EXPLORING THE EXPERIENCE OF EARLY DISCHARGE AFTER TRANSCATHETER AORTIC VALVE IMPLANTATION FOR OLDER ADULTS AND THEIR INFORMAL CAREGIVERS

by

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Abstract

Transcatheter aortic valve implantation (TAVI) has emerged as the gold standard of care for high risk individuals living with severe symptomatic aortic stenosis. Increasing experience, smaller vascular access devices and standardized care pathways have resulted in shorter lengths of stay after TAVI. Early discharge could be beneficial in this population due to higher rates of adverse events for older adults admitted to hospital. Due to high co-morbid burden of the TAVI population, it is essential to explore patient and caregiver experience to help understand how and if the complex discharge planning needs of this patient population are being met. The purpose of this study was to explore the experience of early discharge (≤72 hours) after TAVI for older adults and their informal caregivers.

This study used data collected as part of a larger research program examining the experience of undergoing TAVI from time of referral to four months post-procedure. Interpretive description was employed as the method of inquiry. Semi-structured interviews conducted with ten older adults who underwent TAVI and nine informal caregivers were analyzed through inductive, thematic analysis. This process revealed three main themes and associated sub-themes: (1) Preparing for TAVI and planning for discharge: sources of information, planning for convalescence and hopeful for relief, (2) Early recovery - Transitioning home: readiness for discharge, effects of early complications, and (3) Longer-term recovery - Adjusting to life after TAVI: feeling grateful, managing expectations of recovery.

Participants tended to focus on the procedure itself with little attention paid to preparing for their transition home. Though many felt well prepared to transition from hospital to home, older adults who experienced early complications and their caregivers expressed the need for more information and access to health care professionals for support. Finally, though all

participants were grateful to have undergone TAVI, some experienced their recovery within the context of unmet expectations, perceptions of advancing age and comorbidities. Further research to study possible transitional care models to support early discharge as well as increased focus on identifying those at risk for early complications through individualized care planning guided by comprehensive geriatric assessments were recommended.

Lay Summary

Older adults who undergo TAVI to manage their aortic stenosis and associated symptoms such as dizziness, shortness of breath and fatigue are often discharged from hospital after minimal hospital stays. The purpose of this study was to understand how older adults and their caregivers experienced the transition following early discharge (≤ 72 hours) after TAVI to help develop recommendations to improve the care for these patients. 10 patients and 9 caregivers were interviewed and the study findings highlighted that though most participants experienced a positive transition home following TAVI, those who experienced early complications requested more information and support from health care professionals to navigate their early discharge. In longer term follow-up, many also expressed unmet expectations from the procedure and struggled to recover in the context of advancing age and other medical conditions. Individual care plans and expanded support from the TAVI team were recommended based on study findings.

Preface

This thesis represents the original unpublished work by the author Jennifer Katherine Knoll. The interview data analyzed for this thesis was drawn from a larger program of research looking at the experience of TAVI from the University of British Columbia of which my thesis committee supervisor Dr. Jennifer Baumbusch is the primary investigator. I completed the literature review, developed the study design, completed the data analysis and wrote the final manuscript with the guidance and support of my thesis committee: Dr. Jennifer Baumbusch, Dr. Alison Phinney and Dr. Sandra Lauck.

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I would also like to thank my husband Oscar who has supported me while we planned a wedding, built a house and expanded our family.

Without the support of my family I would not have been able to complete this degree. I would like to thank my mum Jo who has allowed me to tap in to her nursing knowledge and expertise to work through the many road blocks I encountered while writing both my thesis as well as the many papers I wrote throughout my nursing education. Thank you to my dad Sandy who provided me with delicious meals and quiet support as I spent many weekends at their house in an attempt to be productive. Finally, to my sister Carrie, who may live across the country, but who has gifted me with her wise strategies for succeeding in graduate studies and supported me by graciously sitting though the many health care related discussions that tend to dominate at our dinner table.

Chapter One: Introduction

Hospitalized older adults are at higher risk of adverse events such as loss of mobility, falls, delirium, hospital acquired infections and pressure ulcers than are younger patients admitted to hospital (Long, Brown, Ames, & Vincent, 2013). This highlights the possible benefits of reducing hospital stays in this patient population (Durand et al., 2015). The risks of hospitalization for older adults must be viewed within the context of a health care environment geared towards optimal patient outcomes, efficiency and reduction of costs which creates an environment that may not match the complex needs of the geriatric population being discharged after increasingly shorter hospital stays (Bauer, Fitzgerald, Haesler, & Manfrin, 2009).

The need to balance the risk of hospitalization for older adults with the fact some individuals may also require more time for recovery and safe discharge due to their age and medical complexity (Hickman, Newton, Halcomb, Chang, & Davidson, 2007) can be examined within the context of the innovative and minimally invasive procedure of transcatheter aortic valve implantation (TAVI). Aortic stenosis (AS) is the most common valvular disease in the Western world with reported prevalence rates of severe AS of 3 % in adults aged 75 years and older, often resulting in admission to hospital, accessing emergency departments or death (Osnabrugge et al., 2013). Although symptoms can be medically managed, the only effective strategy to manage severe AS is valve replacement (Nishimura et al., 2014). Up to one third of elderly patients are at excessive surgical risk and are therefore not eligible for surgical aortic valve replacement (SAVR). In response, the less invasive transcatheter aortic valve implant (TAVI) has become the standard of care for patients with symptomatic AS and high or prohibitive surgical risk (Alsara, Alsarah, & Laird-Fick, 2014). Increasing procedural experience, improved patient selection and decreasing sizes of vascular access devices has

resulted in the emergence of minimally invasive approaches to TAVI and a focus on decreasing length of stay (Barbanti et al., 2015; Durand et al., 2015; Lauck et al, 2014, 2016; Noad et al., 2016). Due to the frailty, advanced age and high co-morbid burden of the TAVI population, it is essential to assess patient and informal caregiver experience to help understand how and if the complex discharge needs of this patient population are being met from initial contact with the TAVI program to discharge home.

Risks of Hospitalization for Older Adults

The hospitalization of older adults is associated with increased rates of adverse events including falls, adverse drug events, use of restraints, nosocomial infections and procedural complications when compared to a younger patient population (Admi, Shadmi, Baruch, & Zisberg, 2015; Long et al., 2013; Rothschild, Bates, & Leape, 2000). Deterioration of functional status after hospitalization due to restricted activity is also common in older adults (Gill, Allore, Holford, & Guo, 2004). This restricted activity has been shown to result in disability in performing activities of daily living such as bathing and dressing after discharge from hospital (Gill et al., 2004). Evidence of these hospitalization risks associated with poor outcomes for older adults helps support a movement towards working to reduce the length of stay in hospital after both acute and planned hospital admissions.

Parke and Hunter (2014) argue that the context of the acute care hospital results in harm to older adults as the focus on efficiency and acute medical problems does not address the complex and unique needs of the older adults who access these services. The authors also draw attention to the reality that older adults are not a homogenous group and that many have the capacity to function within the current context of hospitalization. Baumbusch, Leblanc, Shaw and Kjorven (2016) identified a “poor fit” between nurses’ understanding of the complex

relational care required by older adults and current organizational care processes and priorities that act in opposition to this need. It is therefore important to attend to the unique needs of a heterogeneous population; this includes a realization that some patients with complex social and medical histories, in addition to advanced age, may require longer periods of time to recover from episodes of illness or enhanced community supports to facilitate the transition home(Parke & Hunter, 2014). Efforts to reduce length of stays must find the balance between reducing the risk associated with hospitalization while being receptive to the unique needs of the frail older adults in their care. Employing evidence-based strategies to facilitate safe and effective discharge planning may be essential to the success of reduced length of stay for hospitalized older adults.

Aortic Stenosis: Diagnosis and Treatment Options

Aortic Stenosis (AS) is the most common valvular disease among older adults in the western world (Olsson, Näslund, Nilsson, & Hörnsten, 2016). Severe AS may exist for a period of up to two years before symptoms develop and is often discovered on routine chest auscultation or imaging (Nishimura et al., 2014). Diagnosis of AS is dependent on patient history, physical exam and transthoracic echocardiogram (TTE) with the addition of other diagnostic testing such as transesophageal echocardiogram (TEE), angiography, computed tomography (CT) or cardiac MRI (Nishimura et al., 2014). Symptoms of AS which often lead to hospital admissions and emergency room visits include: shortness of breath on exertion, decreased exercise tolerance, heart failure, syncope and chest pain (Nishimura et al., 2014). Once symptoms occur, early valve replacement is essential to avoid poor outcomes in this population (Nishimura et al., 2014). Aortic valve replacement is the only effective treatment for severe symptomatic AS. Patients who are at high or prohibitive surgical risk are referred for transcatheter aortic valve implantation (TAVI) or medical management (Nishimura et al., 2014).

Transcatheter Aortic Valve Implantation (TAVI)

The innovative and minimally invasive TAVI has emerged as a treatment option for those at high or prohibitive surgical risk and has been shown to improve symptoms and decrease hospital stays when compared with SAVR without increased rates of mortality or 30-day re-admission (Smith et al., 2011). TAVI is now the gold standard of treatment for those with symptomatic AS, high surgical risk and an expected survival of one year or more (Otto et al., 2017).

TAVI is a minimally invasive procedure as it introduces a new aortic valve through catheter guided percutaneous access, most commonly through the femoral artery or the apex of the left ventricle but also through axillary, carotid and subclavian sites (Noad et al., 2016). These procedures are increasingly conducted with local anesthetic as well as being completed on a beating heart, negating the need for cardiopulmonary bypass. In contrast, SAVR requires a sternotomy, cardiopulmonary bypass and general anesthetic.

Towards a Minimalist Approach and Decreasing Length of Stay

Since the first successful TAVI conducted on a human was completed in 2002 (Cribier et al., 2002), we have seen movement towards an increasingly minimalist operative approach and a focus on standardizing care pathways to facilitate the earliest safe discharge post TAVI (Barbanti et al., 2015; Durand et al., 2015; Lauck et al., 2014, 2016; Noad et al., 2016). These changes in combination with improved operator experience and smaller vascular access devices has resulted in a steady reduction in mortality and complication rates as well as decreasing length of stay post TAVI (Haussig, Schuler, & Linke, 2014).

Quantitative studies have begun to explore the feasibility and safety of earlier discharge after TAVI and have shown that there is no increase in 30-day readmission rates or 30-day mortality in patients discharged up to 72 hours post procedure (Barbanti et al., 2015; Durand et al., 2015; Lauck et al., 2014, 2016; Noad et al., 2016). Movement towards a comprehensive pre-operative assessment completed by an interdisciplinary heart team provides health care professionals with information regarding TAVI patients' functional status and psychosocial supports before they are accepted for TAVI (Lauck et al., 2016). This detailed information gathering within the context of an often-planned elective procedure such as TAVI provides health care professionals with the opportunity to identify patient specific factors that may affect their discharge and develop strategies to plan for a successful transition home throughout the care trajectory.

The Experience of Discharge for Older Adults and their Families

The increasing pressure placed on hospitals to decrease length of stay has resulted in an increasing need for family members to undertake a caregiving role; this is especially true for the informal caregivers of older adults (Bauer et al., 2009). Caregiver involvement has been identified as one of the most important factors in facilitating successful discharge of frail older adults (Bauer et al., 2009; Bull & Roberts, 2001). It is therefore essential to understand the elements of successful discharge planning by ensuring that the voice of the older adult as well as their informal caregiver is included in the research evidence. For the purposes of this study, discharge planning will be conceptualized as a process that begins at initial contact and that continues throughout hospitalization and upon return to the community.

The experience of discharge for older adults. The experience of older adults discharged after surgical intervention (Berg, Zwisler, Pedersen, Haase, & Sibilitz, 2013; Perry et

al., 2012; Uhrenfeldt & Hoybye, 2015) and acute hospital admission (Congdon, 1994; Foss & Hofoss, 2011) has been examined in the research literature. Discharge after surgical intervention in older adults led to feelings of fragility, weakness and a desire to regain independence or "get back to normal" (Berg et al., 2013; Perry et al., 2012). Feelings of vulnerability and suffering while in hospital were expressed by patients who felt their pain was ignored by staff in favour of a focus on early mobilization (Uhrenfeldt & Hoybye, 2015). Patients also report feelings of insecurity on discharge regarding how to respond to post-operative symptoms (Berg et al., 2013). Confidence in their ability to manage at home was mediated by the quality of information received on discharge as well as the perceived competence of the hospital staff (Perry et al., 2012). Patients also expressed motivation and desire to return to their baseline and regain their independence after discharge home (Berg et al., 2013; Perry et al., 2012).

