PATIENT EXPERIENCE OF HEART FAILURE CARE TRANSITION FROM HOSPITAL TO HOME: AN INTERPRETIVE DESCRIPTION

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Abstract

Background: Heart failure is the second most common reason for hospital admission in Canada. Research has shown that failure to plan a safe, smooth transition home results in emergency department visits and hospital readmissions. Despite the existence of national heart failure care transition best practice guidelines, the evidence is largely missing the patient perspective. The purpose of this study was to understand the patient and caregiver’s experience of the transition from hospital to home. Methods: Interpretive description methodology guided this qualitative study. Participants were recruited from two hospitals within the central interior of British Columbia between January and December, 2017. Semi-structured face-to-face interviews were conducted with patients (n=8) and their caregivers (n=3) at their homes, or by telephone, within two weeks of discharge. Findings: Inductive thematic analysis was used to identify four themes related to the hospital stay experience: focusing on the person, not the task; feeling included or excluded from decisions; some information is better than none; and variation in discharge readiness compared to the health care team’s discharge plan. Once at home, two themes emerged: still recovering at home and self-care. Implications: This study highlights the importance of assessing the patient and family’s ideal level of participation in decision-making and discharge readiness in relation to the health care team throughout the hospital stay. Patients prefer heart failure information to be tailored to their needs, and offered early in the hospital stay. Educators should apply a person-centered lens when practicing skills with students. Guidelines and care design should be completed with patients as partners to ensure their perspectives are incorporated. Lastly, researchers should partner with patients and decision-makers to conduct studies with larger
samples of heart failure patient and caregiver groups, in multiple centers across Canada to further validate these findings, focusing on priorities set by patients and caregivers.
Lay Summary

Many people in British Columbia suffer from heart failure and often have to get treated in hospital. The goal of this study was to find out what is like to go home from the hospital after being treated for heart failure. Eight people with heart failure and three family members were interviewed. Overall, they said they had good care in hospital that helped them prepare to go home. But, some wanted to be more included in decisions about medications or when they would go home. Others needed more information on how to take care of themselves, and some needed more help at home. This study will help patients, health care staff, students, decision-makers and researchers see how important it is to include heart failure patients in decisions that affect them.
Preface

This was an exploratory research study done in partial fulfillment of a Masters of Nursing degree. The purpose was to uncover the patient experience of transitioning from hospital to home after being treated for heart failure. Semi-structured face-to-face interviews were conducted with participants and their caregivers in their own home, or on the telephone, within two weeks of discharge. The research data was transcribed, coded, and analyzed using an interpretive description research methodology. Thematic analysis revealed gaps in person-centered care which caused missed care, missed information and missed home support as well as varied responses to medication changes and readiness for discharge.

This research study was approved by the harmonized UBC Okanagan and Interior Health Authority Behavioural Research Ethics Board (BREB) on January 13, 2017. The certificate number is H15-02900.
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Dedication

I dedicate this thesis to people who suffer from heart failure. May they be welcomed as equal partners in transforming our health care system in order to ensure person-centered, safe, high-quality care for all.
1.1 Problem Statement

There are 600,000 people living with heart failure (HF) in Canada, 90,000 of whom live in British Columbia (BC) (BC Ministry of Health, 2015; Heart and Stroke Foundation, nd). Over the next 30 years, chronic conditions such as heart failure (HF) in BC are expected to rise by over 70 percent (BC Ministry of Health, 2015). Worldwide population aging will exacerbate these alarming statistics (Heckman et al, 2014). HF is associated with a 33 and 28% mortality for men and women respectively, and 30-day mortality rate of 16% after hospitalization (Hayes et al, 2015; Heckman et al, 2014). Post diagnosis, the average lifespan in Canada is 5.5 years (Hayes et al, 2015). Patients with HF experience periods of relative stability interrupted by exacerbations that lead to multiple emergency department visits, and hospitalization (Heckman, 2014; Albert et al, 2015). Following chronic obstructive pulmonary disease (COPD), HF is the second most common condition requiring hospital readmission in Canada (CIHI, 2012). The national all-cause readmission rate for patients with HF is 21% (CIHI, 2012). Care quality initiative reports show that one quarter to one third of HF readmissions are avoidable (Altfeld et al, 2012; Bradley et al, 2013). However, 66% of patients and their caregivers disagree with Health Care Providers (HCPs) on the underlying reason (Annema et al, 2009). Research has identified preventable causes of HF readmission such as: self-care deficits related to symptom management and medication adherence, lack of care continuity, poor communication amongst providers, and lack of post discharge community follow up (Betihavas et al, 2013; Jeffs et al, 2014). Despite this awareness, there continues to be high readmission rates for this chronic disease.
1.2 Transitional Care

One posited cause of preventable HF readmission is the existence of gaps in the care provided during the transition from hospital to home (Dennison & Hughes, 2009). According to Canadian Cardiovascular Society (CCS) guidelines, transitional care is described as “patient management that promotes a series of actions to enhance continuity of care, and facilitate safe and timely transfer of care of patients from one level of care to another (Arnold et al, 2008, p.22). Gaps in care during transitions lead to a negative patient experience, poor outcomes such as increased readmission, and potential harm (Dennison & Hughes, 2009; Puls, Guerrero & Andrew, 2014). Persons with HF are able to identify these gaps in care, such as communication and cooperation across health care sectors, especially at the transition between hospital and home (Baudendistel et al, 2015). Patients with HF often experience difficult transitions (Andreasen et al, 2015). The reasons for this are not fully understood, as they have not been well researched. A review of the literature indicates multiple studies that report the effectiveness of interventions to increase the quality of HF care transitions based on reduction of readmission rates or an increase in a quantitatively reported quality of life (Altfeld et al, 2012; Coleman et al, 2004; Naylor et al, 2004). There have been practice guidelines published based on these findings, yet the studies are primarily provider-centric, and not centered in the patient experience (Allen et al, 2014).

The Canadian Cardiovascular Society’s latest HF guideline update does not provide specific interventions to address gaps in transitional care, however, it does refer to general features of a successful health system. These include program integration (shared patient information and care plans), a human resource plan that supports best
HF practices, equal patient access to care and quality improvement programs including outcome measurement (Ezekowitz et al, 2017). Ezekowitz et al (2017) state that successful HF care includes “clearly defined protocols to facilitate seamless transitions and navigation for patients and providers between levels and sites of care, and are anchored in primary care” (p. 1383). The authors provide a small table that outlines necessary features of a successful HF care within the health system. It suggests a patient-centered care approach, shared care plans and shared power as central to the integration of successful transitional care into the health system (Ezekowitz et al, 2017). Although, it is not clear if the intent is to share the care plans and power with the patients, or just between care providers. It also is missing sufficient detail about how to action these items within the health system. Suter, Oelke, Adair and Armitage (2009) conducted a systematic review and subsequently created specific principles of health system integration that include a patient-centered approach; this shows that there is literature that could be drawn upon to add detail within the guidelines. 

The Registered Nurses Association of Ontario (RNAO, 2014) published non-HF specific guidelines for nurses regarding care transitions that provide suggestions for practice that are organized as per the nursing process. The Canadian Institute for Healthcare Improvement (CIHI, 2007) also produced a care quality guideline (Saving 5 Million Lives Campaign) on how to create an ideal transition home for patients, focused on HF. In the American Heart Association (AHA) scientific statement regarding HF transitions, Albert et al (2015) identified four main categories of transitional care concerns: medication management, follow-up appointments, health care provider communication, and non-medication related symptom management. These pragmatic
categories provide structure for researchers and policy makers to identify areas of concern within their own health system context.

In Canada, evidence suggests that one of the contributing factors to hospital readmission may be the considerable variation in transitional care delivery, as before 2017, there were no current focused Canadian HF transitional care best practice guidelines (Hayes et al, 2016). Researchers have studied interventions that improve the quality of transitional care between hospital and home. However, interventions have typically been ‘bundled’ making it difficult to discern which aspect of the intervention is causing the response (Albert et al, 2015). Previous researchers have identified multiple measures of successful care transition interventions such as: a decrease in 30 day hospital readmissions, psychosocial needs, stress, cost or death, or an increase in quality of life, functional status, satisfaction with care and compliance with physician follow-up (Altfield, et al, 2012; Centeno & Kahveci, 2014; Coleman et al, 2004; Englander et al, 2014; Kansagara et al, 2015; Naylor et al, 2004). Overall, transitional care is complex, and requires patient focused research within local contexts.

1.3 Patient Experience

Many qualitative researchers have reported the patient’s experience of HF (Andreasen et al, 2015; Berendsen et al, 2009; Doherty et al, 2007; Gallacher et al, 2011; Gysels & Higginson, 2011; Heo et al, 2009; Jones et al, 2014; Pihl, Fridlund & Martensson, 2011; Sacco et al, 2014; Simon et al, 2013; Stevenson et al, 2015). These studies have explored themes such as physical disability, loneliness, inactivity, breathlessness, dying, quality of life and hospital readmissions. Edmonds et al (2005) studied the symptom of breathlessness and found that patients with HF categorize it as
‘everyday’, ‘worsening’ or ‘uncontrollable’. Gysels and Higginson (2011) also interviewed HF patients about their breathlessness and patients spoke about the nature of it being ‘sudden, and inhibiting’. Dougherty et al (2007) conducted a grounded theory study of patients’ experiences of living with advanced HF and found that most patients do not plan well for end-of-life care and “tend to drift along while vaguely hoping for the best” (p. 480). Most HF research does not include patient preferences regarding their care, so this important information is often missing in the literature and subsequent practice recommendations (Blom et al, 2015).

A few studies have analyzed the HF patient experience with continuity of care between care providers, and identify patient’s unmet needs following discharge in relation to cardiac rehabilitation (Davidson et al, 2008; Uijen et al, 2012). Another study shared the experience of patients with the multi-morbidities of HF and chronic obstructive pulmonary disease post discharge from hospital, and was conducted in the United Kingdom (Doos et al, 2015). In this study, via face to face interview and a quantitative survey, participants identified issues related to medication and diagnosis information transfer, and poor continuity of care after discharge (Doos et al. 2015). Andreasen et al (2015) reported Danish frail elderly patients’ experiences of living with HF one week post transition from hospital to home. Participants described multiple ‘unsafe’ aspects of care transition such as not having adequate home care post discharge and lack of medication information and coordination leading to anxiety and frustration (Andreasen et al, 2015).
While the patient experience of many aspects of living with HF has been researched, overall, there have been few studies focused on the experience of transition from hospital to home, and none within the Canadian context.

1.4 Research Questions

Arnold et al (2015) state that more observational and local research is needed in the area of care transition for HF patients. Andreasen et al (2015) also support this type of research as it is necessary to evaluate current practice and improve care transitions. Consequently, the research question for this study is how do English-speaking adults with chronic HF, living in the Central Okanagan, who have experienced a HF-related admission within the last two weeks describe their experience of the care transition from hospital and home? Sub research questions are: What factors do patients identify that affect their care transition from hospital to home? What gaps in care do they note? What opportunities exist for care re-design in hospital and in the community? Are their care transition experiences congruent with latest care transition guidelines? Do patient’s positive experiences reflect components of patient-centered care?

1.5 Assumptions

1. Patients with HF will be willing to speak about their experiences of the transition from hospital to home.

2. Care transitions are fraught with complex interrelationships that deserve to be studied to understand the relationships, and improve care.

3. Patients will accept a researcher into their home, or meet in a place of their choosing for the interview.
1.6 Limitations

1. Only English speaking persons will be interviewed, unless they have a family member to translate.

2. As it is an unfunded Master’s research study, there will be no monetary compensation given to participants.

3. Participants may not feel comfortable sharing feedback regarding gaps in care for fear of their current care being affected.

To further investigate the scope of this issue, the state of research evidence will now be presented.
Chapter 2: Review of Literature

Hasenfuss & Mann (2015) in Braunwald’s seminal cardiac medical textbook, state HF is “a decline in pumping capacity of the heart” (p.454). Reduced heart function leads to chronic symptoms that the patient experiences such as: ankle swelling, shortness of breath, orthopnea (unable to lie flat), nocturia (waking in the night to urinate multiple times), weight gain, reduced appetite, decreased mental acuity, and fatigue (Hassenfuss & Mann, 2015). These physical symptoms affect the patient’s ability to care for themselves and adversely affecting many aspects of their activities of daily life (ADLs). Patients with HF are especially vulnerable during care transitions and the problem is magnified by a lack of quality of care (Dennison & Hughes, 2009).

Within this chapter, current literature pertaining to patient experience with HF in relation to transition will be presented. The American Heart Association’s latest scientific statement will provide the structure for this chapter. It outlines the primary factors that may negatively affect care transitions from hospital to home (Albert et al, 2015). The four factors are medication management, follow-up appointments, health care provider communication and symptom management. Two additional sections are provided relating to the effect of multiple comorbidities on the patient experience of care transitions, and interventions that have been found to improve the patient experience of transitions in general.

2.1 Medication Management

Factors related to medication management during care transition are described as unclear health provider instructions to patients, and issues related to medication reconciliation, transportation, and cost (Albert et al, 2015).
Unclear Instructions. Multiple medications, a lack of patient education, and the involvement of multiple care providers contribute to unclear instructions for the patient to follow. The latest Canadian Cardiovascular Society (CCS) best practice guidelines state that patients should be on a minimum of four different medications upon diagnosis, and this may increase to six or more depending on their responsiveness (Howlett et al, 2016). Patients often feel overwhelmed by the volume of medications and managing changes in their medications. Andreasen et al (2015) found that one of the main stressors for patients with HF within the first week post discharge was medication-related. Some researchers attribute this to lack of patient awareness. Doos et al (2014) found “73% of participants were unaware of the reasons for medication being prescribed and 64% of participants were lacking knowledge about potential side-effects of their prescribed medication” (p. 2405). Foust et al (2012) completed a chart review and found that half of the patients received partial discharge medication instructions. Unclear medication instructions negatively affect the patient experience during the transition from hospital to home.

Reconciliation issues. The second medication-related factor that affects the quality of care transitions identified by the AHA (2015) scientific statement is related to medication reconciliation. When the patient is admitted to hospital for an exacerbation, medications should be reconciled with what the patient takes at home, and again at discharge to reduce errors (Albert et al, 2015). Despite this, Foust et al (2012) found that 71.2% of patients had a medication discrepancy issue on discharge. After discharge from hospital, regular medication monitoring should occur with the primary care provider. Monitoring may include changes to the medication itself or the dose, until the
desired maximum effect is reached. During titration, the patient may experience side effects such as: low blood pressure causing dizziness or a fall, low serum potassium levels causing arrhythmias, low heart rate or heart block causing syncope, high serum creatinine signifying renal failure, and frequent urination (Howlett et al, 2016). These multiple changes in doses and types, accompanied by frequent side effects, are factors that decrease patient adherence to their medications.

Health care providers want to successfully support medication management, but they report that most “lack the time and support needed to ensure efficient and effective follow-ups and accurate monitoring of HF patients” (Hayes et al, 2015, p. 6). Increasing the quality of patient education, improving health care practitioner interactions in person or by tele-home monitoring, and simplifying the drug regime have been shown to increase the overall success of medication management (Molloy et al, 2012).

