most qualitative studies convenience sampling was used. The disproportionate share of men, participants with health insurance, and good access to primary care may have affected the results. The small numbers of caregivers recruited is also a limitation. A significant decline in the readmission rate occurred between the time this study was conceived and participants were recruited. Thus, the population studied may represent readmissions more challenging to prevent.

Conclusion

Reduction of readmissions in acute care hospitals an important outcome for hospitals, patients and their families. The HBM is useful in exploring the root cause of readmissions from the patients’ and caregivers’ perspectives. Consideration of patient factors beyond sociodemographics is relevant to engaging patients and caregivers in

shaping effective transition plans. Nurses are in a unique position to “hear the voices” of patients and caregivers and tailor their care to meet their individual needs.

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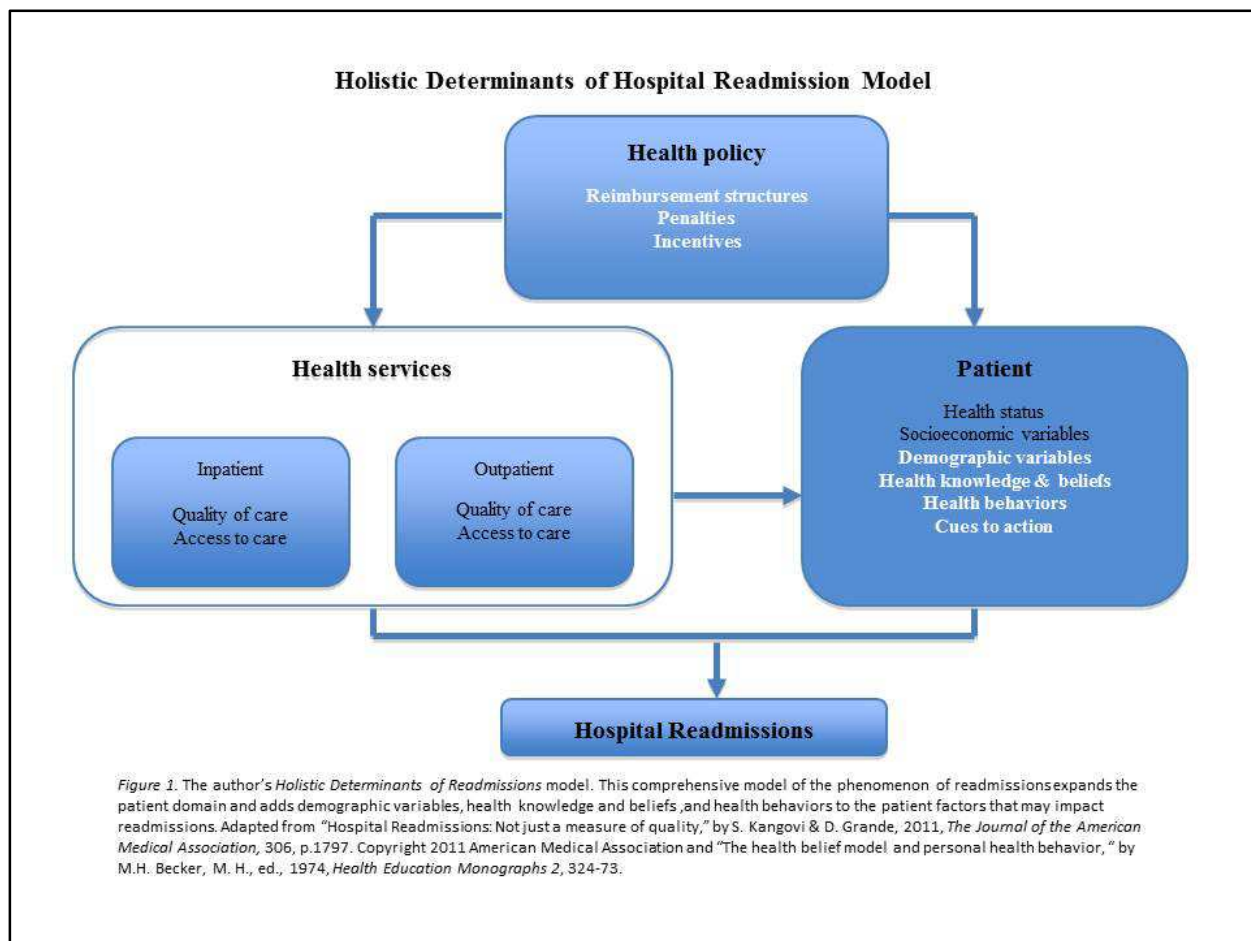
Figure 1