Research on the experience of preparation for discharge and discharge home after acute hospitalization identified some similar themes to the experience of discharge after surgical intervention. Patients also expressed feelings of weakness and distress at being unable to participate in their normal activities, both social and instrumental (Andreasen, Lund, Aadahl, & Sorensen, 2015). Older adults also reported different levels of participation in the discharge planning process and often felt that they did not receive enough information or input into the decision-making surrounding discharge (Foss & Hofoss, 2011). Fragmented care due to lack of leadership of the interdisciplinary team was also reported (Congdon, 1994). With decreasing length of stay, multidisciplinary collaboration and effective communication between the care team and the patient and family is essential to ensure adequate and appropriate discharge plans for older adults (Bauer et al., 2009).

Older surgical and medical patients discharged from hospital spoke of the importance of family member participation in their discharge experience (Bauer et al., 2009; Berg et al., 2013; Perry et al., 2012). The assistance of family members was perceived as invaluable (Berg et al., 2013) and could affect patients' ability to safely return home after hospitalization (Bauer et al., 2009). Patients reported feelings of dependence on assistance from family members and were cognisant of the possible burden they were placing on family members (Perry et al., 2012). These findings support the inclusion of family members in discussion and planning surrounding discharge for older adults as they often provide significant support after hospitalization. The experience of caring for a loved one after discharge is therefore an essential perspective to understand to help structure safe and responsive care processes for older adults discharged home after TAVI.

The experience of discharge for informal caregivers of older adults. Involvement of informal caregivers in discharge planning decreases the risk of readmission, improves satisfaction with care experience and decreases length of stay (Bauer et al., 2009). The role of informal caregivers is widely acknowledged but it is important to understand the caregiver experience to help shape care processes in outpatient clinics, in hospital and in the community. Informal caregivers of older adults' express feelings of stress, fear, responsibility, obligation and increased vigilance (Bragstad, Kirkevold, & Foss, 2014; Ganske, 2006; Hvalvik & Reierson, 2015). As active participants in their family member's recovery, caregivers report having to take an active role as advocate to ensure that the appropriate services and care are accessed for the family member upon discharge (Bragstad et al., 2014). Caregivers also report positive emotions as a result of their caregiving role. Feelings of pride at their ability to navigate the complex health care system and in their ability to provide care and support the well-being of their family

members are common among informal caregivers (Ganske, 2006; Hvalvik & Reierson, 2015). Health care providers must acknowledge the essential role of the informal caregiver and be aware of their need for information, participation and support during the discharge planning process and after transitioning home.

The Experience of Discharge after Day Surgery or Fast Track Surgery

As TAVI patients move towards shorter hospital stays, so do patients undergoing other surgical interventions, either as day procedures (i.e., appendectomy or arthroscopic surgery) or through participation in fast track surgery programs (i.e., hip replacement). This transition requires the patient and their informal caregiver to take a more active role in recovery (Boughton & Halliday, 2009; Norlyk & Harder, 2011).

Same day discharge after surgery is becoming common and some procedures that used to require several days in hospital are now day procedures (Boughton & Halliday, 2009). Both patients and their informal caregivers report feeling unprepared for discharge home, especially with regards to how to deal with unexpected complications (Mottram, 2011; Norlyk & Harder, 2011). They also express a need for clear and comprehensive information as well as the support of professional health care providers to provide reassurance in the immediate post-operative period (Mottram, 2011; Norlyk & Harder, 2011). Although patients and their caregivers expressed feelings of fear and anxiety while at home, they were also happy to be in a familiar environment and to have more control and independence during their recovery (Mottram, 2011; Norlyk & Harder, 2011).

Patients who participated in fast track surgical programs for total hip replacement and colon surgery reported feeling obligated to live up to the expectations of the fast track program

especially with regards to increasing mobility (Jorgensen & Fridlund, 2016; Norlyk & Harder, 2011). When unable to meet the physical demands of the program, patients expressed feelings of guilt (Norlyk & Harder, 2011) and some began to push back against expectations (Jorgensen & Fridlund, 2016). Fast track programs include structured post-operative pathways as well as detailed pre-operative education and preparation for patients who will participate (Norlyk & Harder, 2011). Clear expectations of patient participation and detailed pre-operative education and planning may help to decrease some of the anxiety of discharge for this patient population.

Problem Statement

Older adults admitted to hospital are at higher risk of adverse events (Admi et al., 2015) but may also require more time for recovery and safe discharge due to their age and medical complexity (Hickman et al., 2007). Through careful case selection, standardized clinical pathways and increasingly minimalist procedures, TAVI programs in British Columbia have decreased the average length of stay after TAVI from eight days in 2005 to three days in 2014 with many patients (38.2 %) being discharged the day after their TAVI (Lauck et al., 2016). Comprehensive interdisciplinary pre-operative assessments provide health care professionals with the opportunity to begin individualized discharge planning from eligibility assessment through to discharge home post procedure. It is essential to explore the patient and family member experience of discharge home after TAVI to identify what type of information and support was helpful during this transition and what gaps in care, if any, were identified. This information would help facilitate the development of future care processes which could be integrated throughout the continuum of care to facilitate safe early discharge (≤72 hours) after TAVI.

Purpose Statement

The purpose of this study is to explore the experience of early discharge (≤72 hours) after TAVI for older adults and their informal caregivers. This exploration was undertaken to help understand the phenomenon of early discharge after TAVI for older adults and their informal caregivers and to attempt to generate recommendations for safe and effective discharge from the findings that could be integrated across the continuum of care.

Research Questions

1. How do older adults and their caregivers experience the transition home following early discharge (≤ 72 hours) after TAVI?

2. What recommendations do older adults and their caregivers make to improve the experience of early discharge home after TAVI?

Research sub-questions.

1. What type of preparation for discharge home was found to be helpful? What gaps in care were identified?

2. What concerns or challenges were expressed by older adults and their caregivers in relation to their transition home after TAVI?

3. How did patients and their caregivers experience changes in health status that supported or hindered their transition home?

Chapter Two: Literature Review

To provide the context required to understand the patient and family experience of early discharge after TAVI, a comprehensive literature review was conducted to understand the current state of the research literature and identify any gaps. The purpose of this chapter is to understand and appraise the current literature regarding the experience of early discharge after TAVI. As discussed in chapter one, limited literature in this field as well as a lack of the patient and family perspective necessitate a broadening of scope to include minimalist hospital stays after other surgical procedures, and patient and family experience of hospital discharge for older adults. The following chapter will provide a broader context to understanding the experience of older adults and their families discharged after minimal hospital stay placing emphasis both on experiences as well as a gerontological perspective. To conclude, gaps in the included bodies of literature will be identified and discussed to provide direction to study the identified problem.

The literature review for this study included extensive searches of the following data bases: Cumulative Index of Allied Health and Nursing Literature (CINAHL), PubMed, Web of Science and Google Scholar. The initial search terms used included: “TAVI or TAVR”, “older adult or geriatric” and “early discharge.” When this search yielded no studies that included the patient or family perspective the search was expanded in two directions. First the search terms “surgery,” “experience” and “early discharge” were used to identify literature that included family and patient perspectives surrounding early discharge after surgical procedures. Second to identify literature that looked exclusively at the experience of older adults and their family surrounding hospital discharge the search terms “older adult or geriatric”, “experience” and “discharge” was used. The inclusion criteria varied based on the search terms and context but overall exclusion criteria included: studies not published within the last 10 years (2006-2016)

and studies not published in English. The reference lists of included literature were also reviewed to ensure the inclusion of all relevant literature.

Risks of Hospitalizations for Older Adults

With a movement towards increasingly short hospital stays for TAVI patients, concerns about the disconnect between what the advancing minimalist technology makes possible in terms of early discharge and the ability of patients and their caregivers to safely transition home may arise. Within this discussion, it is important to review and understand the risks of hospital stays for older adults to allow a more complete understanding of the risks and benefits of minimal hospital stays for older adults. This section provides a review the literature that addresses the risk of hospitalization for older adults as well as the literature that addresses the ways in which the context of our health care system fails to address the often medically and socially complex needs of hospitalized older adults.

What are the risks? A systematic literature review on adverse events in older adults admitted to medical units conducted by Long et al. (2013) reported that older adults were at higher risk of adverse events from hospitalization than younger patients. This review identified several types of adverse events that older adults experienced more frequently including the traditionally reported adverse events (adverse drug events, falls, procedural complications, and hospital acquired infections). A prospective study conducted by Szlejf et al. (2012), reviewed the number of medical adverse events experienced in 171 consecutive admissions to an acute geriatric unit. Medical adverse events as defined by the authors included: drug-related, nosocomial infection, diagnostic and therapeutic intervention complications, delirium or surgical complications. The study results showed that 55% of study participants experienced a total of 187 medical adverse events. The results also showed that those who experienced adverse medical

events, had a statistically significant longer length of hospital stay ($p = < 0.001$) and a higher mortality rate ($p = 0.007$) when compared to patients who did not experience medical adverse events. The systematic review conducted by Long et al. (2013) also found that older adults who experienced adverse events were likely to have up to double the length of stay. In addition, older adults were more likely to receive psychotropic drugs, feeding tubes and urinary catheter insertions than younger medical patients. These studies help to identify some of the risks of hospitalization for older adults.

Functional loss or hospital-associated disability is often reported in the literature as a significant risk of hospitalization for older adults (Admi et al., 2015; Covinsky, Pierluissi & Johnston, 2011; Long et al., 2013). Described as the loss of ability to independently complete one or more of the activities of daily living (i.e. bathing, feeding, dressing, toileting or mobilizing) functional loss occurs in up to one-third of acutely hospitalized older adults (Covinsky et al., 2011). This loss of independence can lead to inability to live independently at home and decreased feelings of well-being for older adults who experience functional loss during hospitalization (Admi et al., 2015). Several in-hospital factors have been associated with functional decline including: restricting a patient's mobility, polypharmacy, limiting oral intake and ill designed hospital environments (Admi et al., 2015). Further exploration of the contextual factors affecting the risk of hospitalization for older adults will be reviewed in the next section.

Finally, the literature surrounding hospitalization risk for older adults also reviews the development of "geriatric syndromes" during hospital admission. A retrospective chart review conducted by McRae et al. (2014) of 112 consecutive patients admitted to a vascular and a urology surgical unit defined geriatric syndromes to include: delirium, functional decline, falls and pressure ulcers. Their results showed that 32% of participants experienced a form of geriatric

syndrome for which 21% developed delirium, 14% experienced functional decline, 8% fell and 5% developed pressure ulcers during their surgical admission. Of note, McRae et al. also found that elective patients were less likely to develop geriatric syndromes ($p = 0.01$) than those who were admitted from the emergency department or another hospital. As older adults who receive TAVI may be inpatients, outpatients or transfers from other hospitals, this information may be one way to help identify those at higher risk of developing geriatric syndromes after TAVI.

Why are older adults at risk? The complexity of the older adult as a vulnerable population is beyond the scope of this literature review. Therefore, the following section will provide a brief overview of the main factors that increase older adults' vulnerability during hospitalization identified in the literature. There is a wide range of identified personal factors that affect the risk of hospitalization for older adults. Long et al. (2013) reported in their systematic review that Sari et al. (Sari et al., 2008 in Long et al.) found that there was a 28% increased risk of experiencing an adverse event in hospital for each additional year of life when they controlled for length of stay. Inability to perform one or more ADLs on admission, reduced level of consciousness (Long et al., 2013), poor nutritional status, lack of social support (Admi et al., 2015), polypharmacy, cognitive impairment and frailty (Hickman et al., 2007) have also been shown to increase the risks of hospitalization for older adults.