Transportation and cost. A lack of transportation affects the patient ability to source medication, and to attend follow-up appointments (Arnold et al, 2015). Possible barriers can be that the patient is elderly and unable to drive, does not have family or friends to drive them, or does not own a vehicle because of the prohibitive cost. Although a bus pass is more affordable, mobility may restrict access to the bus system. Overall, the cost of medication personally to the patient combined with the cost of interventional programs related to medication management must be taken into account for discharge planning (Altfeld et al, 2012; Arnold et al, 2015; Nazir et al, 2015). However, for patients who do have mobility issues, post-discharge home visits have been shown to facilitate effective care provider contact (Donaho et al, 2012; Feltner et
al, 2014). In order for the patient to have their medications reviewed post discharge, they must follow up with their primary care provider in the community.

2.2 Follow-up Appointments

The factors listed in the AHA (2015) care transition statement that impact the patient attending follow-up appointments are no appointment scheduled within one week of discharge, and patient awareness of the visit and its location. The most recent Canadian guidelines state that once discharged from hospital, or post-emergency department visit, patients should have a follow-up appointment within two weeks; whereas the latest American Heart Association statement outlines that the follow-up appointment should occur within one week (Albert et al, 2015; Howlett et al, 2016). Bradley et al (2013) found that arranging follow-up appointments before discharge ensured patients attended these visits and correlated with a lower hospital readmission rate. One survey showed that only 28% of hospitals in the United States always schedule the follow-up appointment showing low compliance with the guideline (Kociol, 2012). If the transitional follow-up care does not occur within this one to two week time period, research shows that the patient is at higher risk of readmission (Allen et al, 2014). Giamouzis et al (2011) concluded that “HF re-hospitalization clearly marks a fundamental change in the natural history of the syndrome, significantly increasing subsequent mortality and morbidity” thus making it an important measure of success in treating HF (p. 62). Lastly, discharge documentation should contain detail related to the timing of the follow-up appointment (Arnold et al, 2015).

Patients and caregivers may be unaware, or unsure of, the location, time and date of follow-up itself upon discharge (Albert et al, 2015). Centres often give patients
written and verbal instructions at the time of discharge; despite this, patients report being unsure of the plan for follow-up, where they could get further information, and to whom they should ask questions (Berendsen et al, 2009). Research shows that the health care provider’s capacity to see patients in a timely manner, due to the volume of patients, can also be a barrier to follow-up (Albert et al, 2015). Doos et al (2015) found that HF patients also prefer to have a phone call from the hospital or a telephone hotline to serve as a bridge to this first appointment. One study found that a social worker follow-up phone call, and care coordination post discharge increased the likelihood of physician follow-up (Altfield et al, 2012). Altfield et al (2012) found that one inpatient education session with a HF Clinical Nurse Specialist combined with follow-up phone calls increased attendance at follow up HCP visits, but did not decrease readmission rates. Attendance at the follow up visit is affected by the communication between HCPs.

2.3 Health Care Provider Communication

The transition home from hospital requires a high level of coordination between in-hospital and post-discharge caregivers (Felker & Teerlink, 2015). Research findings often report that patients express considerable uncertainty in relation to the quality of information transfer between hospital-based and community teams (Doos et al, 2015; Tully et al, 2010). One cited barrier to effective care transitions is the lack of, or conflicting information between HCPs, which contributes to patient, and family confusion (Seah, Tan & Wang, 2015). One study addressed this barrier by introducing a standardized paperwork process (Coleman et al, 2004). The researchers showed that when the patient brought a standardized communication tool, in the form of paper, to
each provider interaction, it reduced hospital readmission in the HF population by half (Coleman et al, 2004). Another study found that by partnering with community physicians, having a process in place to send all discharge summaries directly to the patient’s primary physician, and assigning staff to follow-up on test results that return after the patient has been discharged were all measures that decreased readmission rates (Bradley et al, 2013). A patient record, such as an official discharge summary, is recommended as the official handoff tool in the latest scientific statement from the American Heart Association (Albert et al, 2015). If the patient does see the primary care provider post discharge, in part due to effective HCP communication, they should be coached in self-management.

2.4 Non-Medication Signs and Symptoms Management

Another transition to home challenge for patients with HF is managing their signs and symptoms, which commonly include weight gain, shortness of breath and peripheral edema. Persons of advanced age, typical of the HF population, tend to have additional symptoms such as: severe fatigue, cognitive impairment, urinary incontinence, deconditioning, falls, depression, anxiety and pain (Falk et al, 2013; Heckman et al, 2014; Navidian et al, 2015). In a study done in the United States, only 29% of patients interviewed recognized weight gain as a symptom of HF exacerbation requiring hospital admission (Stevenson et al, 2015). Patients need to be aware of, and self-manage these signs and symptoms to create an effective transition from hospital to home, and reduce the chance of readmission. However, this burden often falls heavily on the patient.
**Patient work.** “Chronic HF is an illness that places a great deal of work on the patient” and caregivers (Gallacher et al, 2011, p. 235). Patient work, described as “treatment burden” in chronic HF, is not only physical, but also emotional and spiritual in nature (Gallacher et al, 2011, p. 235). Despite the research and interventions aimed at understanding and intervening to improve self-care and decrease ‘the work’ of the HF experience, studies show that patients still have difficulty integrating knowledge into daily routines (Spaling, Currie, Strachan & Clark, 2015). One modifiable barrier to self-care is the person’s willingness to enact self-care; therefore, nurses should openly discuss self-care with all patients and caregivers (Eldh, Enfors & Ekman, 2004). While in hospital, evidence suggests that the practitioner should include information regarding the potential impact of HF on survival and quality of life, ways to control it (low-sodium diet, activity and exercise, medication adherence), monitoring and managing signs and symptoms of worsening HF to support the transition from hospital to home (Albert et al, 2016). Managing HF is a difficult task for patients and families, a task that is made more difficult by the presence of co-morbid conditions that also need to be managed.

### 2.5 Comorbidities

Although not included in the AHA (2015) scientific statement about barriers to successful care transitions, co-morbidities also complicate the discharge from hospital to home. It is common for patients with HF to have co-morbidities such as chronic obstructive pulmonary disease, atrial fibrillation and mobility issues (Doos et al, 2012). Often, comorbidities restrict mobility and patients are not able to drive themselves thus making them reliant on their social network (Falk et al, 2013). Further, when patients
are discharged from hospital to home, they do not trust their physical capacity and this prevents them from attempting to increase activities that would increase their social ability (Pihl, Fridlund & Martensson, 2011). Social networks, residence, financial capacity, occupation and support groups have all been found to impact self-care, including attendance of follow-up visits (Albert et al, 2015; Strachan et al, 2014). Not maintaining physical ability results in a lower quality of life as patients have difficulty attaining happiness and engaging in fulfilling relationships with others (Heo et al, 2009; Seah, Tan, & Wang, 2016).

2.6 Additional Interventions

Thus far, this literature review has mainly focused on factors that act as barriers to successful care transitions, and the interventions used to address those barriers. The literature also contained other factors that positively impact care transitions from hospital to home. A systematic review reported that three months’ worth of home visits by an advanced practice nurse decreased all cause readmission (Feltner et al, 2014). Tele-home monitoring is another intervention that supports those who live in remote areas. It instructs patients in real-time how to appropriately modify their lifestyle behaviors (Naylor et al, 2004; Seto et al, 2012). Research shows that because tele-monitoring links care providers with patients, it increases awareness of symptoms, decreases anxiety and increases overall patient satisfaction (Graves, 2013; Seto et al, 2012).

In summary, a person’s journey with HF is wrought with multiple symptoms and varying disease progression. This literature review illustrates the state of research related to the concepts of patient experience of HF, care transition, comorbidities, and
interventions. The latest scientific statement from the AHA outlines the four main factors that affects the quality of the transition from hospital to home. Research regarding the HF patient experience of care transition is scarce and therefore more studies must be conducted in this area.
Chapter 3: Methods

The methods for this study are outlined in the following sections: research design, sample and recruitment, data collection, data analysis, rigor, and ethical considerations.

3.1 Research Design

This study was conducted using a qualitative approach to inquiry. Qualitative research ensures that the perspectives of the individual or group within a particular context are uncovered (Agee, 2009). An exploratory research design was chosen for this study because no prior research has been done to gain the HF patient and caregiver’s perspective on their care transitions from hospital to home in Canada. Qualitative research will allow for discovery and induction of themes from the data, and uncover possible factors that affect the care transition experience (Richards & Morse, 2013). The purpose of the study was to understand patient experiences with care transitions, and apply those learnings to practice. Therefore an interpretive description methodology was used as the analytical framework in order to produce practice-relevant findings (Hunt, 2009; Thorne, Reimer Kirkham and MacDonald-Emes, 1997). Interpretive description is built upon the methodologies of ethnography, grounded theory and phenomenology. Ethnographers seek to understand variations in human nature through observation, grounded theorists uncover social processes that drive human action, and phenomenologists relay a deep understanding of individual’s subjective experience. While each of these research methodologies are valuable classical approaches, they are too restrictive in scope for the purpose of this research
study. By using a non-categorical approach, themes can emerge and provide a breadth of useful information to inform practice.

Interpretive description methodology was created in response to the need for a nursing discipline specific framework. Researchers who use this methodology aim to develop knowledge about patient experience that aligns with the applied nature of nursing (Thorne et al, 1997). It honours the individual’s experience, while still considering the aggregate group being studied (Thorne et al, 1997). It takes the researcher “beyond mere description and into the domain of the ‘so what’” (Thorne, 2016). The ‘so what’ is answered by critically examining the findings in relation to the research question in order to readily inform practice.

3.2 Selection of Participants and Recruitment

Study participants were patients who had received transitional care between a hospital stay and home. In order to achieve maximal variation in the collected data, and thus produce a breadth of understanding of their experience, all adults admitted to local regional hospitals’ inpatient units with a diagnosis of HF and had no or minimal cognitive impairment were invited to participate.

Intact cognition and memory were vital for the purposes of this study, as the patient was required to recall the events of discharge up to two weeks before the interview. Therefore, the Mini-Cog screening tool was used to assess for issues with cognition and memory. Lessig et al, (2008) state that the Mini-Cog is efficacious, easy to use and can be used by non-specialists. It contains a three word short term memory test, and requires participants to draw a clock and set a particular time. Participants are given a point for each of the three words they can recall after drawing the clock, and
two points for a completed, correct clock. A point is taken off for each error made on the clock drawing. Participants who score less than 3/5 will not be able to participate in the study, as this has been shown to signify possible dementia (Borson et al, 2003). Consent was given by the author of the Mini-Cog to use the copyrighted tool via email.

The primary caregiver (e.g. partner, daughter/son) could also participate in the study if the participant agreed. Those participants who needed assistance with English were aided by a family member or close friend whom they appointed.

The exclusion criteria for patient participants included: having a cardiac implantable mechanical assist device, receiving cardiac surgery during the same hospital visit, or receiving active palliative care. Due to the intricate nature of the prognosis, patients with these additional considerations require multiple speciality supports put in place by the health care system; therefore, their experience of the care transition from hospital to home would be too diverse for the purpose of this study.

The sample size consisted of eight participants. Thorne (2016) states that if the clinical phenomenon occurs frequently (e.g. discharge from hospital to home) then a smaller sample size is adequate. In addition, time, purpose and resources must be considered when selecting the sample size (Thorne, 2016). The Clinical Nurse Specialist with the local cardiac program shared that this number of patients is typically discharged from hospital to home within the one to two month timeframe of this study. A smaller sample size is also congruent with a Master’s level thesis, performed by a junior researcher with no budget.

**Recruitment.** Following successful harmonized review by the University of British Columbia Okanagan campus (UBCO) and Interior Health (IH) Behavioural
Research Ethics Board, recruitment commenced. Participants were originally recruited from cardiac inpatient units at one tertiary hospital within the central interior of BC. However, due to difficulties with recruitment, a request was made, and granted, to amend the ethics approval to include recruitment from a second hospital within the central interior of BC. A volunteer research assistant (RA) was put in place to aid in recruitment at the additional hospital. The managers of all four units agreed to the inpatient units being used as a study site and to the proposed recruitment process (Appendix A). The researcher and RA visited each unit to orient charge nurses to the recruitment strategy. A research binder was left on each unit which outlined the study purpose, had the researcher and RA contact information, and contained the script for approaching patients regarding participation (Appendix B), the inclusion criteria, the consent to contact form (Appendix C), participant (and caregiver) consent forms (Appendix D & E) and demographic forms (Appendix F).

Each day the charge nurse, who does not provide direct patient care, identified patients with a diagnosis of HF while attending rounds on the unit. The charge nurse approached patients and their caregiver (if present) and following the five-minute long script, introduce the study, and invite their participation. If interested, the charge nurse let the patient (and caregiver) know that they will receive an in-hospital visit from the researcher or research assistant to determine their eligibility, and provide more details about the study. Participants (and caregivers) signed a permission to contact form that included their contact information. The signed permission to contact forms were kept in a locked cabinet on each unit until the researcher or research assistant picked them up in person.
The researcher or (RA) regularly stopped by the units to inquire about interested participants. If there was an interested participant, the researcher or RA visited the patient and caregiver (if present), completed a Mini-Cog assessment to determine sufficient cognitive ability, and answered any questions. The participants were given a copy of the consent forms and a demographic form to take home with them and complete at the time of the home interview. The researcher or RA explained that the patient’s caregiver was welcome to join the interview if the participant indicated this preference on the consent form, and if the caregiver also signed a participant consent form. The total time for recruitment and hospital visit was half an hour.

Completed permission to contact forms and Mini-Cog screening tools were scanned from the local unit printer to the researcher’s UBC email address and uploaded to a UBC secure Workspace folder that only the principal investigator and the researcher had access to. The researcher then called the patient to arrange the face-to-face interview at the patient’s home, or a phone interview if the patient lived over 50 kilometers away from the admitting hospital. The researcher collected the patient information form and the consent forms at the time of the home visit. If the patient lived further than 50 kilometers away from the admitting hospital, the patient was given a postmarked envelope to send the forms back to the researcher via standard mail. The day of the arranged interview, the researcher called the patient prior to the visit to inquire about whether they feel well enough to be interviewed. All interviews proceeded at the planned date and time.
3.3 Data Collection

Data collection was completed via semi-structured, open-ended, face-to-face or telephone interviews with the patient and their caregiver in the patient’s home. Thorne (2016) states that patient interviewing is a method that will identify patterns and themes from patients’ experiences. Face-to-face interviewing was the preferred method of data collection. However, one participant who was screened as eligible for the study lived over 50km away from the hospital. For that reason, it was determined the interview would take place over the phone. The researcher had formed a foundational relationship during the 30 minute recruitment visit in hospital, so the resulting phone interview was of comparable length and depth to the face-to-face interviews.

Each interview took approximately one and a half hours. An interview tool was used as a guide. It contained probing questions reflecting themes in current care guidelines to elicit more in-depth responses where needed (Appendix G). The researcher ensured that the “primary focus (was) on participants, on listening and really hearing, on prompting further depth, on expressing curiosity and genuine interest in the expertise that they [were] offering” (Thorne, p. 131, 2016). The interview was digitally audio-recorded then manually transcribed verbatim by the researcher. Participants completed a demographic form at the time of the interview and results were tabulated on an excel spreadsheet (Table 1). The form included a current medication list to determine the number of medications that should have been reconciled at transition. This provided perspective on a particularly complex discharge, versus one that was more straightforward. During and after the interview, the researcher took field notes.
that captured the researcher’s thoughts about the interview content, process, and observations about the participants’ appearance and living space.