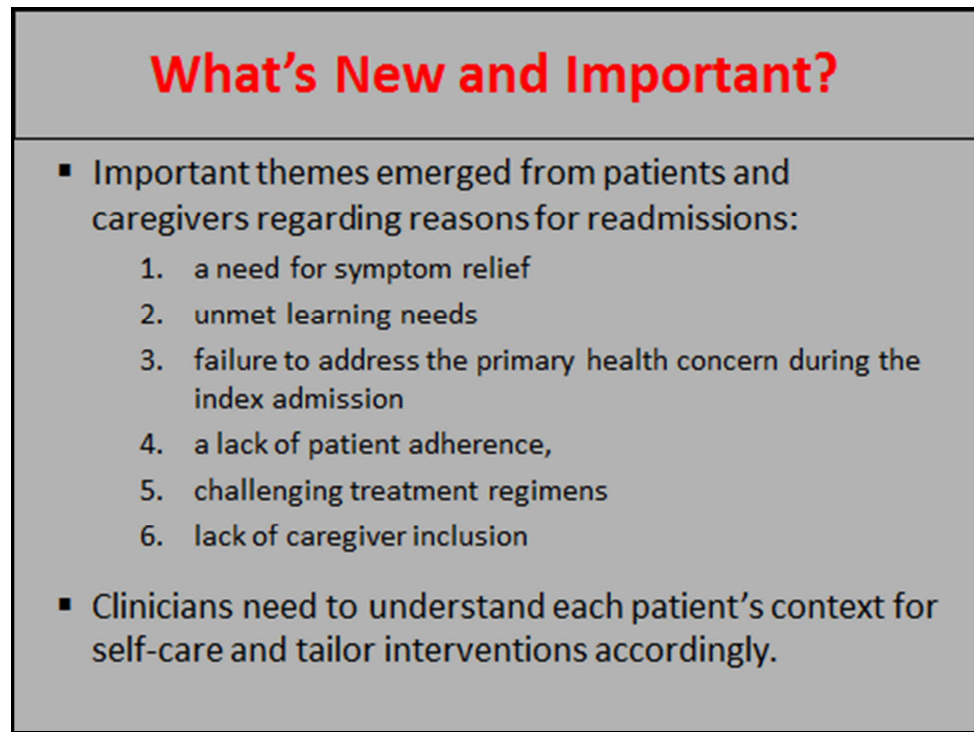
Figure 2

Table 1*Participants Sociodemographics*

Characteristic	Patient (n=11)	Caregiver (n=4)
Age mean (SD)	67.2 (12.4)	64 (4.7)
Gender, n (%)		
Male	10 (91%)	
Female	1 (9%)	4 (100%)
Race, n (%)		
Black	2 (18%)	0 (0%)
White	9 (82%)	4 (100%)
Education		
Bachelor's or higher	1	1
12 th grade	4	1
Some high school	3	2
8th grade or less	3	
Discharge Diagnosis Index Admission, n (%)		
AMI	(4) 36%	
HF	(7) 64%	
Number of medications at discharge		
6-12	10	
13-19	2	
> 20	1	
Comorbidities, n (%)		
COPD	(4) 36%	
Type II Diabetes	(6) 55%	
HTN	(6) 55%	
Renal Disease	(7) 64%	
Payor Source Primary/Secondary, n (%)		
Medicare	(4) 36%	
Medicare/Commercial	(4) 36%	
Medicare/Medicaid	(1) 9%	
Commercial	(2) 18%	
Days Elapsed to Readmission		
0 - 6	3	
7 - 13	2	
14 - 20	2	
21 - 27	4	