The identified personal factors in the literature expand to include health provider factors such as lack of education and experience caring for older adults (Hickman et al., 2007). The lack of existing educational opportunities in the specialized care of older adults has been identified as a barrier to nurses' readiness to provide care to this vulnerable population (Baumbusch, Leblanc, Shaw, & Kjorven, 2016). Nurses who care for older adults have also expressed feeling that their expertise is not valued or respected and believe that many nurses avoid engaging with the

population based on belief that the care of older adults is too easy or lacks excitement (Baumbusch et al., 2016)

The physical environment of hospitals is also identified as an issue in providing safe and effective care to older adults. Hospital environments are described as poorly funded, cluttered, loud (Baumbusch et al., 2016), confusing, busy and with restricted or limited interaction between patient and staff (Calnan, M., Tadd, Calnan, S., Hillman & Read, 2013)

Several systems factors driven by the context of health care are also discussed in the literature as one of the ways older adults are at risk during hospitalization (Baumbusch et al., 2016; Hickman et al., 2007; Parke & Hunter, 2014). One of the main factors contributing to risk of hospitalization for older adults is that the current health care system is geared towards managing acute illness and a perceived lack of time to attend to some of the medical and social complexities inherent in the care of frail older adults who are admitted to hospital (Parke & Hunter, 2014). An exploratory qualitative study conducted by Baumbusch et al. (2016) supports these statements. Interviews with 41 registered nurses identified physical, functional and social needs as requiring more time when caring for older adults. In another qualitative study, health care providers also identified hospitals as task-oriented environments where efficiency took priority over what may have been in the best interest of the patient (Calnan et al., 2013).

The review of the current literature examining the risks of hospitalization for older adults presents a complex interplay of personal, environmental and systems level factors that result in a higher risk of adverse events during hospitalization. Although the majority of the literature focuses on acute hospitalizations, these risks are important to acknowledge, formally assess and address within the context of older adults undergoing TAVI as either an outpatient or as an inpatient. Movement towards decreasing length of stay for TAVI patients to reduce the risk of

hospitalization must be balanced with the increased time often required to facilitate safe discharge for the often socially and medically complex patients undergoing TAVI and their families. The existing research literature surrounding a movement towards shorter hospital stays after TAVI will be examined in the next section to look at both the safety and feasibility of this practice as well as some of the processes in place to facilitate safe early discharge post TAVI.

Early Discharge after TAVI

TAVI specific literature relating to early discharge appears to be a newer focus of the TAVI literature with all four identified studies being published after 2014 (2014-2016). Shorter hospital stay post TAVI is referred to in this body of literature as "early discharge" (Durand et al., 2015; Barbanti et al., 2015) "earlier discharge" (Noad et al., 2016), and "earliest time after TAVI" (Lauck et al., 2016). The time to discharge identified by these studies to qualify as a minimal or early discharge ranges from less than 48 hrs to less than 72 hrs with one study looking at next day discharge (Noad et al.). The literature focuses on two aspects of early discharge: safety and feasibility and description of pathways used by individual programs to identify those who could be discharged early and facilitate the success of early discharge after TAVI.

Safety and feasibility of early discharge after TAVI. The literature addressing the safety and feasibility of minimal hospital stays after TAVI identifies a need to study and quantify the effects of a movement towards earlier discharge facilitated by an increasingly minimalist approach, evidence-based clinical pathways and interdisciplinary case selection (Durand et al., 2015; Lauck et al., 2016; Noad et al., 2016). As there is currently no agreement among experts regarding the optimal length of stay after TAVI, this research has been identified as essential to

help provide evidence to support the current movement towards minimizing hospital stays for this patient population (Durand et al., 2015).

Durand et al. (2015) conducted a retrospective study on 337 consecutive transfemoral (TF) TAVI patients who returned home after discharge. Researchers divided the study population into two groups: length of stay less than or equal to three days (n = 121) and length of stay more than three days (n = 216). The primary end points studied were all cause mortality and readmission to hospital 30 days after discharge. The study showed that there was no significant difference between groups with regards to all-cause mortality (p = 0.32) or readmission to hospital (p = 0.56). Although this study does support the safety of early discharge in post TAVI patients, the lack of matching between unequal study groups and sample sizes may have resulted in some bias and threat to internal validity of the study (Polit & Beck, 2012). Barbanti et al (2015) also retrospectively compared 465 consecutive patients from 2007-2014 who were discharged within 72 hrs (n = 107) to those discharge after 72 hours (n = 358), but employed propensity matching to help control confounding bias. Matched groups in this study also showed no difference at 30 days post discharge with regards to death (p = 0.54), bleeding (p = 0.44), pacemaker implantation (p = 0.33) and rehospitalisation (p = 1.00). Providing further evidence for the safety of early discharge after TAVI, one prospective study was conducted by Noad et al. (2016) to test the effectiveness of an evidence-based early discharge pathway. This study compared three groups: next day discharge (n = 26), discharged in 1-4 days (n = 39) and late discharge (n = 45). Noad et al. also showed that there was no difference between groups in terms of 30-day mortality (p = 0.17) or readmission rates (p = 0.95). These studies provide good evidence to support some aspects of the safety and feasibility of early discharge but fail to address the patient and family readiness and experience of increasingly shorter hospital stays.

Failure to include emergency room (ER) visits in their analysis may miss a group of patients with more minor complications who don't require hospital admission or identify patients and their families who sought medical attention in the ER as they were unsure of how to identify and manage complications.

Pathways to facilitate safe early discharge after TAVI. In support of a movement towards reducing hospital stays while optimizing patient outcomes, some studies outline their development of evidence-based, interdisciplinary pathways to facilitate the safe discharge of older adults after TAVI (Lauck et al., 2016; Noad et al., 2016). Noad et al. (2016) conducted an analysis of retrospective data to help identify patients who would likely be safe to be discharged earlier and develop a pathway to facilitate the process. Candidates for early discharge were identified based on more holistic pre-assessment criteria including: medical history, imaging, planned procedure as well as frailty scores and the presence of social supports. After their procedure, clear discharge criteria were used to identify if a patient was still safe for discharge including: lack of bleeding, absence of respiratory distress, mobilizing and stable kidney function. Although this pathway does identify that patients are provided with nurse-led discharge teaching and a contact number for a TAVI specialist nurse, it appears to be a physician driven pathway with decisions regarding appropriateness of discharge resting with the responsible cardiologist with no identified multidisciplinary input.

Lauck et al. (2016) identify the heterogeneity of the TAVI patient population as a factor that impacts length of stay in post-op TAVI patients that goes beyond procedural characteristics. Importantly, Lauck et al. identify that factors such as age, functional decline, exacerbated co-morbidities and hospital acquired complications often affect the length of stay for older adults undergoing TAVI and argues that care processes to address the different health and social

contexts of the patients in our care are essential. This formed the basis for a multidisciplinary heart team that follows that patient from referral to one-year post-op as well as a formalized nurse-led post-procedure pathway that focused on geriatric care issues such as early mobilization, hydration and nutrition, and avoidance of urinary catheter insertion. The authors also reviewed the length of stay for 397 patients between May 2012 and October 2014 when the reported clinical pathway was introduced. They found that 38% were discharged within 48 hrs and 61.8 % were discharged after 48 hrs. As with the studies previously discussed, Lauck et al. found no difference between groups regarding 30-day mortality or 30-day hospital readmission. In contrast to other studies, Lauck et al. registered concern at the equal rates of re-admission between groups as the early discharge group had significantly lower rates of impaired ejection faction, frailty scores and cognitive dysfunction. The research that outlines evidence-based pathways to minimize length of stay in TAVI patients identifies factors that may be important in improving experience of early discharge for older adults who undergo TAVI and their informal caregivers. To facilitate early discharge after TAVI in hopes of optimizing patient outcomes and minimizing the risks of hospitalization for older adults, it is important to understand the experience of discharge and discharge planning for older adults and their caregivers. These perspectives will be examined in the following section.

The Experience of Discharge for Older Adults and their Families

As older adults may be discharged from hospital with residual care needs, the complexity of the discharge process for older adults can result in increasing length of stay, incomplete assessment of care needs and subsequent readmission to hospital (Bauer et al., 2009). To help assess the experience of discharge and discharge planning for TAVI patients it is important to explore the literature available that assesses the discharge experience for older adults. With the

increasing care requirements of older adults discharged from hospital, the care often falls on informal caregivers (Bragstad et al., 2014). A literature review surrounding best practices in hospital discharge planning identified the role of the family as one of the most important influences on a successful discharge (Bauer et al., 2009). Movement towards reducing hospital stays may therefore result in informal caregivers taking on important roles in the care of their loved ones after TAVI; their insights into what facilitates a safe transition home are therefore essential for older adults discharged home after TAVI.

The experience of hospital discharge for older adults. Five research articles will be discussed with relation to the hospital discharge experience of older adults. The included studies review older adults' experiences from their time in hospital (Foss & Hofoss, 2011; Uhrenfeldt & Hoybye, 2015), to their time in the community (Andreasen et al., 2015; Perry et al., 2012) as well as the experience of being readmitted after a recent discharge (Dilworth, Higgins, & Parker, 2012). Despite different methodologies, study settings and disease groups several common themes emerged in the literature including: communication, feelings of invisibility, interpersonal relationships and gaps in care. These themes will be discussed in the following sections.

Communication. Studies exploring the experience of discharge for older adults' report that participants frequently experienced breakdowns in communication with health care providers which led to feelings of anxiety, uncertainty (Andreasen et al., 2015), powerlessness, confusion (Dilworth et al., 2012) and lack of confidence (Perry et al., 2012). A metasynthesis of the experiences of older adults discharged after orthopedic intervention reported that patients felt powerless and frustrated both by the lack of information provided to them regarding their post-operative care but also receiving different messages from different staff and feeling that they were not invited to participate in the planning process (Perry et al., 2012). A cross sectional

study conducted by Foss and Hofoss (2011) supported these findings by reporting that in a sample of 254 patients over the age of 80, 58% felt they participated in the decision making surrounding the discharge planning process “only to a small degree” or “did not at all”. A qualitative interpretive description study conducted by Andreasen et al. (2015) reported that frail elderly patients discharged to the community often felt they were discharged with little to no information regarding their condition, how to manage their medications and how to interpret their symptoms upon discharge. The authors conclude that these feelings of anxiety and uncertainty could be addressed with clear, patient-centred communication leading up to discharge. When communication was clear and delivered by someone with perceived expertise, this information was found to instill confidence for older adults discharged after orthopedic intervention (Perry et al., 2012). Participants in Foss and Hofoss’ (2011) study also reported a desire to have family members present when discharge information was communicated; only 22% who expressed this desire had it met. The reviewed literature highlights the importance of clear, patient centered communication where information can be shared between health care providers and the patients and their families. The provision of information in this way may help to decrease feelings of anxiety, powerlessness and uncertainty in older adults discharged from the hospital.

***Feelings of invisibility*.** Feelings of loss of personhood resulted from the study participants perceptions that their needs were not met or were ignored. For older adults participating in a fast track program for operative treatment of colon cancer, participants felt that the health care professional’s focus on care pathways and early mobilization resulted in their pain, nausea and suffering being ignored (Uhrenfeldt & Hoybye, 2015). One study participant reported that this care experience made her “feel like an object.” Within this population there

was a disconnect between perceived readiness for discharge between the health care providers and the patients resulting in patients expressing that nurses were abusing their power and feeling that their needs were trumped by the economic needs of the hospital. The participants in Dilworth et al.'s (2012) study also expressed feeling like they had been discharged before they were fully recovered and not well enough to go home. Feelings of their needs being ignored, may occur as a result of and be compounded by health care professionals' failure to successfully and relationally communicate a plan of care with older adults who are being discharged from the hospital.

***Family and patient relationships*.** Participants frequently experienced an alteration in their relationship with their loved ones after discharge from hospital precipitated by increasing care needs (Andreasen et al., 2015; Perry et al., 2012). Positive relationships that were described as supportive and close were felt to be a large factor in a positive recovery experience (Andreasen et al., 2015), but older adults also expressed feelings of guilt about being a burden to their loved ones (Andreasen et al., 2015; Perry et al., 2012). The metasynthesis conducted by Perry et al. (2012) reported awareness of the possible burden placed on their loved ones due to their increased dependency, but acknowledged that their family members provided support willingly. Patients readmitted to the hospital after discharge also acknowledged the important role played by family members in supporting their transition into the community, although these participants felt that their readmission was inevitable despite the support (Dilworth et al., 2012).

Some patients also expressed feelings of isolation after discharge related to limited functional capacity (Andreasen et al., 2015; Perry et al., 2012). Older adults discharged after acute hospitalization reported that a lack of meaningful social life resulted in feelings of isolation and loneliness which they felt negatively affected their transition home (Andreasen et al, 2015.).