3.4 Data Analysis

Thematic analysis was used to code the data. Thorne (2016) suggests that novice qualitative researchers use a broad-based coding technique that allows the researcher to look at the data pieces to see how they are related to one another and organize them into emerging themes. Thematic analysis allows the researcher “to discern patterns within the shared experience of persons with a similar health challenge” (Thorne, p. 42, 2016) such as HF. This approach ensures that as the coding of interviews progresses, it is easier to see the implications of the themes, and towards the completion of data collection, perform fine-tuning of the coding framework (Thorne, Kirkham, & O’Flynn-Magee, 2004).

Transcripts were then read line-by-line and words, phrases, or sentences assigned labels. Manual coding was completed by the researcher using colored markers with different colours distinguishing between codes. Similar codes were grouped into concept categories and served as an initial coding framework. The researcher’s advisor also performed manual coding of the same interview transcripts in order to ensure rigorous coding and to mentor the researcher in coding technique. The researcher also reviewed the collected field notes from each interview after the transcription was completed which allowed the researcher to also capture prominent observations. Thorne (2016) supports the use of multiple data sources within an interpretive description methodology stating that their use may “reduce the likelihood of falling into epistemological traps” (p. 86).
Once the first few interviews were manually coded, a basic coding framework was created. During the interview process, the coding framework was intermittently updated and saved in different iterations. Once all the data were manually coded, multiple techniques were used to assign the inducted themes. These included multiple readings of the transcripts in order to ensure a deep understanding of the data and re-listening of the voice recordings so as to capture voice inflections or tremor that implied strong emotion. The researcher also re-read and incorporated data from field notes and concept mapped each theme in a visual manner to note associations between themes that were not apparent in the written text. The researcher had frequent multiple conversations with the graduate supervisor about each concept and theme in relation to the whole project, context, and research process. Finally, and most importantly, the researcher wrote a self-reflexive journal throughout the process which documented the researcher’s positioning, interviewing technique, potential biases and emerging thoughts about the findings. The field notes, coding framework iterations and reflexive journaling all formed a reliable audit trail. An audit trail is a “thorough collection of documentation regarding all aspects of the research” and contributes to the overall credibility and reproducibility of the findings (Given, 2008).

3.5 Rigor

For the findings of a research study to be credible, the study must be designed with a high degree of rigor. Thorne’s (2016) four main criteria for evaluating rigor in a research study were used to guide the current study. The criteria include epistemological integrity, representative credibility, analytic logic and interpretive authority.
**Epistemological integrity.** In order to demonstrate epistemological integrity, the researcher must ensure the research question is in alignment with the nature of the knowledge being sought (Thorne, 2016). The nature of the knowledge in this study is the patient perspective on a clinical process, and best addressed through qualitative research that is lacking in this otherwise highly researched topic of HF. Interpretive description methodology analyzes the responses and produces results that induct common themes relating to the patient experience within the clinical context and process being studied. Using this method to answer this research question demonstrated threaded congruency throughout the project.

**Representative credibility.** In order to make claims about shared realities within a clinical group, the researcher must ensure the sample is representative of the target population (Thorne, 2016). As the target population is patients with HF experiencing the transition from hospital to home, it therefore follows that the sample is the same. It was decided that in order to achieve maximal variation of this population, but still provide useful transferable findings that reflected common themes, participants included all comers that met broad criteria from cardiac units in two local hospitals. This sampling approach was intended to meet two goals: to uncover common patient perspectives within this population, and to reflect a shared reality within a specific context. Using practice sites that share resources and management ensures the findings will be more applicable to the end users of the research. The researcher also used reflexive journaling to minimize personal bias being imposed upon the participant data.

**Analytic logic.** In the report of a research study, researchers must provide a precise, objective review of how they arrived at their findings. Thorne (2016) suggests
that “careful journaling or note taking of some kind will be essential… to produce a reasonable and defensible” argument for decisions that were made along the course of the study (p.139). Following each interview, the researcher’s impressions and queries were captured in hand written field notes. This ensured concepts identified at the time of the interview were incorporated into the overall analysis. Field notes and reflexive journaling together comprised an audit trail. Meticulous interpretation of these multiple data sources into the research findings ensured a high degree of analytic logic was incorporated into the study.

**Interpretive authority.** This measure of credibility gives “assurance that a researcher’s interpretations are trustworthy, that they fairly illustrate or reveal some truth external to his or her own bias or experience” (Thorne, 2016 p. 225). One method of ensuring unbiased interpretation is for the researcher to be aware of how their worldviews may affect the findings. Because nurse researchers are cultured predominantly within the biomedical model of health care, the researcher must be aware of how this informs their sources of truth.

Myrick & Tremblay (2007) state that ‘teaching can never be innocent’ whereby the teacher must carefully enter into the teaching and learning relationship with sound theoretical grounding, expert knowledge of the topic, and using a personally reflexive approach. The novice researcher is new to the role of researcher, and must heed this warning within the context of performing qualitative research with vulnerable participants. Thorne (2016) also suggests that performing a physical or psychological assessment of a patient in a typical clinical setting is quite different from being a ‘learner’ within the research relationship and that the researcher must be an
“encouraging and neutral facilitator” (p.129). Pillow (2003) suggests that researchers undergo the practice of “uncomfortable reflexivity” in order to increase the validity of study results (p. 193). Thus, before the first interview, the researcher began journaling about the “nature and substance” of their own potential biases about the clinical phenomena (Thorne, 2016, p.109).

**Regular meetings with advisor and thesis committee.** A further check on rigor is to regularly meet and discuss the research findings with the thesis committee. The graduate researcher had regular face-to-face meetings with the research advisor during data analysis to discuss the coding framework, any issues with the interview or data analysis process, or other miscellaneous concerns. Although meticulous design and process within a research study are important, the ethics of who, how or what to study must also be addressed.

### 3.6 Ethics

Each participant was assured about the voluntary nature of participation in the permission to contact and consent forms. They were also informed that the researcher is working with an experienced research team, has clinical expertise in this area, that their privacy will be protected, and that the study follows institutional ethics policy (UBC, 2016).

**Potential risks to participants.**

*Physical risks.* One potential risk to the participants was becoming physically tired by length of the interviews, or the scheduled time being in the middle of a HF exacerbation. To mitigate this risk, the researcher called participants the morning of the interview to ask if they were feeling well enough to participate, and asked again at the
midpoint of each interview. They were given the opportunity to complete the interview at another date and time. A prompt to this effect was included in the interview guide. Also, the researcher is an experienced cardiac nurse, so could identify if a patient was having symptoms, and then decide on an appropriate course of action such as suggesting the participant make an appointment with their primary care provider. However, no participants required medical attention during the interviews or needed to be rescheduled.

**Psychological or emotional risks.** There was the potential for participants to share experiences about the transition process that could have been temporarily upsetting. As participants were sharing their own experiences of care transition, the probability of this being a longstanding issue was remote. If the research participant was still working, interview appointments were made on their days off work at a time that was convenient for them. Participant vulnerability was addressed in a number of ways. The participants were interviewed in the privacy of their own home so as to not affect the care being provided while in hospital. There were no power relationship concerns, as the research assistant and researcher, although registered nurses, were not actively involved in their care. Participants were also recruited without concern for their gender, age, dependency, or socioeconomic status as the sample was intended to provide a breadth of information within this exploratory design.

**Social risks.** Another risk for participants was a perception that any negative reflections they share might impact the quality of care they will receive in the future. Participants were protected from future care provider bias by protecting their anonymity in the data collection process and study finding reports. The clinical nurse specialist
who was involved in the study, is employed by the local health authority, but was not given access to patient names. Only the researcher had access to the names and codes.

**Potential benefits.** A potential direct positive psychological benefit to participants would be to feel that their opinions and voices have been heard. A potential indirect benefit would be the improvement of HF care within the central interior of BC. In addition, findings from this study may help to inform future research, and best practice guidelines.

**Confidentiality and access to data.** Identity confidentiality was assured by coding the names of the participants. Each name was given a unique identifier code by the researcher and the file kept on an encrypted computer, backed up on the UBCO secure server. Only the graduate researcher had access to the participant names and unique identifier code. The rest of the research team (graduate student’s supervisor), and the internal committee member only had access to the transcribed data (with any identifiers removed) and analysis stored on a UBCO secure network. The participant identifier code was used to identify the interview transcriptions, coding, and data reporting. The participant demographic information was kept in a separate file on the secure UBCO network. The audio files were permanently deleted once transcribed by the graduate researcher. The study data and analysis will be backed up on the secure UBCO network for five years after publication and then permanently destroyed according to the UBC BREB (UBC, 2016). All hard copies of consents and demographics will be kept in a locked cabinet in the graduate supervisor’s office for five years after publication and then permanently destroyed via shredding as per the UBC BREB (UBC, 2016). Three caregivers participated in interviews, such that
confidentiality of the particular contents of the discussion for these interview could not be guaranteed. This risk was mitigated by addressing interview content confidentiality on the participant and caregiver consent form, and verbally reiterating this information at the time of the interview.
Chapter 4: Findings

This chapter describes study participants, their journey to the hospital, and presents an in-depth thematic analysis of their experiences during their hospital stay and through the transition to home. Participants included persons with HF and their caregivers. Caregiver comments were included in the analysis as a rich data source to capture the experience of transition. All patients were informed about their caregiver’s ability to participate, however only four completed the consent form. Of those four, one caregiver could not attend the time and date of the interview, but both participant and caregiver wished for the interview to proceed. Participants and caregivers were interviewed together. The interviews took place between January and December, 2017. A total of 12 patients were recruited from hospital, three were lost to follow up and one died. The eight patients included in the study (see Table 1), ranged in age from 50 to 92 years of age. No demographic data were collected about the caregivers. All three were participants’ wives. Participants experienced varied paths to hospital admission. Three used their emergency activation buttons (worn around the neck) to call an ambulance, two called the ambulance directly, two went to the emergency department via their caregiver with leg swelling or wounds, and one drove himself.

The findings are framed according to the patient journey from admission through discharge to home. There were four themes uncovered during the hospital stay, and two from the time of transitioning home. The first theme during the hospital stay described the care that was provided, the second highlighted participants’ responses to medication ‘tweaking’, the third was related to information they did or did not receive, and the last identified their variable readiness for discharge in relation to the health care
team. Once at home, the first theme that arose was ‘still recovering’, and the second was related to how they managed self-care.
Table 1 Participant Demographics

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Sex</th>
<th>Level of Education</th>
<th>Marital Status</th>
<th>Living Arrangement</th>
<th>Type of Accommodation</th>
<th>Co-Morbidities</th>
<th>LOS</th>
<th>Number of Times Admitted</th>
<th>HF Clinic Referral</th>
<th>Timing of Interview (days after discharge)</th>
<th>Received HF Education Resource Binder</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>89</td>
<td>F</td>
<td>High School</td>
<td>Widowed</td>
<td>Alone</td>
<td>Assisted Living</td>
<td>COPD, heart attack, ulcerative colitis, osteoporosis, cataracts, reduced mobility</td>
<td>4</td>
<td>3</td>
<td>no</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>92</td>
<td>M</td>
<td>Junior High</td>
<td>Married</td>
<td>With Spouse</td>
<td>Assisted Living</td>
<td>macular degen, stroke, reduced mobility</td>
<td>6</td>
<td>1</td>
<td>no</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>3</td>
<td>88</td>
<td>F</td>
<td>Junior High</td>
<td>Widowed</td>
<td>Alone (stays with daughter when ill)</td>
<td>Apartment/Condo</td>
<td>hypertension, heart attack, reduced mobility, arthritis, acid reflux</td>
<td>8</td>
<td>2</td>
<td>yes</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td>4</td>
<td>67</td>
<td>M</td>
<td>College Diploma</td>
<td>Single</td>
<td>Alone</td>
<td>House</td>
<td>COPD, Atrial Fibrillation, Depression, epilepsy, hypothyroidism, GI bleed, high cholestrol, reduced mobility</td>
<td>7</td>
<td>6</td>
<td>no</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>ID</td>
<td>Age</td>
<td>Sex</td>
<td>Level of Education</td>
<td>Marital Status</td>
<td>Living Arrangement</td>
<td>Type of Accommodation</td>
<td>Co-Morbidities</td>
<td>LOS</td>
<td>Number of Times Admitted</td>
<td>HF Clinic Referral</td>
<td>Num of Meds</td>
<td>Timing of Interview (days after discharge)</td>
</tr>
<tr>
<td>----</td>
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<td>----------</td>
<td>-------------------------------------------</td>
</tr>
<tr>
<td>5</td>
<td>50</td>
<td>M</td>
<td>Grade 11</td>
<td>Divorced</td>
<td>Alone</td>
<td>Apartment/Condo</td>
<td>HTN, MI, depression, anxiety, emphysema</td>
<td>6</td>
<td>3</td>
<td>no</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>6</td>
<td>60</td>
<td>M</td>
<td>High School</td>
<td>Married</td>
<td>With Spouse</td>
<td>House</td>
<td>HTN, MI, atrial flutter</td>
<td>6</td>
<td>1</td>
<td>yes</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>76</td>
<td>M</td>
<td>University</td>
<td>Married</td>
<td>With Spouse</td>
<td>House</td>
<td>afib, scleroderma, melanoma</td>
<td>12</td>
<td>2</td>
<td>no</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>8</td>
<td>88</td>
<td>M</td>
<td>Trade school</td>
<td>Married</td>
<td>With Spouse</td>
<td>House</td>
<td>HTN, MI, NIDDM, reduced mobility</td>
<td>6</td>
<td>1</td>
<td>no</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Avg</td>
<td>76</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6.8 days</td>
<td>2.4</td>
<td>2/8</td>
<td>7</td>
<td>7.5 days</td>
</tr>
</tbody>
</table>
4.1 The Hospital Stay

Participants’ experiences of the transition between hospital to home began with their hospital stay. Participants had an average length of stay of 6.8 days during which they interacted with a hospital environment that they described as noisy and busy compared to home. Within this environment, and core to their hospital experience, were the HCPs and the care they provided.

The care. Participants described receiving good overall care with each participant making at least one statement about receiving ‘good’ or ‘excellent’ care. One 88 year old female participant described the attentiveness of the nurses when she shared “the staff and nurses were very nice, excellent care…I have no complaints, they took care of me…the nurses, if I had a need, they came” (P3). Overall, participants appeared to be satisfied with their care, but their accounts gave insight into two distinct approaches to care. The two approaches were: ‘attending to the task, not the patient’ and ‘focused on the patient and not the task.’ When the health care provider was focused on the tasks they had to do, instead of the needs or concerns of the patient and family, the patient experience was not as positive.

Attending to the task, not the patient. Participants shared multiple incidences of feeling secondary to the tasks. They described a lack of personal attention to their physical, emotional, and discharge needs. In some cases they described a culture that was generally task oriented and reflected the busyness of nurses. One participant gave a critique of her observations and stated that nurses “spend an awful lot of time writing and reporting notes instead of going around the patient’s beds and asking if there’s something they can do” (P1). The culture of busyness affected participants’ communication with
nurses and other HCPs, as one participant shared, “I knew they were busy, so I never rang the damn bell” (P5). He also mentioned he spent most days off the unit because “well, that [call bell] ding keeps going, you don’t want to hear that ding” (P5). The busyness also conveyed to participants that there was a bed shortage and “they needed the beds” (P3). One participant felt the reason he was discharged quickly was that “they wanted the bed” (P4).

In other cases, participants communicated nurse staffing and busyness accounting for specific unmet needs. For example, one participant lamented how the lack of nurses impacted basic care needs such as morning care, “they are understaffed, they are so busy doing things that they don’t have time to do things like that” (P1). The partner of a male participant who was admitted with a new diagnosis of HF, felt that the nurses and doctors addressed his physical state, and completed their daily nursing tasks, but did not address their emotional needs. She stated not only had her husband “never been sick, and never been to hospital” but that for “him too, it was a very frightening experience” (caregiver of P8). She expressed fear of her husband dying and the need to think about funeral preparations, which no one addressed. She recalls thinking, “what if he dies, what if he dies in there and nothing is done! In some ways I would like to see some things set up so that at least that is not scaring the daylights out of me” (caregiver of P8).

Two caregivers described discharge-specific experiences where HCPs focused on the task, and not on their needs. One partner needed discharge teaching to promote continuity from hospital to home but found the nurse’s communication lacking, [the nurse] “was just more anxious about her end of making sure she got things done for discharge, and was not very communicative to us” (caregiver of P8). There was a lack of
“continuity of care that was supposed to continue from hospital to home” and she felt that they “just didn’t get really good communication at the end” (caregiver of P8). Another family member shared frustration about what seemed like a restricted scope of practice among the nurses that impeded their discharge. They shared that they “were both flabbergasted that it took so many people to discharge him…no one nurse could do two things. It was so complicated, it was unbelievable” (caregiver of P7).

Participants also experienced instances where the HCP completely missed performing a task that was important to them. Two participants lived alone, and both shared that in their opinion, they missed getting a referral to home care services. One said that he was not told that homecare was a possibility, and wasn’t offered it either. Yet he shared that he was unable to make food and do dishes stating he was “not feeling well enough to do it” (P5). Participants shared positive experiences of when the HCPs focused more on them as a person, instead of the task.

**Focused on the patient, not just the task.** When HCPs focused on the patient and family’s needs, and had good personal connections whilst performing a task, participants and caregivers described having a positive experience. During an interview, one caregiver mentioned “the first nurse that you had there, I found her very attentive and friendly, and I enjoyed talking with her myself” and in contrast she pointed out not enjoying the nurses who “just came in, did their thing and left” (caregiver of P8). Two participants commented on the lack of control over the environmental temperature yet one noted good care when he was brought a warm blanket by a nurse, he “slept like a log that night” (P8). One described a particularly vulnerable period and the good care he received that was focused on him, and not the task:
I would get out of bed and I wouldn’t know where I was, and I’d be just lost and stand there soiling myself…never once did they make me feel bad about it. They always would sort of clean me up, make the bed, and leave me with hundred percent dignity (P4).

However, he also experienced variation in the quality of care provided that was related to the different units. He noted that the care was “different in different places…even at [the hospital] it depended on which ward you were on” (P4).

4.2 Medication ‘Tweaking’

Medication change was a major, and often emotionally charged issue for participants. At the time of the interview, (within two weeks of hospital discharge), participants were managing a total of between four and ten different medications. All participants described challenges related to their medications during the transition from hospital to home. These were described as changes in the number, type, dose or frequency of their medications, which patients often referred to as ‘tweaking.’ For some, this tweaking was a continuation of a pattern of changing medications over repeat hospitalizations, such as one participant who described a drugstore of cumulative medications:

I’ve got buckets of pills that I was prescribed for here, I come out of the hospital, cash my prescription, then go back into the hospital and then they give you a prescription when you leave. I’ve got tons of pills that I’m not on anymore (P4).

Participants had variable responses to medication tweaking. Some were content and accepting of the changes, yet others were upset and angry with the disruption to their medication routine. Responses reflected their variable needs for inclusion and participation in their medication decision-making and management.
Acceptable Inclusion. Five participants (P1, P2, P3, P6, P8) were accepting of changes in their medications. They were content with their level of participation and involvement in decision-making related to medication changes. Accepting participants generally had a high level of knowledge about their medications, could administer the medication independently, and felt included in decision-making. An 88-year old female residing in an assisted living facility, administered her own medications from a bubble pack and demonstrated a high level of knowledge about her medications. She stated, “I know there are a lot of people that don’t even know the meds they are taking…..can you imagine?” (P1) She also described a partnership relationship with her family physician, “I like to know why, when, where, and how. Which can be a pain in the neck to some doctors, not to my doctor” (P1). A 92-year old male participant living in assisted living with his wife, similarly was accepting of medication changes his HCPs made in hospital, “well, they just said, they both told me, the cardiologist and (internist), they would tweak your medication, we think it would be worth trying, and they did” (P2).

Angered Exclusion. Three participants experienced frustration and discontentment when they were not included in decisions related to medication changes during their hospital stay and transition home. All participants described HCPs making changes to the dose or type of medications they had been taking prior to admission. Not being included in medication decisions made one participant feel disrespected. One participant expressed his frustration, “it was also something I was quite annoyed about is my mind isn’t as agile as it normally is, but I’m not stupid. And I don’t like being taken for stupid, and [the doctors said] ‘we’re gonna do this, and we’re gonna do that’”(P4).
Particularly upsetting for participants were medication changes made in hospital which they perceived as upsetting a carefully achieved regimen. Two described the long time and effort, or ‘tweaking’ it had taken on the part of the family physician and the patient working collaboratively to achieve the desired therapeutic effect. One described feeling angry when the attending hospital physician “completely changed my prescription around and put me on all kinds of other drugs” (P4). Another participant, who had had three readmissions for HF exacerbations in the past year, similarly experienced the health care team “null and void(ing) all my meds (P5)” without his input. He felt that the HCP countered all the work he and his family physician had done, “I told them they can go to hell cause (family doctor) and I spent a lot of time getting the right ones” (P5).

Contributing to participant frustrations with changing medications were inconsistencies among members of the healthcare team in prescribing practices. One was frustrated over the lack of agreement between providers stating, “one doctor wanted to do this and another wanted to do that” (P5). Another recounted a situation where “The one doctor…freaked right out and he and the nurse had an argument right in front of us about the quantity [of medication] to be given” (P7). The importance of being included in medication management was heightened when participants perceived that the differences among providers had contributed to medication incidences such as an overdose. Ever since this event, he and his wife are “very aware now”, even wary, of any changes that are made and describe an increased need for control over his medications (P7).

Participant experiences with medication issues comprised a major theme in the data analysis. It was fraught with high emotions and the perception of being included or
excluded from decision making. They also described how they received information about their medication and HF management.

4.3 Some Information Is Better than None

Three participants reported not receiving any HF specific information while in hospital (P3, P4, P5). Of the five who did receive information about HF and self-management during their hospital stay, the format, content and source were highly variable. Participants recounted either being given a physical binder, or pamphlets, but few had someone assess their learning needs and tailor the information accordingly. All participants described barriers to information sharing, that is, giving and receiving information with their HCPs. Patients who received information described it delivered in three formats: written, verbal, or a combination of the two.

**Written information.** Participants tended to receive teaching about HF in written format, and medication teaching in both verbal and written formats. Three received a HF education resource binder, the health authority’s standard of care for newly diagnosed patients (that they are asked to bring to all HCP visits), three received pamphlets, booklets or medication information sheets, and two reported only getting verbal information.

Two of the three participants who received the HF education resource binder, were first time hospital admissions and had new diagnoses of HF. They found the resource binder aided them in understanding the pathophysiology, symptoms of HF, and how to manage the condition. One participant “found it very helpful…and I knew what that [HF] was…that’s fluid on the lungs” (P2). Another participant identified the binder as a positive factor in his recovery “I’m managing pretty good with the binder they gave
me and the instructions they gave me” (P6). An 88-year old female with a longer HF history and multiple previous hospitalizations also found the binder helpful. Receiving the binder for the first time, she described it helped in “understanding what HF was all about and why my poor old heart was weak, and I found it very, very good” (P1). However, she recounted the nurse who brought her the binder making an assumption that she was knowledgable about her HF, an assumption that she corrected, “[her nurse] said ‘probably, since you had congestive HF before, you probably know it all anyway’. I said there’s always something new to learn” (P1). When she reflected on why she had not received the HF education resource binder during previous admissions, she stated, “So many young people think that because you’re 88 years old, you are senile, it is not necessarily so.”

The two participants who received pamphlets found they provided some useful information as one reflected “It gave you some indication of what could happen, or what should happen” (P7). All were pleased to receive information, yet one who received the HF resource and other pamphlets said “there’s so much paperwork, it’s ridiculous” (P1).

**Verbal information.** All participants described receiving some verbal education about HF and their medications. When it came to verbal information it was the source of the information that determined its quality for patients. Physicians, whether specialists or primary care physicians, were considered to be the best sources of information. For example, one participant shared that the best information he received was from the cardiologist who completed his angiogram in a different hospital, “he filled me in with more stuff than anybody” (P7). Half of the participants reported nurses as the primary source of verbal medication information during their hospital stay, although the
information they provided was inconsistent. An 88-year old female remarked, “the nurses would say ‘this was your water pill’ and all that. I knew the heart ones, and water pills, they did tell me that” (P3). In contrast, another felt he was left to his own devices stating, “They didn’t tell me what this medication [was] they gave me, I sort of figured it out on my own” (P5). One participant appeared skeptical about receiving “most of my medication information from nurses. Rather than the doctor, unfortunately, or fortunately” (P7). Two described informative conversations with pharmacists as one participant recalls, “they reviewed everything” and his wife agreed stating that “they were very good” (P7).

**Missing information.** Three participants, all of whom had from two to six hospitalizations in the previous year, reported that they did not receive any information related to HF while in hospital. One participant thought that it would be “helpful when it comes to your heart” to have knowledge about HF management” (P3). Another participant, with two HF related admissions, reported not receiving any HF related information while in hospital. She shared that this information gap was filled post-discharge when her “[family] doctor helped give me some [information]” (P3). One received pamphlets about other comorbidities, but, “considering all of the other ailments, I really didn’t get a lot of information [about HF]” (P4). The third participant denied receiving any pamphlets or binders of information about HF (P5).

On top of the variations in information sharing formats and content delivery about HF management and medications, there were also barriers to the information sharing itself.
Barriers to information sharing. Participants experienced barriers to information sharing and recounted them in a highly charged manner. Barriers included absent conversations and information timing issues.

Absent conversations. Participants shared feelings of frustration and confusion about missing information related to their plan of care. One attributed this to not getting enough time to speak with their attending physician in hospital:

They would never sit and talk to you, they would give you whatever, and then they’d vanish, never give any answer back. There was no communication doctor to patient, on a one to one basis, that was a discussion rather than telling you what was wrong and leaving (P7).

His caregiver shared the same sentiment describing what it felt like to wait for the primary physician each day:

They poked their heads in the door, they give you two or three words, and you are left the rest of the 23½ hours worried because you had questions and they didn’t stay around to answer any of them (caregiver of P7).

Absent conversations also resulted when participants felt intimidated by their family physician, and failed to ask questions they had. One caregiver stated:

He told me all kind of things, I sort of got the gist of it…he was talking to me by phone, you could tell that he was in a hurry, and I didn’t get a real clear picture…sometimes he throws out these big words…I wanted to ask him more about it, but I didn’t…in some ways, he intimidates me, and I thought, oh, it’s not important (caregiver of P8).

Timing. Timing was another barrier to information sharing. This was related to either the participant not being ‘ready’ to receive the information, or the HCP giving the
information too late in the hospital stay. One participant appeared to have received a high level of information. He received the HF education resource binder, medication information from his nurses, spent time reviewing medications with the pharmacist and described ample interaction with his attending physician. Yet, this 60-year old male participant still described poor timing when he said:

When you are in the hospital you kinda just pop the pills, and you are wondering what’s going on… I think there is a time that you are ready for the information, you are thinking about ‘ok, when can I get back to my job, I’ve got this to do’, you know what I mean? You have other things on your mind, you’re not paying attention the way maybe you should (P6).

Two participants received information late in the hospital stay. Receiving information late did not allow time for unanswered questions, as one participant conveyed, “they also inserted this Heart Function Clinic brochure, which I don’t know anything about, and I don’t know what their function is… do you?” (P6) Another participant noted receiving information just in time for discharge, “well, I got pamphlets, and I walked out the door” (P5). The third participant said “they never talked about discharge…we corralled her [family physician]” for information the morning he was going home (P7).

Information sharing is a vital part of successful transition from hospital to home. Participants noted that written information was valuable, that they needed to keep the communication lines open with the healthcare team with relation to the plan of care and medication, and noted barriers to this. All had an impact on the patient’s readiness for discharge.
4.4 Discharge Readiness

Discharge readiness was a recurring theme across participants’ experiences of transitioning from hospital to home. It described their sense of readiness to leave hospital and manage at home. Participant readiness for discharge fell into the following three patterns: those ready before the health care team, those on the same page as the healthcare team and those not ready- despite the HCP team discharging them.

Ready before the team. Being ready before the team involved an incongruency between desired and actual discharge in which patients desire to leave was ahead of a confirmed discharge. Three participants described being ready for discharge before the team. Participants in this group all lived at home or assisted living with their wives. Two had had no anticipatory discussion of discharge with the healthcare team. In one case, a discharge discussion was initiated by the participant and in the other the participant waited silently for discharge. A 76-year old male, in hospital for four days, aggressively pursued discharge ahead of the team stating, “they never did talk about discharge…we (he and his wife) forced the issue that ‘hey, we wanted to go home’” (P7). He further stated, “the reason I had to stay here was negligible compared to what I could do at home” (P7). However, a hasty departure, and missed nursing care resulted in an Emergency department visit the following day. An 88-year old male participant anticipated a different discharge date than the team, but didn’t tell anyone. He stated “I thought I would get out before the weekend, that’s true. It didn’t work out that way. I felt ready to go home” (P8). Another participant, a 92-year old male hospitalized for nine days, described how his physician was “reluctant to let me go…he finally agreed, he got backed up against the wall” (P2).
Participants ready for discharge ahead of the team also described barriers to achieving a timely discharge. One barrier related to not feeling qualified to offer an opinion on discharge as one noted, “I’m not a medical person’” (P8). Another barrier was not being able to have a face-to-face discussion with the attending physician. One participant described having to aggressively pursue the doctor. However, after speaking with the physician, (whom was also the their family doctor), he said “I think we were very well informed of what to look forward to” (P7).