In extreme cases, especially those associated with the recent death of a loved one, the distress caused by dependence and isolation may lead to suicidal thoughts (Andreasen et al., 2015). Although older adults recovering from elective orthopedic surgery initially reported feelings of isolation, some also reported excitement at being able to resume activities with friends after their recovery (Perry et al., 2012). These findings support the importance of positive interpersonal relationships as well as the need to facilitate social interactions for older adults discharged home after hospitalization.

***Gaps in care*.** The last common theme present in the literature of older adults' experiences of hospital discharge includes feelings that there were gaps in care compounded by the issues of poor communication and lack of involvement in discharge planning. The frail older adults interviewed by Andreasen et al. (2015) felt that the services that they needed were standardized as opposed to tailored to individual needs, or they felt they received worse service if they lived further away from the city. They also expressed that the services provided were inadequate or not in place before they were discharged leading them to feel unsafe after their discharge home. Perry et al. (2012) reported that the home environment was often not adapted before discharge to help manage their affected mobility. Although this was of concern, some participants expressed feelings of pride at being able to adapt to their environment with less assistance. (Perry et al., 2012). The older adults interviewed by Dilworth et al. (2012) expressed feelings of vulnerability when they were discharged home quickly before supports were in place. The authors felt that these gaps in care and inadequate discharge planning resulted in the preventable readmission of the study participants within 28 days of discharge from hospital.

The common themes of communication, feelings of invisibility, patient and family relationships and gaps in care help to highlight older adults' experience of being discharged after

a hospital admission in multiple care settings. These commonalities may help guide the development of discharge planning care processes for older adults who undergo TAVI as a planned elective procedure provides caregivers, patients and their caregivers with the opportunity to begin discharge planning at first contact with the TAVI team. The experience of caregivers is also important to understand as they are often involved in the care of older adults before and after discharge and this involvement is vital to success. These perspectives will be addressed in the next section.

The experience of discharge for the caregivers of older adults. Four qualitative studies examining the caregiver's experience of discharge will be discussed in the following section. Two studies examine caregivers' experience within the context of discharge after an acute medical unit admission (Bragstad et al., 2014; Hvalvik & Reierson, 2015), one describes the experience of discharge within the context of an early readmission to an acute medical unit (Slatyer et al., 2013) and the final study looks at the experience of providing care to patients 80 years and older who have undergone coronary artery bypass grafting (Ganske, 2006). Five common themes emerged from this literature including: lack of preparation, lack of influence, acting as advocates and monitors, adjusting to change, and pride in accomplishments.

***Lack of preparation*.** A feeling of being unprepared for the role of informal caregiver was common throughout the literature. These feelings were often described within the context of poor communication with health care providers and a lack of understanding of roles and responsibilities. A qualitative descriptive study conducted by Slatyer et al. (2013) found that family members expressed that they did not understand the complex care needs of their loved ones due to the stress of admission and the busy environment in the hospital. Participants felt that there was a lack of communication surrounding their roles and responsibilities before discharge

despite the fact they were expected to provide the care at home (Slatyer et al., 2013) The theme of lack of preparation was also expressed with relation to the patient's readiness for discharge home (Bragstad et al., 2014; Hvalvik & Reierson, 2015). The phenomenological hermeneutic study conducted by Hvalvik and Reierson (2015) found that family members often experienced fear and stress related to their perception that their family members were discharged too early; before they understood significant information required for their care. Participants expressed concern over the fact they had several responsibilities upon discharge but were uncertain as to what they were or how to deal with complications. Bragstad et al. (2014) found that this lack of preparation manifested in family members having to take an "active role" to seek out required health care services after discharge as this information was often not provided or inadequately set up during the patient's time in hospital. Finally, lack of preparation to provide specialized physical care after discharge such as dressing changes caused caregivers to express concerns that their family member was discharged too early from the hospital after CABG (Ganske, 2006). Ganske (2006) found that although there was an expectation for caregivers to perform these functions after discharge, there was no insistence of the skill being mastered before the patient was discharged. The literature examined highlights that lack of preparation before discharge leads to feelings of fear, lack of understanding of their responsibilities, and uncertainty for informal caregivers of older adults discharged after hospitalization.

Lack of influence. As with lack of preparation, lack of influence was seen to be related to busy hospital environments and lack of communication with health care providers. Hvalvik and Reierson (2015) found that participants expressed feeling invisible in busy hospital units where they felt hospital staff avoided contact with them and did not address their questions and concerns. Participants also expressed wanting to be involved in the discharge planning process

but felt that their needs were often ignored. These sentiments were echoed by the caregivers interviewed by Bragstad et al. (2014) who often resorted to drastic measures to achieve influence in the discharge of their family members. For example, when they felt their discharge planning needs had not been addressed, one caregiver went away for the weekend and another took her mother's keys and clothes so their family member could not be safely discharge by the health care providers (Bragstad et al., 2014). These stories are examples of the importance of involving caregivers in the discharge planning process to facilitate their influence and subsequently gain a deeper understanding of needs of both the patient and their caregivers.

***Acting as advocates and monitors*.** Review of the literature found that family members often experienced a strong sense of responsibility and obligation to act as an advocate or "intermediary" for their family members who were no longer able to actively participate in their care due to increasing dependency (Bragstad et al., 2014; Hvalvik & Reierson, 2015). Participants in these two studies expressed inadequate services in the community as a common reason that this advocacy was required. Caregivers interviewed by Bragstad et al. (2014) expressed feelings of vulnerability and the need for resourcefulness to help them navigate the complexities of the services available within the community. One participant stated "no one will seek you out to provide services…unfortunately you have to take action yourself" (Bragstad et al, 2014, p. 7). This highlights the important role of advocate that is played by the caregivers of older adults who are discharged from hospital.

Caregivers of older adults also expressed the need to act as vigilant monitors in the post-discharge period. Those providing care to older adults after CABG interviewed by Ganske (2006) felt a responsibility to ensure their love one's safety by maintaining frequent contact often in the form of living with them 24 hours a day. Some family members caring for patients after

acute medical admission expressed distrust in the community services provided and felt they needed to be present to unsure care was being provided appropriately and that there was adequate information sharing between hospital and community (Hvalvik & Reierson, 2015). Caregivers interviewed by Slatyer et al. (2013) reported that their monitoring helped ensure the patient's safety by noticing changes in status and intervening by taking their family member to the hospital when required. The time needed to perform these essential functions and the effect on caregivers' lives is discussed in the next section.

Adjusting to change. The requirements of advocacy to gain influence and vigilant monitoring resulted in a change to the everyday life of participants interviewed in the four included studies. This often took the form of juggling schedules as especially younger caregivers often were responsible for the care of the older adult as well as their family and work responsibilities. The sheer volume of medical appointments after CABG made one caregiver feel as if she was performing a "juggling act" to manage her father's care needs with the demands of her own life (Ganske, 2006). As their loved ones became more frail, informal caregivers reported changing roles as they needed to be increasingly involved with their family members due to higher levels of anxiety or physical care needs (Hvalvik & Reierson, 2015). The need to be available 24 hours a day in the immediate discharge period often resulted in caregivers having to place their own needs behind those of their loved ones often resulting in avoiding social activities so they could be prepared to assist their family member at any time (Hvalvik & Reierson, 2015).

Feelings of pride. Although the literature presented regarding caregivers' experiences of caring for older adults after discharge uncovered feelings of fear, frustration and exhaustion related to lack of preparation and influence as well as their roles as advocates and monitors,

caregivers also expressed positive feelings of pride in their role as caregivers. The caregivers interviewed by Hvalvik and Reierson (2015) were proud of their hard work and what they were able to accomplish and obtain for their loved ones within systems they felt were inadequate to ensure the safety of their family member. Ganske (2016) found that as time passed, caregivers felt increasingly comfortable with their roles and were able to acknowledge their success in facilitating recovery at home for their loved ones.

Although they may have different roles and responsibilities during the discharge process both patients and their informal caregivers expressed similar concerns surrounding discharge including the importance of communication with health care professionals as well as feelings of invisibility or that they lacked influence within the context of this communication. The importance of communication and patient and family involvement is supported by the reviewed literature and must be integrated into the care processes designed for older adults discharged after minimal hospital stay post TAVI. With the exception of the study conducted by Uhrenfeldt and Hoybye (2015), the reviewed literature did not isolate older adults identified for minimal hospital stays but rather those discharged after acute hospital admission. As care pathways for TAVI are increasingly identifying and preparing for early discharge (Lauck et al., 2016; Noad et al., 2016) it is important to understand the experience of discharge within the context of structured programs, such as surgical fast-track programs that are aimed at minimizing the length of stay after surgical intervention. To provide context to the experience of early discharge after TAVI, the literature examining the experience of participation in a fast track surgical program as well as day surgery will subsequently be reviewed.

The Experience of Discharge after Day Surgery or Fast Track Surgery

Movement towards less invasive interventions and improved pain management has resulted in it becoming feasible to discharge patients much earlier following surgical intervention. This requires a more independent participation in the recovery process for patients and their caregivers (Boughton & Halliday, 2009; Norlyk & Harder, 2011). The literature examining the experiences of patients and their caregivers following either day surgery or a fast track surgical program will be reviewed to provide the context of patient and family experience that must also be explored in addition to safety and feasibility of early discharge. The experience of day surgery and fast track will be explored separately due to the distinct natures of the programs including disparities in education and preparation between both groups.

The experience of discharge after day surgery. Some procedures previously deemed to be major surgery which required days of hospitalization are now being performed within the context of day surgery (Boughton & Halliday, 2009). The reason for this transition has been attributed to cost-containment, self-care philosophy and advances towards less invasive surgical techniques (Mottram, 2011). Many patients and their caregivers who underwent day surgery procedures expressed feelings of uncertainty and a need for support. Patients and their caregivers who were interviewed by Boughton and Halliday (2009) consistently expressed feeling uncertain and anxious surrounding discharge due to what they felt was a lack of preparation and information for their transition to home. Participants requested concrete written instructions about what to expect and how to respond to complications and direct contact information to provide needed support. Boughton and Halliday found that participants wanted reassurance from health care professionals that they were “doing the right things” and would have appreciated a routine visit from a health care professional after discharge. This need for reassurance found by

Boughton and Halliday was echoed by the participants studied by Mottram (2011). The grounded theory study of 145 patients and 100 caregivers conducted by Mottram found the major category to emerge from their data was that professional support after discharge was lacking. This experience occurred within the context of participants feeling unsure about how to manage unexpected outcomes such as pain, weakness and surgical complications and a perceived lack of adequate aftercare in the home. Both studies concluded that adequate discharge planning in these patient populations was essential due to their limited contact with health care providers. Morton (2011) insisted that discharge planning must place patients at the center of the planning process to help empower patients to care for themselves and decrease anxiety after discharge with the provision of individually adapted plans of care.

The experience of discharge after fast track surgery. Fast track surgical programs are becoming increasing common as they have been shown to decrease length of stay without increased rates of morbidity or early readmission. (Jorgensen & Fridlund, 2016). The success of these programs is dependent on evidence-based interdisciplinary clinical pathways that focus on early mobilization, adequate pain relief, pre-operative education, post-operative follow-up and active participation by the patient and their family (Jorgensen & Fridlund, 2016; Norlyk & Harder, 2011). Where the TAVI literature related to earlier discharge has not yet addressed patient experience, the experience of discharge after fast track orthopedic or colon surgery has been examined in three studies.

The ethnographic study of older adults' experience of well-being while participating in a fast track program after colon resection to treat colon cancer completed by Uhrenfeldt and Hoybye (2015) found that participants reported feeling like objects. These perceptions were due to the fact participants felt that the expectations and focus of the fast track program resulted in

nurses ignoring their suffering to ensure patients remained on the fast track recovery pathway. The authors concluded that there was a “clash of perspectives” between staff and patients and different motivations resulting in patients experiencing an assault to their well-being while participating in a fast track surgical program.