‘They wouldn’t let me go if I wasn’t ready’. Three participants experienced readiness congruent with the judgement of the healthcare team as to their discharge readiness. They deferred to the healthcare team to determine when the timing was right for discharge and felt able to self-advocate if they did not feel ready for discharge. One 89-year old who lived alone in assisted living, expressed confidence the healthcare team had her best interests in mind, “I didn’t feel they were pushing me out, if I’d have said I don’t think I’m ready, they would’ve kept me, they all got in the act…they were a team” (P1). Another participant, an 88-year old female, who was transitioning to her daughter’s home to convalesce, described feeling aligned with the HCP team when she said, “I felt that I was ok, that I was ready to go home. If I was really sick, I would have said something” (P3). A 60-year old male living with his wife, relayed trust in his health care team to determine discharge timing saying “I honestly don’t think they’d send me home if I wasn’t ready. I was feeling better, it was probably time to go home” (P6). The attention to his symptoms by the healthcare team reinforced for him that discharge would happen when he was ready:
The doctor asked ‘How are you feeling?’ I said, ‘today, I don’t know if it’s in my head, but I’m feeling very uh, almost anxiety with my breathing’. And he checked my lungs and he said ‘you know what? We are going to keep you one more day, and give you another shot of Lasix and let you go home tomorrow.’ They were actually paying attention and reading me (P6).

The major factor for discharge readiness for this group was a patient-care provider relationship that showed they felt like a partner in their care, and their opinions were valued. Others had the opposite experience.

‘I’m not ready’. Two participants, who lived alone and had had multiple HF related hospitalizations, did not feel ready for discharge despite the HCP team’s judgement of their readiness. This incongruency resulted in participants feeling ‘pushed out’ of the hospital. One participant reported this lack of readiness during multiple previous hospitalizations, and that one time “they released me, I verbally, this came out. ‘I’m not ready’. Well, it was kind of early” (P5). Similarly, another 67-year old participant who lived alone in a rural area lamented: Basically, they kicked me out of (hospital)…I wasn’t better, it’s ‘well you’ve been here too long, you’ve got to go’…‘oh you’re fine, get the hell out of here’…they considered me to be well, wanted me out of there as quickly as possible…I ended up in (the hospital) afterwards and being (re)admitted after three days (P4).

According to the participants, lack of readiness was related to a lack of discharge planning for home support.

Lack of discharge planning for home support. Both participants who felt they were discharged before they were ready described gaps in planning for their home
support needs. According to a 50-year old participant, who lived alone, “they just told me” (P5). One stated, “I figured maybe send a home care worker or something, and not a damn thing! Last time, I walked into my old home and said ‘how in the fuck did I live like this?’” (P5) Another identified the need to be able to contact someone when he needed help. During the discharge process, one participant was told by “all these sort of nurses and social workers ‘if you have any problems, phone’, and (he) never got a reply from any of them” (P4). Those who lived alone and had little support, while still enduring HF symptoms, shared that they were feeling socially isolated. One stated, “I would love to have someone else in there. I’m tired of being alone…y’ know?” (P5) The other had previously had a roommate and reflected positively on the experience, “It was working out quite well having someone else in the house, just having someone else in the house” (P4).

In summary, participants were either ready for discharge in congruence with the HCP team’s decision, or not. When there was incongruency, they experienced frustration, a lack of home support, and in some cases, hospital readmission. Once at home, all experienced struggles with recovery.

4.5 Still Recovering at Home

‘Still recovering’ was a concept that dominated the participant experience of being at home after discharge. Each relayed a sense that they were not back to where they were before this admission. Because the interviews were conducted within two weeks of discharge, participants gave rich descriptions of the first few days at home. Some were interviewed within as little as three days from discharge, while others were as long as 14 days. Average time to interview was 7.5 days. As expected, there was an overall trend
toward recovery in those who were interviewed later rather than right after the transition home. All participants reported ongoing HF symptoms and described the burden of self-care management in relation to their Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). The IADLs which participants spoke of included food preparation, doing laundry, handling finances, filling prescriptions, shopping for groceries, mobility, and home maintenance. Factors that facilitated recovery were related to having good support at home and in the community and assistance with transportation. Barriers included living alone, especially in a rural setting, and lack of financial or social support.

**Dealing with ongoing HF symptoms.** All participants described still experiencing HF symptoms after discharge from hospital at the time of the interview. Symptoms included weakness, shortness of breath, a lack of mental ability and leg swelling. Ongoing HF symptoms greatly affected patients’ ability to perform ADLs and IADLs, necessitating help at home. Those who lived in an assisted living facility, or with a supportive spouse or adult child, were managing well at home, despite their symptoms. Those who lived alone struggled to manage their ADLs and IADLs.

**Weakness.** Weakness was the most prevalent symptom among participants in the immediate hospital recovery period. It ranged from mild to severe, immobilizing weakness. One described, “for a while, I was pretty weak…I’d rest lots…no power, ran out of steam” (P7). Weakness negatively affected participants self-care, ADLs and IADLs, mobility, ability to work, and for some threatened safety and put them at risk of falls. Another gave the analogy “I’m as weak as a kitten,” and found that weakness affected his ability to get back to work (P6). One 67 year-old participant who had
difficulty walking around the house described recurring physical weakness as his biggest barrier to doing rehabilitation exercises he had been given by the nurses in hospital:
I did try to get some exercises and everything to do, but um, after coming out of the hospital, I’m fine for the first two to three days, and then I get weaker and weaker and then um, ah, until I can’t do ‘em (P4).

For another participant, weakness affected his ability to perform basic house cleaning tasks, such as doing the dishes. When he first was discharged he recalled thinking, “no it’s like, dishes? I ain’t fucking doing dishes, I’ve got my remote in front of me, and that was about it. Not feeling well enough to do it” (P5). So severe was another’s weakness, that he was relegated to one part of his house, “I had to stay up, I couldn’t go down stairs, if I went down, I couldn’t get back up” (P7).

Participants managed their weakness in a number of ways: balancing ‘doing’ and rest, receiving help with ADLs from their partner or family, using installed safety equipment or mobility devices such as wheelchairs, and finally asking neighbours to accompany them to appointments. The weakness had mostly resolved by the two week visit for most. Caregivers noted relief as their spouses slowly regained their strength and resulting independence with ADLs. One participant’s wife had to help at first but said “I was happy to see when he progressed to being able to shower himself, and dress himself and dry himself off without too much exhaustion” (P7). One 50 year old male shared, “I’m managing a lot better (now) because there’s more strength”(P5); however, a few noted that they still had to adjust their usual pace. Another stated, “It’s hard for me to, to, just slow down, do everything at a slow speed. I have to reign myself in, slowly, slowly, or otherwise I get into trouble” (P4). This participant lives alone in a rural location and
shared how his weakness not only caused reduced mobility in his home, but also getting his IADLs attended to outside of his house:

Well, mobility I guess is my big one. If I lived a little bit closer, there is people that will drive you in and out of town and stuff like that. I live too far out to get one of those. Like, at the moment, I’ve got a whole wack of banking and laundry and this that and the other, things like haircuts, and stuff like that. You can get someone to drive you to town, but they don’t want to wait for you while you get a haircut. It’s not something they accept as being important (P4).

**Shortness of breath.** Three participants reported still experiencing shortness of breath after discharge. An 89 year old stated “I do find it harder to breathe when I’m laying down…easier to sleep in a chair…I can fall asleep in this chair without any problem at all!” (P1) and another shared that “as soon as I jump up to go and answer the phone, I lose all the air in my lungs” (P4). Another stayed at her daughter’s house and described what it was like going to the bathroom when she first got home, “if I tried to hurry, then I’d be in big, big trouble” (P3). She noted shortness of breath also affected her ability to get her IADLs attended to. She reported her “(daughter) has been helping me…I have a wheelchair, I really can’t walk too too far, I think because I run out of air” (P3).

**Swelling.** Two participants shared their experience with continued leg swelling. One 89 year old female stated “I notice a bit of swelling, but you know, I’m on such strong water pills now, that they are doing their job…big time” (P1).

**Lack of mental ability.** The lack of mental ability was particularly distressing for one individual. He stated one of his biggest ongoing problems was “the depletion of my
mental agility. Coming from having a super-fast mind, to not so much” (P4). He also stated that support from friends “doesn’t really take away any of the frustration” (P4).

Upon discharge, participants described ongoing HF symptoms that greatly affected their transition from hospital to home. They identified some factors that helped them cope with these symptoms, and some barriers. They also spoke about how they managed their HF self-care.

4.6 Self-Care

Once home from the hospital, participants described performing different levels of HF self-care. These included self-monitoring, which was watching for signs and symptoms of HF, and then self-managing, which was performing skills such as restricting fluid intake or increasing diuretic doses. Six participants were vigilant in the demanding ‘work’ of self-care. Participants who were less vigilant, were struggling.

**Vigilance.** Participants who were vigilant in self-monitoring adopted routines such as taking daily blood pressures, pulses and weights. Most reported that they were asked by their physician either in hospital, or at follow-up visits to do this monitoring. A common finding was that those who were managing well at home used notebooks and a home blood pressure machine (located on the kitchen table) to keep a record. One participant described this process:

[Family physician] stressed that we keep track of, in the coming days, of the weight and blood pressure and vital signs to record it and to come in after a week or something for follow-up, for a visit, which we did. We keep track of it every day (P7).

Self-monitoring also involved participants listening to their bodies, often in a way they had not been accustomed to. An 89 year old female said “I listen more to what my
body’s telling me now. I have to listen to my body now more than I have done in the past, you are basically responsible for your own body” (P1). The participant shared that she wasn’t always this in tune with her body:

Before [this admission], there were many times when I was, what I call in denial, but my heart was telling me ‘slow down’ you’re going too fast when I was doing the exercise program...now I’m fully aware of how far I can go as far as exercise is concerned. I was going at it too hard for my age and my heart (P1).

Self-monitoring provided increased awareness of the subtle signs and symptoms of HF issues. Participants then had to take steps to manage these symptoms.

Participants managed their HF by keeping salt intake low, raising extremities with edema, restricting water intake and adhering to medication regimens. To maintain his wellness, an 88 year old male outlined a few specific actions. He remarked that he now had to “keep low the salt intake, put my ‘hocks’ up when I sit down” (P8). However, he found this difficult to remember. His caregiver remarked shortly after, “You’re sitting with your feet down right now!” (caregiver of P8). One participant used technology as an aid to self-manage her HF medication administration. During the interview, an alarm went off and the participant said “That tells me it’s time to take my water pill” (P1).

Although many of these patients were managing well, it was also challenging to make these changes. One participant found the fluid restrictions particularly difficult, “I’m a little choked at how little water I’m allowed to drink. That’s my biggest fight right now” (P6). A 76 year-old, demonstrated his medication adherence when he shared, “I take the water pills and they may have to change that medication to get rid of the extra water”
While some struggled with these lifestyle changes, most performed effective self-care of their HF.

**Struggling.** Two participants reported struggling with self-care. In addition to their lack of home support and HF information, decreased mental ability, living alone, and financial issues, both participants mentioned experiencing mental health issues. A 50 year-old stated that he was having “panic attacks” that he kept forgetting to tell his family doctor about (P5). Another described having suicidal tendencies, but being physically unable to carry them out:

I was like ‘what do I do, slash my wrists or what’? How would you commit suicide anyway? Ah, you can’t walk up the mountain, y’know, I don’t keep a gun on the premises. The best I could do was throw a toaster in the bath (P4).

Effective self-care of HF requires work on the part of participants and caregivers. Factors that positively affected participants’ self-care vigilance were following care provider directions, closely monitoring and managing symptoms and living with a supportive caregiver or in assisted living.

Participants shared insightful, rich descriptions of their experiences in hospital and through the transition to the first few weeks at home. They spoke of the care they received, and whether they were ready to be discharged home or not. They shared multiple issues related to medication, difficulties in information sharing, and how weak they still felt after discharge. All required some level of support at home, although some did not receive it. Those who could provide self-care themselves, lived in assisted living, or lived with supportive caregivers, managed well. After reviewing these experiences and
the concepts that they reveal, HCPs can learn how best to provide care for patients undergoing the complex transition from hospital to home.
Chapter 5: Discussion

The purpose of this research study was to explore the experiences of persons with HF and their caregivers with the transition from hospital to home. This discussion chapter provides a comparison of this study’s findings in relation to current literature on HF and care transitions. The strengths and limitations of the study are outlined and conclusions are shared regarding the goals first presented in the introduction. Finally, this chapter suggests local and national implications for patients as participants in care, education, practice, and research.

5.1 Comparison of Findings

Findings of this study are mostly in alignment with current literature on patient experiences of HF and care transitions. Common issues were gaps in their transitional care related to person-centered care, missed information and missed home support. Findings that were unique to this study were the need to assess the preferred level of patient and family participation in their medication decision-making and discharge readiness throughout the hospital stay.

Person-centered care. Although participants repeatedly described receiving ‘good care’, nevertheless, they described situations when care was not person-centered, and subsequently adversely affected their transition experience. Person-centered care has been defined by the BC Ministry of Health (2015) as a system whereby:

Patients, families and caregivers are partners in health care, supported and encouraged to participate in their own care, decision-making about that care, choosing their level of participation in decision-making, quality improvement and health care redesign (p.1).
The lack of person-centered care (PCC) was evident in the way participants discussed nursing care which was ‘focused on the task, not the patient’. Participants relayed that they had personal concerns and worries that were not attended to such as missing work and end-of-life planning. If the HCP team members ‘attend to the patient’ and engage in meaningful discussion whilst completing tasks, they may uncover these patient concerns. Researchers have shown the importance of assessing elderly patient and caregiver priorities of care while in the hospital, as they are often different from the HCP team’s priorities (Hickman et al, 2011).

The Canadian HF guideline states that HF systems should provide “person-centered goals of care” (Ezekowitz et al., 2107); however, many participants in this study made reference to being unaware of the care plan or goals while in hospital (p. 1383). The patients and caregivers identified that their unaddressed concerns affected their ability, for example, to perform self-care once at home. Kane et al (2015) found that HF patient preferences with regards to their immediate clinical care choices can be uncovered more easily within a patient centered care approach. A systematic review by Ulin et al (2015) further suggests that a patient-centered approach to care provides benefits to HF patients such as increased self-efficacy, quality of life and a decrease in uncertainty. Howlett et al (2016), in a position statement from the Canadian Cardiovascular Society, also support the inclusion of patients in decision-making and suggest that HCPs “need to view the patient as a partner and adopt a collaborative approach” (p. 307).

Ekman et al (2012) found that a patient-centered care approach within the hospital improves participants’ ability to perform ADLs post discharge, thus increasing their ability to cope with the burdens of self-care. Jaarsma, Cameron, Reigel and Stomberg’s
(2017) literature update to their middle range theory of self-care of chronic illness identified factors influencing self-care in the context of a chronic disease such as HF. These are listed as habits, function, cognition, support from others, experience, skill, motivation, culture, confidence and access to care (Jaarsma, Cameron, Reigel & Stomberg, 2017). Participants in this study also noted similar barriers to self-care such as decreased mental agility, a lack of support from others once at home and limited ability to function due to weakness.

**Inclusive medication management.** Concerns with medication changes in hospital were a recurring issue for patients in the current study and were also related to a lack of person-centered care. Participants had varying needs for inclusion and participation in their medication decision-making and management during their hospital stay. Some were content to let the HCPs make changes without their input, which was named ‘acceptable inclusion’, while others felt ‘angered exclusion’ when they felt their physicians changed medications without consulting them. In the community and primary care settings, persons with HF have been cultured to be active participants in their own care. If patients are included in their healthcare decisions, they become confident in their own self-care. Reigel and Dickson (2008) provided a now, well-researched theory of HF self-care which posits that confidence plays an important role in self-care efficacy. This theory was first published twenty years ago, however, the acute care context hasn’t been able to fully integrate a person-centered care approach. Because of this, when patients and caregivers are admitted to hospital, they experience a disconnect. Discontentedness of the patients, with regards to a lack of shared decision-making, is potentially situated within this paradox.
**Missed care.** When care is missed, it is often described as ‘unmet needs’. Unmet social needs in hospital are often found to be more important to patients during transition than physical needs (Davidson, 2008), and the same was true for participants in this study. For example, two participants described being unable to perform ADLs by themselves because they lived alone, and did not have a primary caregiver who could assist them. Unmet needs originating in the hospital setting could be related to many factors. One could be the culture of ‘busyness’ that the participants noted. Researchers have found that “the busier the nurse is, the higher the nurse workload” (Baernhold, Cox & Scully, 2010). Researchers have identified high workload (related to low staffing levels), as a cause of missed patient care such as patient teaching (Baernhold, Cox & Scully, 2010; Orique et al, 2016). Weiss et al (2011) found that increasing nurse to patient ratios decreased the odds of readmission. The Canadian HF guidelines state that a successful HF health system or program has adequate clinical staff and program support, however, the guideline does not contain specific staffing levels (Ezekowitiz et al, 2017).

**Missing information.** Patients in this study had an average length of hospital stay of approximately one week compared to the national average of nine days (CIHI, 2016). Despite a number of days in hospital, patients described considerable variability in the type, format, source and timing of the education. For example, three participants reported that they received no written information. Five of eight patients in this study received some form of printed information related to HF. However, only three of those five received the standard of care HF educational resource binder. Insufficient HF education before discharge has been well documented (Altfield et al, 2013, Arnold et al., 2015;
Berendsen et al, 2009). Regardless of the format, patients agreed that any information they received was useful.

Participants and caregivers noted that nurses were the ones doing most of the discharge teaching and planning. The literature often points towards the bedside nurses as best positioned to provide discharge teaching and planning. However, Nosbusch, Weiss & Bobay (2011) found that acute care nursing staff experience many challenges to successful discharge planning: role confusion, poor team communication, a lack of time in the busy day, a lack of care continuity, not enough disease-specific knowledge, a lack of systems and structures, and feeling of being ‘invisible’ in this role. There exists tensions amongst bedside nurses and the rest of the healthcare team as to whom discharge teaching belongs to.

HCPs must ensure that patients understand and comprehend the discharge information they receive (Regalbuto et al., 2015). It has been shown that up to “(59.6%) patients [are] able to accurately describe their diagnosis post-discharge”, making it that much more important to emphasize in the teaching sessions (Horwitz et al, 2013, p. 2). Most study participants evidenced comprehension in application of information through their self-monitoring and self-managing activities. Regalbuto et al (2015) found that hospitalized patients with HF who did not attend high school or college have inadequate comprehension of discharge instructions and higher rates of 30-day readmissions. Three participants in the present study fell into this category. Research has shown that there are various effective teaching methods that ensure knowledge comprehension for HF patients with low health literacy (Evangelista et al, 2010). They suggested that success can be achieved if HCPs “recognize the consequences of low health literacy, screen patients at
risk, document literacy levels and learning preferences, and integrate effective strategies to enhance patients’ understanding into practice (Evangelista et al, 2010). One such strategy often used in HF patient teaching is the ‘teach-back’ method. It involves the HCP asking open-ended questions to explain the information provided to the person during the education session (Haney & Shepherd, 2014). This technique, as well as home visits and telehealth contact post discharge, have been shown to decrease hospital readmission (Evangelista et al, 2010; Hansen et al, 2013; Vedel & Kanassov, 2015).

Another information-related concern from participants in this study was a lack of time to communicate and receive information about their diagnosis, plan of care and discharge times with their physicians in hospital-even when their own GP was the attending physician. A lack of communication has been shown to impede a successful care transition from hospital to home (Arnold et al., 2015).

**Missing home supports.** Participants who lived in supportive housing or with a supportive spouse were coping well at home. The two patients who described not coping well physically or mentally, lived alone and had evidence of substance use issues. The CCS guidelines state that the health system should have “standardized risk stratification criteria to ensure timely referral and access to appropriate care” to catch the patients who need it (Ezekowitz et al, 2017). Also, patients should be screened for those at highest risk for readmission, and if the screen is positive, a specific plan of care should be created with the patient and team (Bixby & Naylor, 2009). Participants who lived alone reported that HCPs in hospital did not arrange home care and social supports. Nielsen et al (2008) outline that HCPs often make errors in their assessment of patient’s need for home support when they fail to involve the patient and caregiver in discharge planning.
Barnason, Zimmerman and Young (2012) report that these errors in assessment cause not only unmet physical needs, but unmet psychosocial needs which adversely affect self-care of HF. Those without proper psychosocial support have been shown to have a higher number of physical symptoms, higher emergency department visits and readmissions (Barnason, Zimmerman & Young, 2012).

**Discharge Readiness.** Discharge readiness emerged as an important issue for patients/caregivers in the current study. On average, 30% of patients report receiving less than one day’s advance notice of discharge, which is in line with the findings of this study (Horwitz et al, 2013). Although some patients in the current study spoke of discharges occurring quickly, it was differences in *perceived discharge readiness* between patients and health providers that was of greater importance. Although the concept of assessing patient and family discharge readiness is not addressed in national guidelines, evidence suggests that discordance in readiness between patient and provider can have negative outcomes for patients (Wallace et al., 2018). Because of this possible disconnect, it is important to gain the patient perspective on discharge readiness, and not rely solely on HCP judgement, as studies have shown that these two can differ (Molywan et al, 2015). There have been some tools that have been validated for use in hospital to assess patient readiness, such as the patient completed Readiness for Hospital Discharge Scale Short Form (Fuchs, 2013). It has been shown to positively correlate with seven day self-care of HF scores, and may reduce patient bias (Fuchs, 2013). Having a scoring tool is helpful, as the older adult HF population, which is largely represented in this study, has a tendency to ‘appear and act abled’, which may falsely inform HCPs of their readiness (Rush, Kjorven & Hole, 2014).
A lack of discharge readiness was found to be associated with poorer coping at home and lower perceived quality of the hospital to home transition (Wallace et al., 2018). Further, patient education level, and patient living situation (alone vs. with others), contributed to patient-reported experiences of their transition from hospital to home (Wallace et al., 2018). In the current study, living situation influenced readiness. Both participants who lived alone stated they were not ready at the time they were discharged.

In summary, this study’s findings were mostly in alignment with current research and best practice guidelines in HF care, and care transitions. This study afforded the patient and caregiver view of transition, one which is lacking in the literature. Participants reported gaps in care related to a lack of person-centered care which caused missed care, information and home support. It also highlighted the importance of shared decision-making in relation to medication changes, and frequent discharge readiness assessment.

5.2 Strengths and Limitations of the Research

The greatest strength of this study is that it is the first qualitative study that has accessed HF patients’ experiences of the transition from hospital to home within the Canadian context. The voice of the caregiver was also heard in this study. All participants were welcome to have a caregiver present for the interview, so all had an equal chance to be involved. There is only one other mixed method study of patient and carer experience found in current literature, and was conducted in the United Kingdom (Doos et al, 2014).

Another strength is the timing of the interviews. They took place within two weeks of discharge. Research shows that the first few weeks after discharge are the most vulnerable period for readmission (Anderson, 2014; Andreasen, 2015; Balaban et al,
The short time period between the discharge and the interview also ensured that the experience was fresh in participants’ memories, and easier to recall.

Interviewing participants in their home environment gave the researcher an opportunity to observe the patient context, which helped to complete a picture of the participant experience. The only exception was the one interview conducted over the phone. Interpretive description methodology includes an ethnographic perspective which allows researchers to “understand human nature as the object of studying variation” (Thorne, 2016, p. 32). This context also gave the researcher a sense of how they were functioning post-hospitalization beyond their words.

Another strength of this research study was that the researcher transcribed the recorded interviews. Thorne encourages junior researchers to engage in the transcription process as it “can be amazing what you hear when you focus on words and sounds and silent spaces rather than simply on storyline” (Thorne, 2016, p.144). The researcher’s supervisor, an experienced qualitative researcher, also coded the initial transcripts to ensure the student was creating and following a rigorous coding structure.

The main limitation of this study is the small sample size. However, Thorne (2016) suggests that small sample sizes are appropriate when, “certain phenomenon occurs commonly within clinical populations…then we can likely determine that engaging with a small number of individuals experientially familiar with it” (p. 94). Thorne (2016) also states that “it is not uncommon or inappropriate for time and resources to become a reasonable element in the decision to constrain sampling” (p. 96). Because of the length of time it took to recruit eight participants, and for a Master’s degree level research study, it was decided that this sample size was sufficient. However,
qualitative researchers are commonly expected to reach ‘data saturation’ to ensure there is “the variance required to make certain theoretical claims about the full range of configurations within the basic social process behavior” (Thorne, 2016, p. 98). But, this study was designed as exploratory research of a clinical process, not a deep understanding about a specific part within that process. It is meant to “offer a meaningful clinical description, framed in such a manner that it raises the questions and concerns that a disciplinary lens can bring to bear on a complex problem” (Thorne, 2016, p. 96).

While conducting the interviews within two weeks of discharge ensured participants had the details of their transition fresh in mind, it also meant that a few had not yet had a follow-up appointment with their primary care provider, and potentially had not yet experienced discharge-related complications. Another potential limitation is that participants were not asked to include how long they had been diagnosed with HF. This information could have provided more context to the amount of HF or medication information they needed, or wanted during the transition.

This study included participants from one geographic area, limiting the transferability of the findings to other areas. The participants were recruited from two hospitals within one geographic area. One was a tertiary hospital and one a community hospital. Compared to a tertiary centre, community hospitals often have less specialty staff and expertise which may have affected the depth of cardiac focused education the patients received, however, there was no specific trend in this study’s data to suggest this.

The interviews were spaced out over one year due to difficulty with recruitment. Sampling over the course of a year could have affected the participants’ experiences with transportation issues, or symptoms related to seasonal changes with heat or cold. It could
also reflect changes to the care being provided in the hospital, as some program related changes or improvements could have affected care delivery and subsequently, the patient and caregiver experience.

5.3 Overall Significance of the Study

The aim of this research study was to uncover the patient experience of transition from hospital to home within the central Interior BC context. Secondary goals included discovering what gaps in care exist, what opportunities there may be for care redesign, to see if the care patients reported aligned with best practice, and what experiences reflected a person-centered care approach. This study did meet its goals. It found, for example, that patients were able to identify gaps in care. Once at home, they were weak, and relied heavily on supports to complete ADLs and IADLs. A few participants provided the perspective of those who did not have these supports, and the unique challenges that they faced. Many participants identified gaps in care in the hospital such as missing care, missed information and missed home referrals. Some were passionate about control over their medication, and shared strong, negative feelings when their HCPs did not include them in the decision making process.

Current best practice guidelines are largely missing the patient and caregiver lens on this issue (Blom et al, 2015). This study provides a small sample of patient and caregiver experiences of what it was like to be a patient discharged home with HF in the central Interior of British Columbia. There has not been a study done with this population in this context previously, so the exploratory research findings afford a beneficial starting point that can be used to inform patients, HCPs, educators, decision-makers, and to possibly begin to build a program of research in this area.
5.4 Implications

Due to the exploratory nature and small sample size of this study, the findings of this study suggest limited implications for patients, HCPs, education and research. Findings will be most pertinent for the local context, beginning with persons with HF in the Central Interior of BC and concluding with some broad implications for national guidelines.

**Persons with HF and Caregivers.** For those admitted to hospital for HF treatment, this study suggests that they should expect to be actively involved in decision-making throughout the hospital to home transition, as this is best practice. However, they should also be informed that this approach has not been well taken up in the hospital setting, compared to what they experience in the community. Therefore, some suggestions can be given to increase their level of involvement during their stay. For example, patients and caregivers should be encouraged to request written or verbal information related to the HF diagnosis from the health care team. They should ask questions related to their diagnosis(es), treatment and plan of care until they can reiterate it back and receive confirmation that it is correct. They should feel welcome to share personal concerns and priorities with the team, knowing that the HCP team will likely have different priorities, but that it will help keep everyone on the same page. Patients should ask when the anticipated discharge date will be, and openly share any concerns with the plan. In order to affect change in the health system, patients may consider joining the British Columbia (BC) Patient Voices Network (PVN). An affiliate of the BC Patient Safety and Quality Council, the mission of this network is to support patients and health care partners in co-designing care (PVN, 2018).
Health care practitioners. Participants noted a lack of person-centered care while in hospital, yet the local health authority espouses patient and family centered care. Therefore, hospital-based HCPs should inform themselves of PCC and integrate a person-centered approach into the care that they provide. One way to accomplish this was recently suggested by the PVN, and suggests HCPs ask: “What are some things that are important to you right now?” and “What can I do to best support you in your care today?” (PVN, 2018). HCPs should assess each patient’s need for inclusion in decision-making regarding their care (especially related to medication changes) and adjust their approach accordingly. The HCP team should then offer the patient and caregiver a chance to participate in their plan of care. For example, HCPs should discover and track patient and family readiness from the time of admission in a visible location in the patient hospital room, such as a white board. HCPs should also advocate for patients and families to stay in hospital until they are in alignment with the HCP team’s plan for discharge (Wallace et al, 2018). The plan should also include person-specific interventions which ensure that psychosocial issues, not just physical issues, are addressed and an action plan is in place to address them throughout the transition home (Evangelista et al, 2010).

Some participants missed receiving HF information while in hospital. HCPs should be familiar with existing HF educational resources, such as the health authority HF educational resource binder, and make the time to offer and review the resource with patients and families who have a HF diagnosis.

Health care provider educators. Participants in this study noted lack of a person-centered approach to their care. This research can inform this aspect of college or university-based curricula. This approach should be embedded in a more applied manner
within the curriculum, in order to create a culture shift away from provider-centric practice. For example, when teaching skills to students or HCPs, educators should provide contextual psychosocial or physical patient variation that forces students to alter their approach. They would need to insert marks for person-centered decisions that could be added to existing rubrics. This will ensure that students see the importance of integrating the person-centered approach into the psychomotor task at hand.

Educators should support the use of the ‘teach back’ technique for teaching patients and caregivers about their HF. HCP training programs could consider interprofessional experiences with social work students in order to learn about what support they may provide for patients who are missing home supports or live alone. Educators should advocate for simulated scenarios where the student or orientee has to identify a patient who is at high risk of readmission (using a validated risk screening tool), and ensure they know how to mobilize patient and situation-specific resources for patients and families in the community.

**Hospital-based clinical educators.** Clinical educators should build upon the HF teaching content that was delivered to HCPs when they were students. They should support incoming staff by providing simulated HF patient teaching scenarios as part of the orientation process. Educators should ensure that new and current employees are oriented to teaching materials, how the materials are intended to be used and shared with patients and families, and how to navigate issues such as low health literacy. Educators are often asked to ensure written materials are routinely available by educating the charge nurses and partnering with other HCPs present on the unit. They should also share with unit managers any concerns that HCPs and patients have with the usage of the written
materials, and work with the greater educator network in the health authority to ensure standardization throughout.