A descriptive phenomenological study conducted by Norlyk and Harder (2011) also looked at patients’ experience with a fast track surgery program for patients treated for colon cancer. This study included 16 participants aged 53 to 77 who were interviewed at two weeks and two months post-discharge. Although the authors do not focus exclusively on older adults as in the study conducted by Uhrenfeldt and Hoybye (2015) they focus more explicitly on the experience of being at home after discharge from a fast track program. Norlyk and Harder (2011) found that the participants expressed their experience as a transition process from fear, uncertainty and lack of control while overcoming the operation to being on the way to recovery. Participants felt that during hospitalization they were forced to ignore their body’s signals to adhere to the fast track regime, but as they transitioned home they began to take control and understand their symptoms. Although participants enjoyed the increased control and independence, they often expressed feelings of guilt if they were unable to follow the recommendations of the fast track program due to pain or fatigue. Participants expressed frustration with how their everyday lives were forced to change based on the physical limitations of their bodies after surgery and a need for things to “return to normal.” Both studies reviewed above must be seen within the context of treatment for a cancer diagnosis which may increase feelings of fear and uncertainty that may be experienced differently by patients undergoing the corrective procedure for TAVI.

The final study looking at fast track programs conducted by Jorgensen and Fridlund (2016) employed a grounded theory approach to explain the processes involved in coping with participation in fast-track programs after total hip arthroplasty. The authors uncovered four distinct coping types but found that all were driven by a desire to meet the requirements of the fast track program to allow them to restore their former active life. Jorgensen and Fridlund found that despite varying coping styles all participants credited the fast-track program with their recovery and appreciated that there was a clear division of tasks with clear expectations between health care providers, family and patients. The patients with the highest levels of anxiety were found to push back against expectations when they were pushed by staff to meet fast track targets that they felt were beyond their limits of capability. This was also seen in the study of older adult patients interviewed by Uhrenfeldt and Hoybye (2015) where participants expressed feeling that their concerns were ignored in favour of adherence to the program experienced as nurses exercising their power.

Where the literature related to day surgery uncovers experiences related to lack of preparation and lack of support, the literature surrounding fast-track programs focus more on patients striving to meet the requirement of a strenuous program. The fact that patients who participated in fast track programs expressed less concerns about lack of support and preparation could be related to the more structured care processes involved pre, peri and post-operatively for this patient population. These findings help provide some insights into the diverse experiences that TAVI patients may encounter once they are discharged after a minimal hospital stay.

The Experience of Discharge after Heart Valve Replacement

Review of the literature surrounding patient experience of heart valve replacement uncovered one phenomenological hermeneutic study performed by Berg et al. (2013). Although

this study does not explicitly address the discharge experience of older adults, look specifically at the experience of early discharge after TAVI, or provide data regarding the participants length of stay in hospital, it does include interviews with five participants who have undergone TAVI and seeks to understand their recovery experience. The authors found four main themes within the patients' experience including: disturbed network, disturbed body, recovery and reflection. Participants experienced changed roles in their interactions with loved ones such as increased dependence and felt that their caregivers were essential to their recovery as they provided both instrumental and emotional support. Good interactions with health care providers helped participants feel supported and those who did not have good experiences felt lost and rejected. The disturbed body was represented by anxiety related to how to manage complications as well as a heightened attention to how their body was recovering; this sentiment was echoed in the research surrounding fast track surgery. For the theme of recovery, patients experienced that their life had been interrupted, and that the weakness they experienced made it impossible to resume their previous activities as they struggled towards a slow recovery and the way back to normal. Finally, participants reflected on their experience of heart valve surgery and expressed not regretting having the procedure and many reported that their everyday tasks had become easier. In contrast, some participants felt little difference and expressed feeling depressed and fragile during recovery. Berg et al. concluded that these findings support the need to structure discharge planning, rehabilitation and follow up to include attention to mental recovery as well as physical recovery and provide patients with information regarding the possibility of feelings of fragility, impacts of the procedure on daily life and the body and the temporary role changes within the family. These findings may provide insight into the examination of the care processes

and discharge experiences of patients and their caregivers who are discharged post TAVI after a minimal hospital stay.

Summary and Gaps

In this chapter, the literature surrounding the risk of hospitalization for older adults, the safety and feasibility of minimal hospital stays, the care pathways designed to facilitate decreased length of stay after TAVI and the experience of discharge and discharge planning for older adults and their caregivers was examined. This review was guided by the identified research question: How do older adults and their caregivers experience the transition home following early discharge after TAVI? As there is currently no research that examines the identified research question, the literature review consisted of four distinct but linked reviews to look at risks of hospitalization for older adults, early discharge after TAVI, the experience of discharge and discharge planning for older adults and their caregivers, and finally the experience of discharge after day surgery or a fast track surgical program.

This chapter reviewed the literature surrounding the risks of hospitalization for older adults. The movement towards minimal hospital stays can be supported by the clear risks experienced by older adults in hospital. The review identified that older adults are at higher risk of several events during hospitalization than are younger patients including: falls, adverse drug events, functional loss, delirium and infections. Of notable concern, older adults are not only more likely to experience these complications but they are also more likely to have urinary catheter or feeding tubes inserted or to be restrained than are younger patients, placing them at further risk for adverse events and functional decline (Long et al., 2013). The literature also uncovered that older adults are vulnerable during their hospitalization as the current health care system is geared towards managing acute illness and the social and medical complexity of some

frail older adults is felt to take too much time or is not viewed as prestigious or important care within the hospital setting. The extra time required for discharge planning that may be required to manage complex medical and social needs of older adults is often ignored, placing older adults at risk after inadequate discharge planning. For these reasons, balancing decreasing the risk of hospitalization with the increased time and support required for recovery of a heterogeneous TAVI population must be acknowledged and addressed within the context of minimal hospital stays after TAVI.

This chapter also discussed the quantitative studies that have helped support a movement towards early discharge by showing that there is no difference between those discharged 72 hours or less after TAVI to those discharged later with regards to mortality or 30-day re-admission. The literature reviewed also highlighted the importance of evidence based, interdisciplinary care pathways to help identify and prepare those who may benefit from a minimal hospital stay. Case selection ought to be based on multimodal assessment that goes beyond medical and procedural information to include functional status and social supports for the patients who undergo TAVI (Lauck et al., 2016; Noad et al., 2016). Although this literature helps to support the argument that it is safe to continue to move towards early discharge after TAVI, it fails to address the patient and family experience and does not look at emergency room visits which do not require admission. These gaps in the literature are important as they may fail to identify some of the needs not addressed by the current care processes for patients and their families who are discharged post TAVI.

Finally, the unique needs related to the discharge of older adults were reviewed by examining the literature surrounding the discharge experience of older adults and their caregivers who were discharged from hospital. Both patients and their caregivers identify poor

communication during the discharge planning process. This breakdowns in communication is experienced as a lack of preparation and a lack of influence and is the trigger for feelings of anxiety, being unsafe, frustration, exclusion and invisibility during the discharge process. Both groups express the desire to be involved in the discharge planning process to ensure their needs are addressed and that they know what to do in case of emergency; this need is rarely addressed. The important role of the caregiver is also identified as decreasing functional ability requires family members to step in to provide instrumental and emotional support and to help navigate complex health care systems. The literature identifies clear, patient and family-centered discharge planning as the most effective way to combat feelings of anxiety and exclusion for patients and their families who are discharged after hospital admission. With the exception of one study (Uhrenfeldt & Hoybye, 2015) this body of literature looked at discharge experience after acute medical admission. This provides important context as some TAVI patients undergo surgery as an inpatient, but a large portion of the population will undergo TAVI on an elective outpatient basis which provides the opportunity to identify and develop the care processes that will facilitate a successful discharge after a minimal hospital stay well before their admission to hospital.

In addition, the experience of being discharged after day surgery and participation in fast-track surgical programs was examined. Where the patients who underwent day surgery expressed similar concerns regarding communication and lack of support as did the older adults and their caregivers discharged after acute admission, those who participated in a fast-track program focused on their recovery and return to baseline. Those who underwent day surgery expressed feeling disappointed at the perceived lack of quality of community service provided, but fast-track participants reported appreciating the clear roles and task division between them and the

health care providers. The differences may be explained by the structured pre, peri and post-operative care processes in place and may also be seen in the minimal stay TAVI population which is also increasingly being identified early and care providers are using evidence based multidisciplinary care pathways.

Finally, the single article looking at the experience of recovery after heart valve surgery was presented. Like the participants in fast-track programs, those studied by Berg et al. (2013) also focused on moving towards recovery or a return to normal and increased attention to their bodies. Like the older adults discharged from hospital and day surgery patients, patients who underwent heart valve replacement also expressed concern, anxiety, and fear surrounding their decreased functional capacity and lack of understanding as to how to deal with complications.

In sum, there is a lack of literature that explicitly addressed the identified research question: How do older adults and their caregivers experience the transition home following early discharge after TAVI? This required the expansion of the literature review to understand the broader literature and to help contextualize the identified problem. The identified literature provides context as to the importance of addressing this gap in literature by exposing the risks of hospitalization for older adults, feelings of fear, invisibility and uncertainty surrounding the discharge process, and the need for clear, comprehensive and individualized discharge plans for patients being discharged from hospital after acute hospitalization or surgical intervention. The unique experiences of older adults and their family members who are discharged early after TAVI will be examined in this study to address the identified gaps in the TAVI literature and provide recommendations for practice. The methods used to undertake this analysis will be discussed in the next chapter.

Chapter Three: Research Methods

The following chapter will provide an overview of the methods employed to examine how older adults and their caregivers experience the transition home following early discharge after TAVI. This thesis project was conducted using data collected as part of a larger research program based out of the University of British Columbia that has followed TAVI patients from eligibility assessment to two to four months post-procedure (Adaptation and Innovation: Bridging Older Adult Care and Advances in Cardiovascular Practice; Primary Investigator Baumbusch, J.). This research will be referred to as the "TAVI study" within this thesis for clarity. A clear review of methodology therefore necessitates that the methods employed by the original investigators as well as those employed for this thesis project are both reported in this chapter. This chapter will review study design including the method of inquiry, interpretive description, and rationale will be provided for the choice of methodology to answer the designated research questions. Chapter three will also describe the study setting and study sample. This will be followed by a description of data collection methods, a review of the methods employed for data analysis, ethical considerations and finally the limitations of the employed study design.

Study Design

The aim of this thesis project was to highlight the experience of early discharge after TAVI for older adults and their caregivers in the hope of developing recommendations for discharge planning that could be integrated into the clinical environment. To help answer the research question: How do older adults and their caregivers experience the transition home following early discharge (≤ 72 hours) after TAVI? data from the TAVI Study was examined

and analyzed. The TAVI Study sought to explore the experience of undergoing TAVI for patients, their informal caregivers and health care providers from referral to up to four months post-procedure. The researchers used focused ethnography as their method of inquiry, and their sampling plan, data collection and data analysis were informed by the aforementioned. Focused ethnography is a type of inquiry based in the roots of ethnography but which is "problem focused and context specific" (Higginbottom, Pillay & Boadu, 2013, p. 3) where the researcher has prior knowledge of the area to be studied (Knoblauch, 2005). It is characterized by research questions guided by knowledge of the field, short term field visits, intensity of data collection and analysis, and data sessions where researchers view the data together (Knoblauch, 2005).

This study employed interpretive description as the study methodology. Interpretive description is a method of qualitative inquiry proposed by Thorne, Kirkham and MacDonald-Ems (1997) to respond to a growing need for a practice-oriented methodology that would allow the generation of interpretations to be applied in clinical practice. The purpose of interpretive description is described by Thorne, Kirkham and O'Flynn-Magee (2004) as "capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical practice" (p.3). It does not provide prescriptive methodological steps to guide study design but encourages researchers to drawn from multiple research traditions to best answer their stated research questions (Thorne, 2016). Findings applicable to practice are generated through inductive reasoning and grounded in context and the existing knowledge of the discipline (Thorne, 2016). Interpretive description was chosen to guide the thesis project based on its pragmatic and flexible approach to generating knowledge. In addition, it was chosen because interpretive description provides the scaffolding from which to explore the experiences

of early discharge for older adults and their care givers who undergo TAVI while maintaining a focus on generating knowledge to guide clinical practice.

Study Setting

The setting for the TAVI study from which this thesis project was drawn was a high-volume referral center for TAVI located in a tertiary hospital in Western Canada where over 1400 TAVIs have been performed since the program's inception in 2005 (Lauck et al., 2016). Care for TAVI patients is delivered by an interdisciplinary heart team and guided by standardized care pathways. Patients and their families who are referred for TAVI undergo extensive testing including angiography, computed tomography scan, echocardiogram, assessment by a cardiac surgeon and an interventional cardiologist, as well as a comprehensive psychosocial and functional assessment to help determine a patient's eligibility for TAVI (Lauck et al., 2012). At the study site, the development of an interdisciplinary heart team to support triage, clinical care and team decision-making as well as risk-stratified minimalist procedures, and standardized care pathways has resulted in a decrease in the mean length of stay of TAVI patients between 2007 and 2014 from seven days to three days with many being discharged the next day (Lauck et al., 2014). This study setting therefore provided the opportunity to study the experience of early discharge after TAVI based on a commitment to advancing practice and to work towards safely reducing length of stay after TAVI.