**Health care system decision-makers.** Participants in this study noted that the busy, noisy hospital environment adversely affected their experience. Therefore, the local health authority should strive to ensure nurse to patient ratios are appropriate for the acuity (both social and physical needs) of HF patients in acute care. This will allow bedside care providers to be less ‘busy’ and complete personal care, and co-create rich care plans that identify and address patient-specific needs. The lack of person and family centered care has been associated with high provider to patient ratios (Baernhold, Cox & Scully, 2010; Orique et al, 2016; Weiss et al, 2011). Also, Health authority program changes should be made with patients as partners. For example, a standardized educational pathway could be created which ensures that patients are provided an opportunity to identify their learning needs are met in a timely manner, within a person-centered approach.

Some participants in this study noted they did not receive sufficient social or physical home support. Research shows that a standardized risk stratification process should be put in place by administrators to identify those patients at high risk of readmission (Anderson, 2014; Bixby & Naylor, 2009). This patient population should be connected with a social worker, and with necessary home supports like nursing care, meals, mental health follow-up, and ultimately, post discharge home follow up (Allen et al, 2014).

Participants noted a lack of continuity between the primary care provider (family physician) relationship characterized by shared decision-making, compared to the
approach by the hospital HCP team in which they felt excluded in decision-making. Acute care HCPs should attempt to include patients and families in decision-making, in order to increase the continuity of care experience. Not only does increasing patient involvement in decision-making improve the overall transition experience for patients and caregivers, increased cross communication between family physicians and the hospital based physicians has been shown to reduce rates of readmission (Coleman et al, 2004). One study was able to achieve this through providing the patient and caregiver with a personal health record booklet which they completed with the support of a transition coach. This served as an information resource for all physicians as to each individual patient’s active problem list, red flags of physical deterioration, and a transfer information checklist (Coleman et al, 2004).

This study found great variance in the HF information, written and verbal, that patients and caregivers received while in hospital. Hiring a hospital-based advanced practice nurse could help ensure that information is kept consistent between units and HCPs by providing inservices, doing chart audits, and assessing patient and caregiver understanding. Bryant-Lukosius et al (2015) found that in a systematic review, Clinical Nurse Specialist (CNS) care of persons with HF while in hospital improved both patient satisfaction and treatment adherence. Conversely, heart function clinic nurses from the community could visit new patients in hospital, so patients and caregivers have a familiar face and name to reach out to once home, however this intervention has not been tested in the literature.

Conversely, hiring a community-based HF clinic nurse who visits the hospital would raise awareness of the function of the clinic, something that the patients in this
study stated they were unaware of. The HF community nurse could also visit the HF patients who are readmitted and be consulted with the in-hospital care and discharge plan. They are well-positioned to facilitate the creation of person-centered care plans while in hospital and improve continuity of care to the community.

A standardized HF pathway would also increase the continuity of care provided amongst the acute care units. Research shows that the health care system should support HCPs to create a standardized HF patient pathway so there is consistency with information and process (Albert et al, 2015).

Guideline developers. The latest best practice guidelines produced by the Canadian Cardiovascular Society primarily focus on the physical management of the patient’s symptoms and test results. In the introductory paragraph, it states that the guideline is “for specialists and allied health professionals obliged with the duty of bestowing optimal care to patients and families” (Ezekowitz et al, 2017). The text used in this statement illustrates the HCP’s role is to direct care uni-directionally to the patient, instead of the care being provided in an equal partnership. Therefore, this research suggests that participants felt like they were the recipient of care, instead of a partner in their care. The guideline language should shift from describing care done ‘to’ a patient, towards care given ‘with’ the patient input in order to shift this paradigm towards a person-centered approach. This could be accomplished by partnering with patients and caregivers to develop the wording of these sections.

5.5 Future Research Directions

There are many possible research directions that could stem from this study. Due to the paucity of qualitative research on the person’s experience of their care transition,
more research needs to be done in this area (Doos et al, 2014). The most effective research approach that would address the lack of person-centered care found in this study, would be to do patient oriented research which involves patients from the beginning of the research study and including what is most important to them that needs to be researched (BC Ministry of Health, 2015; Newhouse, 2015).

The study itself could be replicated with a larger sample size which would increase the reliability of the findings. Interventional studies could be designed to test the effectiveness of a tool that tracks patient and family discharge readiness in comparison to the HCP team’s projection. One such tool was created through rapid improvement cycles on a patient care unit with the bedside staff (Tyler et al, 2016). The literature contains reports of tools being used, or tested, however most are focused on collecting and interpreting data from the electronic health record, and omit patient preferences (Banoff et al, 2016; Tyler et al, 2014). Another local interventional study could determine the efficacy of heart function clinic community nurses visiting patients in hospital on either increasing attendance at HF clinics, or reducing readmission. This research has been performed in other areas, but the Central Interior of BC context may provide unique findings.

The current study protocol could also be intermittently reproduced as a part of Quality Improvement initiative within the local health authority. This would help identify any new potential factors affecting patient’s care transitions, or track changes in current themes.

In conclusion, this thesis research study provided an overdue opportunity for persons with HFand their caregivers, who have experienced a recent hospital admission,
to share what it was like to transition home within the central interior of British Columbia. They shared personal stories, insights and perceived barriers to their discharge experiences. The research question has been answered, gaps in care have been identified and implications for education, practice and research have been made. The results of this study will inform participants, educators, HCPs, policy makers and future researchers.
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Appendices

Appendix A Health Authority Director and Manager Approval

Monday, February 20th, 2017

I have no objections to approaching 2nd floor patients. Best wishes on the success of the research.

Regards

[Redacted]

Manager, Medical Inpatient

2 East & West and Health Care Aides

Hospitals and Communities Integrated Services (HCIS)

Vernon Jubilee Hospital

Room 227, Jubilee Buiding

2101 32 Street Vernon, BC V1T 5L2

t. 250. 558.1200 ext. 1722

m. 250.309.8251

Hi Colleen

More than happy for level 6 to be part of this.

Kind regards

[Redacted]

Manager level 6 Medical / Telemetry and RN floats

Vernon Jubilee Hospital

Tel office:- 250 503 3796

Cell : -250 308 8216

From: duManoir, Colleen [mailto:cduman01@mail.ubc.ca]

Sent: Friday, February 17, 2017 12:25 PM
To: 

Subject: Recruiting for Heart Failure Study
Importance: High

Good afternoon,

I am a Masters of Nursing student from UBC Okanagan. I have been recruiting patients from KGH for my heart failure study, but due to the BC Tech4home Heart Failure study recruiting that just started at KGH, I need to recruit patients from another facility. The purpose of my study is to explore the patient experience of their transition from hospital to home.

I was wondering if you may allow [redacted], one of your nurses from the ED at VJH, to approach patients with a heart failure diagnosis on your units to see if they meet the criteria? I would then visit them at their home within 2 weeks of discharge. I only need 8 or 9 more patients.

I have attached the approval from [redacted] and study information for you to view. If you agree, I will submit an addendum to UBC/IH harmonized ethics, and could start recruiting again within about 2 weeks.

Please feel free to call me on my cell if you have any concerns or questions. [redacted]

Sincerely,

Colleen duManoir BScN, RN

School of Nursing
Faculty of Health & Social Development
University of British Columbia, Okanagan Campus
ART 145 - 1147 Research Road, Kelowna, BC V1V 1V7
Tel: 250-807-9984  Fax: 250-807-8655  Cell: 250-215-3809

Thursday, Nov 24th, 2016

Hi Colleen,
Great to hear from you.

Thank you for your email. This sounds like a great project and very relevant to the current priorities within IH. I did have some questions and concerns about the timing of this work as we have another Provincial Heart Failure Research project starting at the end of January. Kathy and Jeannine have assured me that this should not be a conflict. Therefore, you have my full endorsement to conduct this project on our in-patient Cardiac Units. Good luck. I would love to see the learnings once you have them compiled.

Jaymi Chernoff
Program Director – Cardiac Services
Health Service Director – KGH Critical Care
Hospitals and Communities Integrated Services (HCIS)
Interior Health Authority
2268 Pandosy Street Kelowna, BC V1Y 1T2
DIRECT: 250-862-4422  MOBILE: 778-214-3513

From: duManoir, Colleen [mailto:cduman01@mail.ubc.ca]
Sent: Sunday, November 20, 2016 10:17 AM
To: [redacted]
Subject: FW: Research Proposal

Good morning [redacted]

As you know, I have been working on my heart failure research proposal, and am now in the final stages of getting approval. I have been in contact with [redacted] about the impact on the PCCs and the unit. Below are the details about the process.

Please let me know if you approve, and what else you may need from us.

Respectfully,

Colleen duManoir BScN, RN, CCN(C)

Graduate Student
School of Nursing
Faculty of Health & Social Development
University of British Columbia, Okanagan Campus
ART 145 - 1147 Research Road, Kelowna, BC V1V 1V7
Tel: 250-807-9984  Fax: 250-807-8655  Cell: 250-215-3809
Hi Colleen

Apologies for my delayed response, yes from my perspective you would have permission to recruit patients on 2E and 2W as per your outlined process below. This of course, dependent on approval from Program Director [redacted]. Thanks,

[redacted]

Manager, Cardiac In-Patient (2 East, 2 West, CSICU, CCU) – KGH

Hospitals and Communities Integrated Services (HCIS)

Interior Health Authority

2268 Pandosy Street Kelowna, BC V1Y 1T2

DIRECT: 250-862-4300 x2230

From: duManoir, Colleen [mailto:cduman01@mail.ubc.ca]
Sent: Thursday, November 10, 2016 10:00 AM
To: [redacted]
Cc: Rush, Kathy
Subject: Research Proposal

Good morning [redacted],

I am submitting a research proposal that involves interviewing patients with heart failure, and their caregivers.

I would like to formally gain your approval to recruit these patients from your inpatient cardiac units (2 East and 2 West). Once I receive approval from yourself, I will email the charge nurses the details. Kathy Rush, my supervisor, or I will contact Cardiac Program director [redacted] [redacted] to have her sign an official study authorization form.

Then, I will submit these forms to the Behavioural Ethics Board to receive approval, which takes on average 2-3 weeks. Once I receive approval, I will contact you to arrange for me to discuss
with the bedside staff. Once all is ready to go, the recruiting process begins (estimated the second week of December). The proposed process is laid out below:

The Manager and Charge Nurses, (often referred to as Patient Care Coordinators (PCCs) in this context), of inpatient telemetry units from Kelowna General Hospital will be contacted via email to request the patient recruitment on their clinical units. The email will include information about the study such as: proposed participants, timeline, and roles. Once the manager and PCCs are in favour, and the Director of the Cardiac Program has signed the impact assessment form (see Appendix A), the researcher will contact the charge nurses via telephone to confirm their assistance with participant recruitment, and answer any questions. The researcher will attend the unit staff meeting on each unit to inform the staff of the research project and answer any questions. The researcher will then deliver a binder to each unit that outlines the study purpose, has contact information, and contains the Consent to Contact forms (see Appendix B), participant (and caregiver) consent forms (see Appendix C & D) and demographic forms (see Appendix E).

Once all is in place, each day the charge nurse will identify patients with a diagnosis of heart failure after attending rounds on the unit. They will determine whether the patient meets the study inclusion criteria outlined in the binder. If the patient meets the criteria, the PCC will use the provided script (see Appendix F) and approach eligible patients and their care giver (if present), introduce the study, and invite their participation. Interested patients (and caregivers) will be asked to sign a permission to contact form. The PCC will let the patient (and caregiver) know they will receive a visit from the researcher in the hospital before discharge. The signed permission to contact forms will be kept in a locked cabinet on the unit until the researcher is able to pick them up in person.

The researcher will call or stop by the unit each day to inquire about interested participants. If there is an interested participant, the researcher will then visit the patient and/or caregiver, complete aMini-Cog assessment to determine sufficient cognitive ability, (score of at least 3 out of 5), answer any questions, and complete the demographic form. The participants will be given a copy of the consent forms, and told that they do not have to complete them at that time and may wait until the time of the interview. The name of the participant and caregiver will then be assigned a unique identifier number and kept on a secured laptop computer. The researcher will use an Excel sheet to track the completion of forms for each participant. The demographic data will also be input into this spreadsheet. The name of the participant will be kept in a separate file from the spreadsheet.

The researcher will call or visit the unit each day to inquire about participant discharge dates. Once the patient is ready for discharge, the researcher will visit the participant once again to schedule an interview within two weeks of the identified discharge date. The signed consent forms, and permission to contact forms will both then be collected from the locked cabinet on the unit and moved to a locked cabinet in the researcher’s supervisor’s office on campus for five years after publication as per the UBC
BREB guidelines and then permanently destroyed (UBC, 2016). The day of the arranged interview, the researcher will call the patient prior to the visit to inquire about whether they feel well enough to be interviewed. The interview will be rescheduled at the patient and caregiver’s earliest convenience.

Please let me know if you would like copies of any of the forms ahead of time, or have further questions/concerns.

Kindly,

Colleen duManoir BScN, RN, CCN(C)

Graduate Student
School of Nursing
Faculty of Health & Social Development
University of British Columbia, Okanagan Campus
ART 145 - 1147 Research Road, Kelowna, BC V1V 1V7
Tel: 250-807-9984  Fax: 250-807-8655  Cell: 250-215-3809
Appendix B Script for Charge Nurse to Approach Research Participants

Script for Charge Nurse to Approach Research Participants

- Bring two Permission to Contact Forms to the bedside with this script

Script

“Hello Mr or Mrs __________. I am here to let you know that you meet the criteria to be considered for a research study being done by a graduate student, who is also a Registered Nurse, and her research team from the School of Nursing at UBC Okanagan. The student, Colleen duManoir, is studying the experiences of patients with heart failure going home from hospital.

There is information about the study in this form.

(Hand them the Permission to Contact form)
This is a form for you to give your permission to be contacted about the study. If you give permission to be contacted, the student researcher doing the study will visit you in hospital to explain more about the study, and to answer any of your questions. Please sign and return the form to the nursing station within 24 hours if you are interested. The student researcher contact information is on the form, so please feel free to call or email them.”

**Please refer them to the form or the student researcher for any further details.

Thank you!
Appendix C Participant Permission to Contact Form

Patient Experience of Heart Failure Care Transition from Hospital to Home: An Interpretive Description Study:
Participant Permission to Contact Form
*(may also be used for caregivers of participants)

This letter is to tell you about a research study of people with heart failure and their experiences of going home from hospital.

A Master of Nursing student is doing the study from UBCO. She is supported by a research group from UBC Okanagan School of Nursing, and an Interior Health Cardiac Program nurse.

The purpose of the study is to find out what is like for patients going home from the hospital after being treated for heart failure. The information you share will tell us ways we can make improvements.

If you sign this form, a research assistant will come to meet you and your caregiver in the hospital. They will give you a thinking test to make sure that you can think clearly and will remember the events that happened when you went home from the hospital. It will take about two minutes. For the study, a student researcher will interview you at your own home for about an hour and a half within two weeks of going home from the hospital. The interview may also be done by telephone.

You do not have to join the study. At any time, you can remove yourself from the study.