Sampling Plan

Study population. Purposive sampling was employed by the TAVI research team to ensure the study sample was able to provide rich data to answer the proposed research questions (Polit & Beck, 2012). In the original study, the inclusion criteria for the patients were i) the

ability to converse in English and ii) age greater than 65 years. Patients were excluded if they lived in a facility with health care providers present or if they had a condition that limited their cognitive capacity. For informal caregivers, interested participants were included in the study if they planned to be present throughout the TAVI process, including clinic visits and during hospital stay, as well as had the ability to converse in English.

Two additional eligibility criteria were employed to complete this thesis project. First, to facilitate a deeper understanding of the discharge planning over time and to see how this informs the experience of transitioning home after early discharge post TAVI, participants were only included in this study if there was available data from eligibility assessment through to two to four months post-procedure. To explore the phenomenon of interest, discharge experience after minimal hospital stay, participants were only included in the study sample if their length of stay in hospital or that of their family member was less than or equal to 72 hours. The cut off of 72 hours was employed as this was often used to define early discharge in the currently published quantitative studies looking at early discharge after TAVI (Durand et al., 2016; Lauck et al., 2016 & Noad et al., 2015).

Recruitment of study participants. Participants were recruited to the TAVI study by mailing a letter to all patients referred for TAVI between January and April, 2013**.** If patients had not responded at the time of their initial visit to the TAVI clinic, they were asked if they had received the information letter and additional information was provided at that time if required. To recruit informal caregivers, patient participants were asked if they had a caregiver and if so a letter of information inviting participation was mailed to the caregiver. No further recruitment strategies were undertaken for this thesis project as it was conducted to explore a specific aspect of the TAVI experience from existing study data.

Sample size. The source study recruited a total of 31 patients and 15 informal caregivers. The sample size for this thesis project was guided by the imperative to answer the proposed research question. Sample size was limited compared to the original TAVI study sample as only those who had had been discharged before 72 hours post-op and their informal caregivers were included for analysis. As previously discussed, in an attempt to understand the experience of discharge over time, participants were only included if they had interview data available from eligibility assessment through two to four months following their discharge. After excluding original study participants from the sample, there remained ten TAVI patients and nine informal caregivers who were included in the study sample. Though not a large sample, the multiple time points of data collection (referral, eligibility assessment (pre-procedure), two weeks and two-four months post procedure) provided a large amount of data from which to draw allowing for an in-depth analysis of the included individuals.

Data Collection

Data was collected for the TAVI study using two sources, semi-structured interviews and participant observation. The importance of interviews to understand the phenomenon being studied is premised on the idea that the experience of health or illness is only known by those who experience it (Thorne, 2016). Semi-structured interviews are employed when researchers want to ensure that specific topics are covered during participant interviews (Polit & Beck, 2012). This process is facilitated through the use of topic guides which specify issues or questions to be covered while still encouraging study participants to speak freely about all of the identified topics (Polit & Beck, 2012). Interview data for patients was collected at four separate time points: between referral and pre-assessment, at eligibility decision, two weeks post-procedure and between two to four months post-procedure. The researchers sought to interview

informal care givers twice (before and after TAVI) to understand their role in the TAVI process. All of the patient sample included in this thesis research had three interviews available for analysis (N = 10) with five completing all four interviews. These interviews were mostly conducted over the phone, with one conducted in the hospital and ranged between 15 and 60 minutes in duration. Of the caregiver interviews in the included sample, 15 interviews were conducted with both caregiver and patient present, where only three caregiver interviews were completed separately.

Participant observation was employed to help supplement the self-reported data of the semi-structured interviews to observe study participants from within a group to generate insights into everyday interactions that may be taken for granted (Polit & Beck, 2012). By stepping outside the subjective language used to describe experience, the researcher is able to "pose a different set of questions pertaining to what people seem to be doing rather than what they say they think they are doing" (Thorne, 2016, p. 134). In the case of TAVI study, participant observation was conducted at two time points: during eligibility assessment clinic visits and at the time of participants stay in hospital post-procedure. The included sample for this thesis study included six instances of participant observation and focused on the lay out of the TAVI interview room and hospital environment as well as describing the interactions between staff and TAVI patients. By including both interviews and participant observation in data collection one hopes to decrease the risk of misinterpreting what you are told and what you see by way of the triangulation of multiple sources of data (Thorne, 2016).

Data for this thesis employing interpretive description was pulled from the original full transcripts of participant observation and semi-structured interviews for each included patient and caregiver. Based on the extended inclusion criteria, all the transcribed data for patients and

their care givers who had data from eligibility assessment to two to four months post TAVI were isolated from the larger sample into a separate NVIVO project. The next section will discuss data management used for both the TAVI study as well as this thesis project

Data Management

Data management for the TAVI study involved entering the study data including field notes, interview transcripts and documents into the qualitative software NVIVO10 to facilitate the organization of the data. The data unique to the identified study sample was cleaned of individual identifiers by the TAVI project research assistant and word documents of the interview transcripts and field notes was created and housed on a remote UBC server for analysis. Access to the isolated project was limited to myself, the TAVI team research assistant and the primary investigator (PI) J. Baumbusch.

Data Analysis

To explore the experience of early discharge after TAVI for older adults and their care givers, the process of thematic analysis was used as a guide. The method of data analysis is described by Braun and Clarke (2006) as "a method for identifying, analysing and reporting patterns (themes) within data" (pg. 79). Thematic analysis seeks to identify patterns found within the data and attends to both manifest (able to be directly observed in the text) and latent (implicit meaning) content within the data set (Marks & Yardley, 2011). Vaismoradi, Turunen and Bondas (2013) argue that the analysis used in published research often uses a thematic analysis but is rarely described as such, leading to a lack of clarity of methods. Thorne (2016) argues that interpretive description requires:

> "…an analytic form that extends beyond taking things apart and putting them back together again. It requires that we learn to see beyond the obvious, rigorously testing out that which we think we see, and taking some ownership over the potential meaning and impact of the visions that we eventually present in our findings" (p. 142)

To facilitate a clear method of data analysis, this study employed the six-step method for thematic analysis as outlined by Braun and Clarke (2006).

The first phase entailed efforts to become familiar with the data through multiple readings of the data as a whole and the writing down of initial ideas of what is contained in the data set and what is of interest (Braun & Clarke, 2006). Thorne (2016) encourages asking general questions such as "what is happening here" and "what am I learning here" while engaging with the data: this was accomplished with a dated word document to record emerging ideas. Familiarizing oneself with the data is followed by the second phase of initial coding where aspects of the data deemed of interest to the research question are identified and named and examples of data that demonstrate the codes are isolated (Braun & Clarke, 2006). Thorne (2016) cautions against premature coding and advocates instead the use of "generic codes" which allows one to bring together data that may be related and compare them to other groups with different properties without committing to a rigid coding structure. To avoid early coding, the highlight function was employed in word to identify broad categories in the findings including: communication, information, complications, support, expectations, preparations and geriatric concerns and comorbidities. Guided by Brawn and Clarke's (2006) third phase of analysis "searching for themes" these categories were then reviewed to attend to the broader themes that help group codes together over larger encompassing themes and sub-themes. At this stage in data analysis, I developed a mind map to provide a visual representation to help guide analysis by helping to organize early findings and understand links between emerging codes. This reflective process highlighted how the emerging findings were appearing in a more temporally linear

structure, where participants' experiences and priorities were shaped by where they were in the TAVI trajectory: pre-procedure, early recovery or longer-term recovery.

Stage four worked to review the identified themes and create a thematic map derived from the data ensuring that all coded data fit within identified themes or was examined again (Braun & Clarke, 2006). Here the final mind map was reviewed and further developed into a coding book with exemplars to ensure that all data relevant to the research questions fit within identified themes, subthemes and categories or was further reviewed. The fifth stage of thematic analysis included the step of "define and refine" (Braun & Clarke, 2006, pg. 92). At this stage, one prepares the themes to be presented in the final analysis of the data set to answer the identified research questions. At this period of data analysis redundancies were further identified and some subthemes were collapsed into each other. The final step involved the presentation of the data in the report. To help present the data in the final report, a visual representation of the research findings was developed and will be presented in the results chapter to help guide the reader. The process of data analysis was described in detail identifying the process of data analysis and maintaining a clear audit trail to help support rigour (Polit & Beck, 2012).

Rigour

Thorne (2016) argues that health researchers' "moral obligation towards benefiting individuals and the collective" (p. 223) forces the evaluation of credibility of research findings to go beyond following methodological rules to examine the meaning and application of the research findings. The concept of credibility refers to the level of confidence one has in the truth of the data and the reported findings (Polit & Beck, 2012). In interpretive description, Thorne (2016) argues credibility is assessed by evaluating: epistemological integrity, representative credibility, analytic logic and interpretive authority. Epistemological integrity is dependent on

the research question being guided by the study design employed and that the data sources used and the analytic strategies employed can logically lead one to answering the proposed research question (Thorne, 2016). As this study seeks to explore the experience of a particular phenomenon as well as generate recommendations for practice, the use of interpretive description as the study design is defensible. Representative credibility examines if the claims made are consistent with how the study was sampled and what data was collected (Thorne, 2016). Data triangulation using two sources of data (semi-structured interviews and participant observations) as well as the use of multiple data collection points over time were employed in this study to address issues of representative credibility (Thorne, 2016). Analytic logic is the clear and explicit inductive reasoning process employed by the researcher (Thorne, 2016). This study will allow for the evaluation of analytic logic through the use of rich description when presenting the study findings as well as a clear audit trail which facilitates the readers understanding of the decisions made while generating findings and allows them to judge if the abstractions are defensible (Thorne, 2016). Finally, interpretive authority refers to the need for findings to be trustworthy and to report results that reach beyond the researchers own bias or previous understanding of a phenomenon (Thorne, 2016). To attend to and acknowledge bias, a reflexivity journal was kept throughout the data analysis process to work to limit the effects of bias and discover the subjective truth of the participants (Thorne, Kirkham, & MacDonaldEmes, 1997). In conclusion, the credibility of this thesis project was enhanced though a clear research question, data triangulation, rich descriptions of data, an audit trail as well as engagement in reflexivity.

Ethical Considerations

Ethical approval for the original study was obtained from the review ethics board at the University of British Columbia, Providence Health Care and Vancouver Coastal Health. Participants were aware that the collected data may be used for further sub-analysis as was conducted through this interpretive description guided analysis. Informed consent was stressed to participants as an ongoing process based on the nature of the study which collected data at multiple time points to ensure participants were aware that they had the right to withdraw their consent at any time (Polit & Beck, 2012). The analysis of risk and benefit for study participants within the context of a qualitative research study highlights the risk to a participant's right to privacy (Polit & Beck, 2012). The rich description of individual participants interview data required to provide context and credibility to study findings will make patients more easily identifiable than in larger research studies. To address this ethical issue many individual identifiers were removed from the original transcripts before I was able to access them. To help increase anonymity in the results section description of participants were left vague and all names were removed to help improve confidentiality (Polit & Beck, 2012).

Limitations of Study Design

Unlike the frequently used methodologies to conduct qualitative research such as grounded theory or phenomenology, interpretive description does not provide a clear set of steps to ensure data collection, sampling and analysis is methodologically sound. Although this provides the necessary flexibility to engage in discipline-based questions, for a novice researcher, the need to adequately defend methodological choices made can be difficult. To

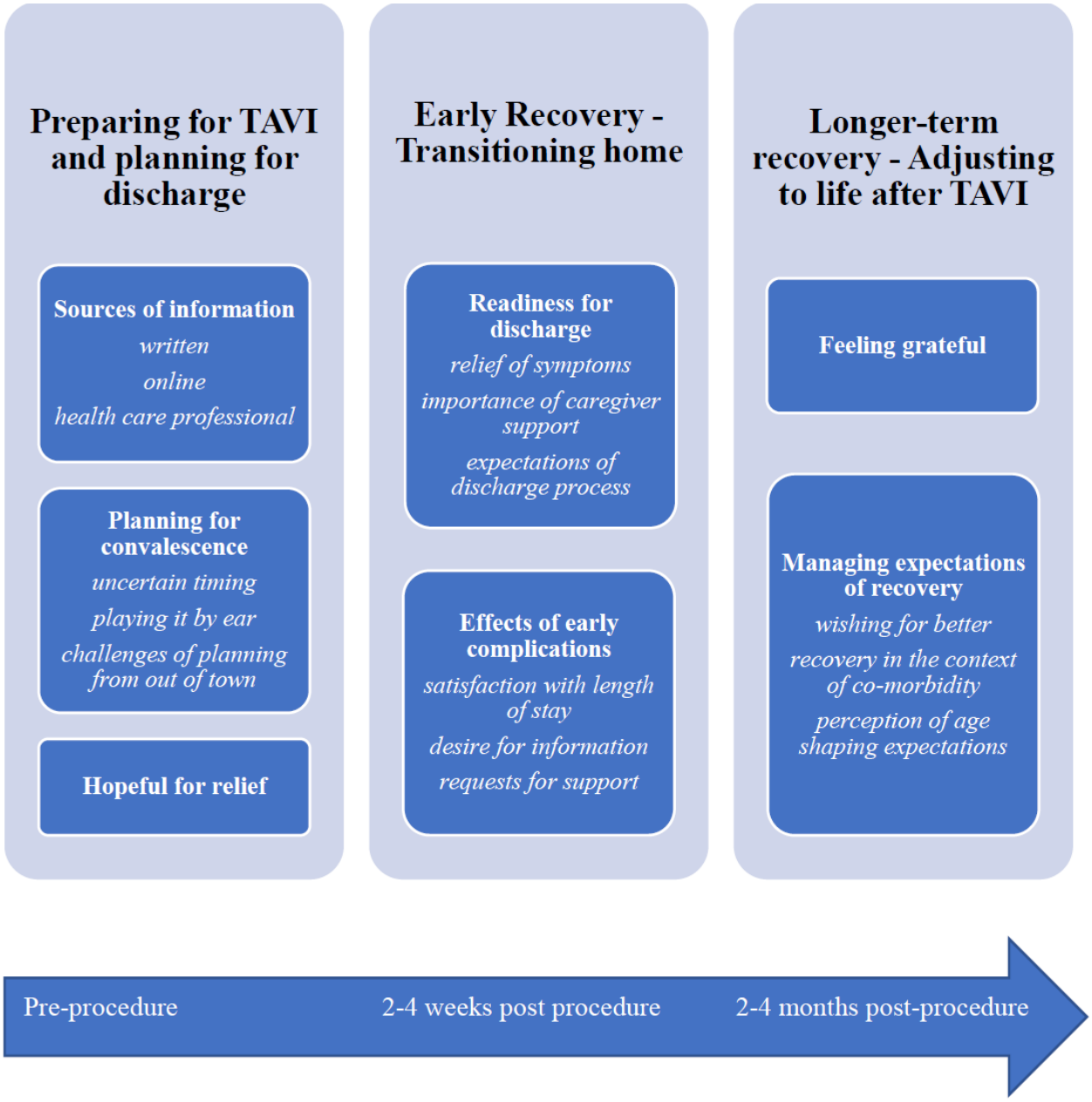
manage this limitation, assistance was sought from my thesis committee to help articulate and defend methodological decisions.

As this thesis project was completed by engaging with existing data to understand the experience of transitioning home following early discharge after TAVI, I was unable to undertake member-checking which could have strengthened the credibility of my findings by asking participants if developing understandings of the data resonated with them (Polit & Beck, 2012). As the data had already been collected, I was also unable to engage in theoretical sampling which is recommended for interpretive description (Thorne, 2016). Finally, as the data had already been collected there was no opportunity for me to ask more probing questions related to the discharge experience of the study participant which may have lead to some gaps in understanding the phenomenon of interest.

Chapter Four: Research Findings

The experience of transitioning home after early discharge following TAVI for older adults and their caregivers was a temporally linear experience beginning in the pre-procedure period, progressing though the early discharge period and finishing several months after their TAVI procedures. Throughout the process of data analysis, I found that patients and their caregivers expressed different priorities and concerns depending on where they were temporally in the trajectory of TAVI recovery. Those who were waiting for their procedure focused on seeking out information pertaining to the procedure, began to plan for the procedure and reflected on what they hoped to gain from undergoing TAVI. During the early recovery period, the focus shifted and participants spoke about the factors affecting their readiness for discharge and those who experienced early complications provided insight into possible gaps in discharge planning and transition home. Finally, in longer term recovery, older adults and their caregivers began to reconcile feeling grateful for undergoing TAVI with the experience of unmet expectations for their recovery. These expectations were often viewed within the context of existing co-morbidities and advancing age. The research findings will present the main themes, which reflect the periods of discharge: i) Preparing for TAVI and planning for discharge, ii) Early recovery – transitioning home and iii) Longer-term recovery – adjusting to life after TAVI. Each theme includes sub-themes and categories, which are visually presented in Figure 1.

Figure 1. Research Findings



Description of Participants

Patient characteristics are described in table A1 (Appendix A) and caregiver characteristics are described in table A2 (Appendix A). The ten older adults included in this study ranged in age from 70 to 93 with a median age of 86 years old. The sample of patients was

split evenly between males (n=5) and females (n=5). A small majority (60%) of patients lived "in town" at a distance of less than 100km from the TAVI procedure site and 60% of patients resided independently with their spouses. The length of stay after TAVI ranged from one to three days with a median length of stay of 1.5 days.

The total sample of informal caregivers consisted of nine participants who provided informal support after TAVI for eight older adults. The age of the caregivers ranged from 58 to 94 with a median age of 73 years old and 56 % of caregivers were female (n=5). None of the caregivers were employed at the time of data collection with the majority being retired (n=8) and one being on disability leave from work (n=1). Spouses of TAVI patients were the most common informal caregivers (n=6) in the sample with the exception of one adult child and two friends. All spouses providing support lived with the patient (n=6) whereas the other caregivers did not reside with the patient.

Research Findings: An Overview

For the patients and informal caregivers included in this study, the experience of early discharge after TAVI was shaped by where they were in the procedure and recovery trajectory. Their experiences, priorities and concerns were different both before, during and after their TAVI procedure as they navigated their transitions home from hospital. These experiences, priorities and concerns shaped the sub-themes and categories which will be explored below. This temporally linear experience was consistent throughout the sample and therefore the experience of early discharge after TAVI will be explored through these three main periods of time which have shaped the three main themes of the research findings: 1) Preparing for TAVI and planning for discharge 2) Early recovery – transitioning home and 3) Longer-term recovery – adjusting to life after TAVI.

In this study, during the pre-procedure period (extending from eligibility assessment to the day of procedure), older adults and their informal caregivers used multiple "sources of information" to help prepare including written, online and interactions with health care professionals to begin to understand what to expect from TAVI and how to plan for eventual discharge. During this pre-procedure stage, participants also worked to start "planning for convalescence" and expressed uncertainty about the amount of care required in the post-operative period as well as the timing of the procedure. Both the patients and caregivers expressed undertaking little in terms of planning for the transition home. Preparing for TAVI from out of town highlighted some of the unique challenges for this group of participants. During the pre-operative period, all participants expressed feeling "hopeful for relief" from the symptomatic and functional limitations of aortic stenosis either for themselves or their loved ones.

Once older adults and their informal caregivers entered the early recovery period (2-4 weeks post-TAVI) many factors affected their "readiness for discharge". Many older adults felt prepared to go home as early as the next morning reporting early, noticeable and at times surprising relief of their symptoms such as shortness of breath. Though the majority of older adults felt prepared for discharge, both they and their informal caregivers acknowledged the importance of caregiver support to facilitate this transition. In addition, some participants did not have their expectations of the discharge process met and therefore expressed concerns about early discharge after TAVI. During the early recovery period the "effects of early complications" highlighted how the experience of an early complication could affect the satisfaction with the length of stay and lead to an expressed need for more information and support in the post-operative period.

During longer term follow up (2-4 months) older adults and their caregivers began to speak about how they were beginning to adjust to life after TAVI. Though the majority of participants expressed "feeling grateful" for the relief of symptoms following TAVI, they also began to "manage expectations of recovery" by wishing for better as well as understanding their recovery within the context of their comorbidities and advancing age. The themes, sub themes and categories identified above will be analyzed in depth in the following sections.

Research Findings

Figure 2. Research Findings: Preparing for TAVI

Preparing for TAVI and planning for discharge. During the pre-operative period, older adults and their caregivers began to prepare for TAVI and started to think about their eventual transition home. The pre-operative period which extended from the eligibility assessment with the TAVI team to the day of the procedure ranged from 16 days to 292 days with a median length of 62 days for participants. The cause of the range of waiting periods was likely multifactorial and guided by the clinical status of individual patients. For example, the shortest wait of 16 days was due to a deterioration of health status and urgent inpatient TAVI, whereas the longest wait was due to the procedure being delayed so the patient could go on vacation. During the pre-operative period, participants focused on what to expect from the TAVI procedure itself including the timing of the procedure and what to expect from the procedure itself with little attention paid to the post-operative recovery period. Older adults and their informal caregivers engaged with multiple

sources of information to understand what to expect and to plan for the future. The uncertainty surrounding the timing of procedures led to feelings of frustration related to the inability to plan for their procedures; this was experienced more acutely by those who lived away from the TAVI site.

Finally, older adults and their caregivers alike expressed concerns about the symptoms of aortic stenosis and were hopeful that the TAVI procedure would provide some relief for themselves or their loved ones. These experiences during the pre-operative period form the three main sub-themes that appeared throughout the transcripts: sources of information, planning for convalescence and feeling hopeful for relief. These sub-themes will be explored in detail here.

***Sources of information*.** This first sub-theme highlights the different sources of information older adults and their caregivers received or accessed to allow them to prepare for TAVI and begin to plan for discharge. The search was at times passive and at other times active as participants sought to understand what to expect from their procedures and transition home.

Written information. The main source of written information for older adults who experienced early discharge was a booklet provided by the TAVI program titled "Deciding to have a transcatheter valve implantation." This booklet provided information regarding the process of eligibility assessment as well as what to expect from the procedure and recovery. TAVI patients expressed different levels of engagement with this written information. Those who had not yet read the material prior to meeting the TAVI team voiced uncertainty surrounding what to expect from the procedure. One participant who had not read any written information prior to her interview said:

> Well you know, I have not read the booklet yet on…what's that booklet called I've got out here? Oh, it says "Deciding to Have a Transcatheter Aortic Valve Implantation" I've

> got the book; I haven't even opened it up to look at it so I don't really know what it involves (Participant 24, Interview #1)

Many patients reported that they had read the booklet provided by the TAVI team and felt well informed about the procedure after reading the information mailed to them by the TAVI program. Participant 7 described feeling prepared for TAVI due to having read the written information provided "and that booklet that you've read about being…telling you all about the TAVI procedure, I think its very good and clear" (Interview # 2). Though the older adults who participated in this study felt well informed about what to expect from the procedure and therefore prepared, one caregiver reported not knowing much about the procedure but being happy with this stating "they say ignorance is bliss" (Informal Caregiver 10, Interview #1). This desire to stay disengaged from the process may have been a result of some of the fear associated with invasive procedures while acknowledging the belief that the procedure was necessary for recovery and relief of symptoms. Though all patients received written information from the TAVI program, they chose to engage with it at different levels when preparing for TAVI and planning for discharge. Those actively seeking out answers to their questions, tended to access the internet for answers.

Seeking out information online. Several participants reported that they sought out information online to help understand what to expect and to prepare for TAVI. For those who looked for information beyond that provided by health care professionals many expressed this was due to perceived gaps or lack of information. One older adult explains that his search for information online was as a result of the gaps in the information he received from the TAVI program and other health care professionals:

> Well the first information I got, I just got in pieces; I've ended up on the internet. And in

> fact there's an excellent site where you – I think you even get to see – yeah you can [Doctor 10] and his people doing an actual performance…and then I have read a fair amount about the whole program, so in general I think I am fairly familiar with what happens (Participant 28, Interview #1).