For more information, please contact:

Colleen duManoir, BScN, RN
UBC Okanagan, Masters of Nursing Student
Tel: 250-215-3809 or email: colleen.dumanoir@ubc.ca

___________________________________________  _____________________________
Participant Name (please print)                             Telephone number

___________________________________________  _____________________________
Signature                                                                             Home Address

___________________________________________
Date
Appendix D Participant Consent Form

Patient Experience of Heart Failure Care Transition from Hospital to Home: An Interpretive Description Study

Participant Consent Form

1. Who is running the study?
Kathy Rush, PhD, RN  Associate Professor, School of Nursing, UBC Okanagan
Email: kathy.rush@ubc.ca
Phone: 250-807-9561
Nelly Oelke, PhD, RN  Assistant Professor, School of Nursing, UBC Okanagan
Email: nelly.oelke@ubc.ca
Phone: 250-807-9980
Jeannine Costigan, MScN, APN, RN  Clinical Nurse Specialist, Interior Health
Email: Jeannine.costigan@interiorhealth.ca
Phone: 1-250-862-4300 Ext 2434
Colleen duManoir, BScN, RN  Graduate Student, School of Nursing, UBC Okanagan
Email: colleen.dumanoir@ubc.ca
Phone: 250-215-3809
Peter Hubbard, BSN, RN  Research Assistant
Email: peter.hubbard@interiorhealth.ca

2. Why are they doing this study?
The study is to assist with ensuring the best possible care for people with heart failure when they go home from hospital. People with heart failure can have many stays in the hospital. Some hospital stays can be prevented. We want to learn about issues that you and your caregivers experience when you go home from the hospital.

3. Why should I take part in this study?
The information you provide will help us learn more about the experiences of persons with heart failure when they go home from the hospital. This will help us make changes that are important to you. It will also give the researchers ideas of what other research is needed.

4. What will I have to do?
The research assistant will visit you in hospital to talk about the study, answer questions you or your caregiver may have, and give you a two-minute thinking and memory test. This test helps to make sure that at the time of the interview, you can remember what happened two weeks ago. If you are having trouble with your memory, you may not be able to join the study. The research assistant will give you a form to complete that has information such as the medications you take, who you live with, and what other illnesses
you may have. He will also give you a copy of this consent form to take home. It will take about a half an hour in total for these two visits.

The student researcher will then call you to arrange a one-and-a-half hour interview time and date at your home. The interview will be scheduled within two weeks of when you go home from the hospital. If you live farther than 50km away from Vernon Hospital, the interview may be completed over the phone. If you are still working, interview appointments will be made on your days off work at a time that is convenient for you.

The day of the interview, the student researcher will call you at home to make sure you are feeling well enough for the interview and still wish to be a part of the study. When the student researcher arrives at your home, she will answer questions, and confirm your consent to participate in the study. The interview will be audio recorded and the student will take notes. Your caregiver’s answers will also be included in the study data. In the middle of the interview, the student researcher will pause and ask if you feel well enough to continue. The interview may also be stopped and continued at a later date and time that is convenient for you and your caregiver.

Sample interview questions:
Tell me about your experience of going home from the hospital.
What supports were in place when you went home from the hospital?

5. How will my identity be protected?
Your name will not be used in the information you provide, and the information you provide may not be linked back to you. Instead code numbers will be used on all of your information you are used on all audio-files and notes. Your name and code number and consent forms will be stored separately from the information you provide. Only the research team will review the audio-files and notes. All paper copies will be stored in a locked filing cabinet at UBCO. All electronic files will be stored on a UBCO secure computer network. All paper and electronic files will be kept for five years after the study is published, and then permanently destroyed as per the UBC Okanagan guidelines. If your caregiver is present, we cannot guarantee that your answers will be kept confidential, but we will ask both of you not to share information from the interview with others.

6. What will happen to the answers I give?
This study is being done as a part of a student thesis. The full results will be reported in the student researcher’s report which will be available on cIRcle, which is publicly available on the internet. Some quotes or ideas that you share will be published in journal articles or presented at conferences. If you would like to receive a summary of the findings, please let us know on this form below. We will also give a summary to the Cardiac Program leadership team at Interior Health so they may learn from your answers.

7. What are the possible risks of joining this study?
Because we are asking you to share personal experiences, it may be uncomfortable for you. You may choose not to answer a question that makes you feel uncomfortable. You may also feel tired or short of breath during the interview. You may stop the interview and
continue at a later time/date that is convenient for you and your caregiver. Participation in this study, including the information you share, will have no impact on the healthcare or the services you currently receive.

8. **What are the possible benefits of joining the study?**
Your answers may help improve care for heart failure patients. Participating in this study may bring you the gratification and/or satisfaction that you are helping others like yourself with heart failure.

9. **Will I be paid for participating?**
This is a graduate student research project so there is no payment, and also no cost to you.

10. **What do I do if I have complaints or concerns about the study?**
Contact the Interior Health Research Ethics Board at 250-870-4602 or by email to researchethics@interiorhealth.ca.

    AND/OR
Call the Research Participant Complaint Line in the UBC Office of Research Ethics toll free at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832. It is also possible to contact the Research Complaint Line by email at RSIL@ors.ubc.ca.

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to leave the study at any time without giving a reason and without any negative impact on your employment, access to healthcare services, or your relationship with UBC Okanagan or the Interior Health authority. The information that you have provided will be permanently destroyed and not used for this study.

I consent to audio recording of the interview      Yes ☐ No ☐

Your signature below indicates that you have received a copy of this consent form
Your signature indicates that you consent to participate in this study

____________________________________________________
Participant Signature

____________________________________________________
Printed Name of Participant

________________________
Date

Telephone number(s) home: (  )_________________________mobile: (  )_________________________
If you agree to include your caregiver in the interview, and add the information they provide to the research study, please indicate below:

☐ Yes, I want them included in the study
☐ No, I do not want them included in the study

If you would like a summary report of our results mailed or emailed to you at the end of the study, please indicate below:

☐ Yes, I would like a copy sent to me after the study is finished to:

Address: ____________________________________________________________

OR

Email Address: _______________________________________________________


Appendix E Participant’s Caregiver Consent Form

Patient Experience of Heart Failure Care Transition from Hospital to Home: An Interpretive Description Study

Participant’s Caregiver Consent Form

1. Who is running the study?
Kathy Rush, PhD, RN Associate Professor, School of Nursing, UBC Okanagan
Email: kathy.rush@ubc.ca
Phone: 250-807-9561
Nelly Oelke, PhD, RN Assistant Professor, School of Nursing, UBC Okanagan
Email: nelly.oelke@ubc.ca
Phone: 250-807-9980
Jeannine Costigan, MScN, APN, RN Clinical Nurse Specialist, Interior Health
Email: Jeannine.costigan@interiorhealth.ca
Phone: 1-250-862-4300 Ext 2434
Colleen duManoir, BScN, RN Graduate Student, School of Nursing, UBC Okanagan
Email: colleen.dumanoir@ubc.ca
Phone: 250-215-3809
Peter Hubbard, BSN, RN Research Assistant
Email: peter.hubbard@interiorhealth.ca

2. Why are they doing this study?
The study is to assist with ensuring the best possible care for people with heart failure when they go home from hospital. People with heart failure can have many stays in the hospital. Some hospital stays can be prevented. We want to learn about issues that you and your loved one experience when you go home from the hospital.

3. Why should I take part in this study?
The information you provide will help us learn more about the experiences of persons with heart failure when they go home from the hospital. This will help us make changes that are important to you. It will also give the researchers ideas of what other research is needed.

4. What will I have to do?
The student researcher will visit your loved one in hospital to talk about the study, answer questions you or your loved one may have, and give your loved one a two-minute thinking and memory test. This test helps to make sure that at the time of the interview, your loved one can remember what happened two weeks ago. If they are having trouble with their memory, you both may not be able to join the study. The research assistant will give your loved one a form to complete that has information such as the medications they take, who they live with, and what other illnesses they
may have. He will also give you a copy of this consent form to take home. It will take about a half an hour in total for the visit. You are welcome to share any concerns and ask questions about both of your roles in the study with the student researcher. You may also directly contact any one of the researchers listed at the top of the form. Then the student researcher will contact your loved one to arrange a one-and-a-half hour interview time and date at their home. The interview will be scheduled within two weeks of when your loved one goes home from the hospital. If you are still working, interview appointments will be made on your days off work at a time that is convenient for you and your loved one. If your loved one lives farther than 50 km away from Vernon Hospital, the interview may be completed over the phone.

The day of the interview, the student researcher will call your loved one at home to make sure they are feeling well enough for the interview and still wish to be a part of the study. When the student researcher arrives at their home, she will answer questions, and confirm your consent to participate in the study. The interview will be audio recorded and the student will take notes. Your answers to the research question are welcomed, and will be included in the study data. In the middle of the interview, the student researcher will pause and ask if your loved one feels well enough to continue. The interview may also be stopped and continued at a later date and time that is convenient for both of you.

**Sample interview questions:**
Tell me about your experience of going home from the hospital.
What supports were in place when you went home from the hospital?

5. **How will my identity be protected?**
Your name will not be used in the information you provide, and the information you provide may not be linked back to you. Instead code numbers will be used on all of your information you are used on all audio-files and notes. Your name and code number and consent forms will be stored separately from the information you provide. Only the research team will review the audio-files and notes. All paper copies will be stored in a locked filing cabinet at UBCO. All electronic files will be stored on a UBCO secure computer network. All paper and electronic files will be kept for five years after the study is published, and then permanently destroyed as per the UBC Okanagan guidelines. We cannot guarantee that your answers will be kept confidential, because there are two of you in the interview, but we will ask both of you not to share information from the interview with others.

6. **What will happen to the answers I give?**
The full results will be reported in the student researcher’s report which will be on cIRcle which is publicly available on the internet. Some quotes or ideas that you share will be published in journal articles or presented at conferences. If you would like to receive a summary of the findings, please let us know on this form below. We will also give a summary to the Cardiac Program leadership team at Interior Health so they may learn from your answers.

7. **What are the possible risks of joining this study?**
Because we are asking you to share personal experiences, it may be uncomfortable for you. You may choose not to answer a question that makes you feel uncomfortable. Your loved one may also feel tired or short of breath during the interview. You may stop the interview and continue at a later time/date that is convenient for you and your loved one.

8. **What are the possible benefits of joining the study?**
Your answers may help improve care for heart failure patients. Participating in this study may bring you the gratification and/or satisfaction that you are helping others with heart failure.

9. **Will I be paid for participating?**
This is a graduate student research project so there is no payment, and also no cost to you.

10. **What do I do if I have complaints or concerns about the study?**
Contact the Interior Health Research Ethics Board at 250-870-4602 or by email to researchethics@interiorhealth.ca.

AND/OR
Call the Research Participant Complaint Line in the UBC Office of Research Ethics toll free at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832. It is also possible to contact the Research Complaint Line by email at RSIL@ors.ubc.ca.

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to leave the study at any time without giving a reason and without any negative impact on your employment, access to healthcare services, or your relationship with UBC Okanagan or the Interior Health authority. The information that you have provided will be permanently destroyed and not used for this study.

I consent to audio recording of the interview [ ] Yes [ ] No

- Your signature below indicates that you have received a copy of this consent form
- Your signature indicates that you consent to participate in this study

____________________________________________________
Participant Signature

____________________________________________________
Printed Name of Participant

_________________
Date
Telephone number(s) Home: (  )___________________

Mobile: (  )___________________

If you would like a summary report of our results mailed or emailed to you at the end of the study, please indicate below:

☐ Yes, I would like a copy sent to me after the study is finished to:

Address: ____________________________________________________________ OR

Email Address: _______________________________________________________

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Appendix F Participant Information Form

Patient Experience of Heart Failure Care Transition from Hospital to Home: An Interpretive Description Study

Participant Information Form

*not for caregivers

Name: __________________________

Age: ______

Sex: Female ☐ Male ☐ Other☐

Highest education level: Junior high ☐ High school ☐ College/University diploma/degree ☐

Marital Status: Single ☐ Committed Relationship ☐ Legally Married ☐

Widowed ☐ Divorced ☐

Living Arrangement:

Lives alone ☐ Lives with spouse ☐ Lives with family ☐

Other ☐ (list relationship e.g. friends)

______________________________

I live in a(n): Apartment ☐ House ☐ Assisted Living ☐

Other: _______________________

Other conditions I have:

COPD ☐ Diabetes ☐ High Blood Pressure ☐ Previous Heart Attack ☐

Kidney Failure ☐ Atrial Fibrillation (A-Fib) ☐ Reduced Mobility ☐

Depression ☐ Anxiety ☐

Other: _______________________________________________________

Number of times I was admitted to hospital to treat my heart failure (including this visit): 
I have attended a Heart Function Clinic

Yes ☐ No ☐

These are the medications I am taking at home (since discharge):

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix G Interview Guide

Research objective: To explore the experiences of persons with heart failure being discharged from hospital to home.

Collected: Demo form ☐ Consent Form ☐

Script
Do you have any questions for me before we start? I would like to remind you that the session is being audio-recorded, and that what is said in this interview should not be shared with others. You may refuse to answer any question if you feel uncomfortable. We have one and a half hours. Are you ready to begin?

Main questions are numbered, probing questions are bulleted.
1. Tell me about your experience of going home from the hospital.
   Probe: what comes to mind when you think back?

2. How did you find out that you were going home? (Patient Centered Care)
   Probes:
   How did you feel when you were told you were going home?
   Why do you think you felt this way?
   Who made that decision?
   When did you hear about it?

3. At that time, how prepared did you feel to look after your heart failure at home? (Self-Care)
   (If they felt prepared) tell me who helped you feel prepared and how did they help you prepare?
   If not, tell me why do you think you didn't feel prepared?
   Probes:
   What were the key things they told you about looking after yourself
   Who provided this information?
   How confident (Reigel’s Self Care Theory) did you feel about managing your symptoms once at home?

4. Who talked to you about going home and helped you prepare? (Communication)
   Describe any differences you noted between information you were given
   What worked well, and didn’t work well?
   Did you receive any written materials? If so what was helpful about them? Or not helpful?
5. Did someone review your **medications** with you?
   If yes, who?
   How did you feel when receiving information about your medications?
   How well did you think you knew your medications before going home?
   How confident (Chronic Illness Theory) you felt that you would be able to take them as prescribed at home?

6. Please describe what arrangements were made for **follow up** with your family doctor or nurse practitioner?
   How was the follow up appointment made?
   What concerns did you have about these arrangements (or lack of)?
   Did you attend the appointment? Why or Why not? Or are you planning on keeping it?
   Describe what your family doctor or NP told you about your heart failure.

***We are half way through the questions, are you feeling well enough to continue? (Shortness of breath, fatigue etc)***

7. Tell me about how you got home.
   Describe any difficulties getting back home (**transportation**)
   Was there a **cost** to getting you back home?

8. When you got home, describe what **supports** you had in place.
   Which ones were new after this hospital visit?
   Describe the help you received from family and friends, home care support etc.
   What supports were missing? Are they still missing? Why were they missing?

9. How well have you been managing your heart failure **symptoms** at home? (**Self-Care**)
   Probes:
   Describe any symptoms that you have been having
   Describe how you have been taking care of your heart failure
   How confident (Chronic Illness Theory) have you been feeling about managing your symptoms at home?

10. Since you’ve been home, how well have you been able to take your **medication** as prescribed?
    What has made it difficult to do this?
    What has made it easier to do this?

11. Overall, what went well with your discharge from hospital to home?

12. How could we have supported you during your discharge from hospital to home?
    Could you describe any **gaps** in the care that you received?

13. Is there anything I haven’t asked you that you feel is **important** for me to know?