Another participant sought out information online when she felt that her cardiologist was not able to provide her with the information she required regarding TAVI: "He never said anything about it, never told me anything about it. I'm just…what I've read okay, I go on the computer, which is maybe stupid because I should be talking to a doctor about it" (Participant 29, Interview # 1). In the pre-procedure period, the patients who were seeking information online were mostly focused on engaging with information that was directly related to the TAVI procedure itself.

The focus on information seeking pertaining to the procedure itself as opposed to what to expect when they transitioned from hospital to home highlights the fact that few patients or their family members were beginning to plan for discharge in the pre-operative period. Only one older adult accessed the internet to begin to understand what he could expect during the recovery period as well as expected length of stay:

> Participant: Yeah, and by the way, generally you're only kept in the hospital for a couple of days.
>
> Researcher: Yeah, that's it. It's pretty quick.
>
> Participant: A few weeks later and you're doing your normal things.
>
> Researcher: This is what I've heard.
>
> Participant: That's what I read – again on the internet – from people who have gone through the procedure. (Participant 28, Interview #2)

During the pre-operative period TAVI patients sought to augment their understanding of their upcoming procedure through online resources but tended to focus on the procedure itself as opposed to seeking to understand what to expect from and plan for their eventual transition home. This sub-theme displays an active search for information to address self-perceived gaps in the information - both written and verbal - provided by health care professionals. However, it is unclear from the interview transcripts which online sources were used to seek information and how medically accurate they were.

Information from health care professionals outside of the TAVI specialists. In the time prior to meeting with the TAVI team, older adults received information about TAVI from their health care professionals including cardiologists and their general practitioners. The information received from health care professionals outside the TAVI program tended to focus on either the participant's need to have the procedure to fix their aortic stenosis or what they can expect after the procedure in terms of symptom relief. TAVI patients often based their expectations of the procedure on what they had been told by their general practitioner "they said if I got this procedure done I could go back on the hills. It's pretty limited to where you walk if it's got to be level" (Participant 25, Interview #1). Older adults basing their expectations of the TAVI procedure on information provided by health care professionals was common while preparing for TAVI and many expressed looking forward to feeling less anxiety based on this expected relief of symptoms:

> Well I understand the heart procedure's going to – supposedly if all goes well – I get a new heart valve and I won't have the shortness of breath, hopefully, and I won't have water in the lungs which is frightening, and I won't have to restrict myself (Participant 24 Interview #2).

Information provided by community cardiologists and general practitioners helped shape expectations for patients who would undergo TAVI. These expectations could shape the experience of transitioning home after early discharge following TAVI based on whether these expectations were met or not.

Overall, older adults and their caregivers sought information to prepare for TAVI and their eventual discharge from multiple sources including written, online and from health care professionals. While some chose to actively engage and seek out further information, others chose a more passive approach to gathering information choosing to allow their care providers to provide the information. Of note, the majority of the information sought by older adults and their caregivers focused on what to expect from the procedure itself as opposed to how to plan for their transition home. With this in mind, I will now explore the sub-theme "planning for convalescence".

Planning for convalescence. This sub-theme shows how older adults and their caregivers who were preparing to undergo TAVI began to plan for their transition home. Many expressed uncertainties around the timing of their procedure as well as the type of care they might require in the post-op period. This led older adults and their caregivers to *play it by ear* and hope no extra support was required. Finally, planning for convalescence highlighted some of the challenges unique to those travelling from out of town for their TAVI.

Uncertainty of timing. In the pre-operative period older adults and their caregivers expressed feelings of frustration and unease related to the uncertainty of the timing for their procedure which hampered their ability to plan ahead. Some expressed feeling like they were unable to stray far from their homes due to the uncertainty of procedure timing:

> [We] probably would've liked to have known how long it was going to be waiting – how long we were going to be waiting because it seemed like forever…So all winter basically we were stuck. We couldn't go very far from home because we didn't know when we would get a call (Informal Caregiver 11, Interview # 3).

In addition to being limited by issues of timing in terms of planning for procedure and discharge, this uncertainty at times led to feelings of unease for participants in the pre-op period.

> I'd like to get this all over with, because I don't know how long you sit around waiting for things to happen, but this has been probably a couple of months anyways, and if we could only pin it down it would put my mind a bit more at ease than it is now (Participant 8, Interview #2).

Many participants had little warning in terms of the timing of their procedures, and some participants found out they would be having their TAVI the week of their procedure. Though this short notice may have made it more difficult to plan, participants were grateful and willing to adapt to program needs to have their TAVI done even when they had to come from out of town:

> There was a phone call from the hospital saying that she was…this was on Tuesday, and she was having the procedure on Friday. Had to make arrangements for a hotel and…it was a bit rushed, but that didn't bother us. (Informal Caregiver 6, Interview # 3).

Similar to how TAVI patients and their caregivers tended to focus on the procedure itself when seeking out information, much of their unease during the pre-operative period was based on planning around the timing for the procedure itself as opposed to how this uncertainty may affect their transition home after TAVI. As the older adults and caregivers in this study tended to focus on the logistical challenges surrounding the procedure itself, it may be important for health care professionals to help families preparing for TAVI identify and plan for some of the challenges

that they may face when transitioning home. The concerns expressed around lack of planning for discharge are highlighted in the category "playing it by ear."

Playing it by ear. In addition to uncertainty surrounding timing of the TAVI procedure, some participants also expressed being uncertain about the type of care or assistance that may be required in the post-operative period. When researchers asked an older adult if she had starting planning for her recovery period, she answered "No because I don't know what state I'll be in. Everyone tells me I'll be much better, so I really don't know" (Participant 22, Interview # 2). Some also experienced a lack of knowledge about expected length of stay after TAVI and a desire for this information to allow them to begin to plan for the transition home. One informal caregiver expressed that sentiment:

> One thing I'd be interested in knowing is when he's discharged, how does that happen? Do they phone you up? Whoever is driving, which would likely be us, would they let us know the day before, the morning of? Would they be like, "you have to get him now in the next hour"…Of course we don't want him to have to stay in hospital any longer…I know some places are just like, "Okay you're ready. Goodbye. Here's your stuff in a bag" (Informal Caregiver 5, Interview # 1).

Lack of clarity surrounding the timing and process of discharge left this caregiver unsure about how their transition home would be experienced while acknowledging the importance of a limited hospital stay after TAVI.

The interviews revealed that when preparing for TAVI, older adults had done little to plan for their eventual discharge home and that a fair bit of uncertainty remained. One older adult who lived more than 100 km outside of the TAVI site was feeling uncertain about where they would convalesce after having to leave the hospital, feeling that many details would be

decided in the post-operative period: “Well we’ll probably stay at the [street 6] depending...after I can leave the hospital then we’ll probably go out to my brother’s place in [City 1]. Anyways, there’s a lot of if, ands and buts about it” (Participant 29, Interview # 2). This uncertainty and lack of planning was common among patients and some expressed feeling hopeful that the transition home following TAVI would be smooth and support could be organized after discharge if they were required. When reflecting on their planning in the pre-operative period Participant 31 stated: “Well I was going to play it by ear, which I did, and it all worked out” (Interview #3). Few older adults or their caregivers had concrete plans for their convalescence in the time leading up to TAVI. Though participants expressed some concerns about how their transition home would unfold, many felt confident that they would be able to adapt to any challenges that may arise.

Challenges of planning from out of town. The sub-categories of *uncertainty of timing* and *playing it by ear* highlighted some of the challenges faced by older adults and caregivers when planning for their transition home after TAVI; these effects were compounded for those who lived out of town (100 km or more from implanting site). One caregiver explained the multiple logistical factors affecting their preparations:

> The one thing that has got us concerned is because of the distance we have to travel and the arrangements that we have to make, the sooner we can get that…you know because this girl’s going to come in and look after the dogs and look after the house while we’re gone. We have to make arrangements. We can’t just jump in our car and drive down like last time (Informal Caregiver 11, Interview #2).

This statement highlights how the inability to “jump in our car and drive down” was a result of living further away from the TAVI implanting site as well as the multiple logistical challenges of

leaving home for an unknown period of time. In addition, those coming from out of town were also required to pay for and plan for transportation and accommodation to a greater extent than those who live close to the TAVI site. Many had to take ferries or drive for long periods of time to receive their TAVI and organize a place to stay either in a hotel or with family members for those who were able, all at a cost. Though these costs were acknowledged by both older adults and their informal caregivers as necessary to receive specialized care some did express concern surrounding the costs:

> Informal Caregiver 9: Oh, well, she wants the procedure done so she'll do anything to get the…Sure. Oh yeah.
>
> Participant 25: I don't feel good about the cost…But I'll pay it. (Interview # 1).

Older adults awaiting TAVI who lived closer to the implanting site may have experienced less financial burden to undergo their TAVI and could possibly have had a shorter wait time for their procedure as they may have been more likely to be called when procedures were cancelled due to the logistical complications of coming in from out of town.

The sub-theme "planning for convalescence" showed that during the pre-operative period older adults and their caregivers undertook minimal planning for their recovery and tended to focus on the challenges of uncertainty regarding when they would have their procedures done. The uncertainty of timing of the procedure and in some cases the care needs post procedure was common and led to feelings of unease and frustration. Those travelling from out of town for their TAVI had additional logistical challenges and costs that affected their ability to plan for their procedure and eventual discharge home.

Hopeful for relief. In the period before undergoing TAVI, older adults and their informal caregivers spoke frequently throughout the interviews about how their quality of life and functional capacity has been limited by the symptoms they attribute to their aortic stenosis. All participants articulated what they hoped to get out of the TAVI procedure as a desire or hope for relief of these symptoms. These expressed hopes for relief shaped the expectations of the transition home following TAVI. Older adults who were interviewed experienced significant challenges living with aortic stenosis based on their symptom burden. One participant reflected on the challenges of living with aortic stenosis and the associated shortness of breath:

> I'm pleased I'm accepted for TAVI, I know full well that I need a valve replacement, because recently I've had these heart failures or whatever you call them and have to go to the hospital because I had fluid on my lungs, and that was really caused by the valves not working. And then it was shortness of breath…and so you know, I just don't want to live with getting spells of shortness of breath and fluid on the lungs. You know what I mean? (Participant 24, Interview #1).

Beyond being hopeful for a relief from their symptoms of shortness of breath, many older adults also spoke about a desire to get back some of the energy they had prior to their diagnosis of AS: "I am just hoping that I won't be as tired, will have a bit more get up and go" (Participant 7, Interview # 1). TAVI patients also expressed a wish to be more active in the post-operative period as a result of undergoing TAVI. Participant 8 described this desire as: "I am hoping I won't be as idle as I am now. I am hoping to get some of my zip back" (Interview # 1). Informal caregivers who were interviewed focused on a desire for their loved ones to get back to a "normal" level of functioning that would allow them to participate in more social activities.

> Well I would expect that he would be at a level where he could just go out for a nice walk on the beach, go and have a golf game with some of the families that are here and just resume a normal level of activity for a person his age you know? (Informal Caregiver 3, Interview #1).

Feeling hopeful for an improved quality of life as a result of the TAVI procedure was also expressed by caregivers and TAVI patients alike:

> Informal Caregiver 6: I think we are both upbeat about it because we hope it will change her quality of life…
>
> Participant 22: we hope to be able to travel a bit more and go back to a more normal life
>
> (Interview # 2)

Overall, older adults and their caregivers who were preparing to undergo TAVI had high expectations for the relief that this procedure would be able to provide them. As they prepared for TAVI and the eventual transition home, the belief that they would experience a significant reduction in symptom burden could have helped shape how they prepared for their transition home. A desire for more energy, relief of symptoms, increased social engagement and an improved quality of life was echoed throughout the early interview transcripts.

As older adults and their informal caregivers prepared for their upcoming TAVI procedure and transition home multiple sources of information were accessed to help understand what to expect from undergoing TAVI while the uncertainties surrounding the timing of procedures and the challenges of planning from out of town tended to result in limited planning for the transition home in the pre-operative period. In the pre-operative period, older adults and their caregivers who experienced early discharge after TAVI were hopeful for a relief of symptoms, improved energy levels and a return to normalcy as a result of undergoing TAVI.

How these expectations were experienced in the early post-operative period will be explored in the next section: Early recovery – transitioning home.

Figure 3. Research Findings: Early Recovery

Early recovery – transitioning home. During the early post-operative period (2-4 weeks), older adults and their caregivers who experienced early discharge (discharged in 72 hours or less) worked to navigate the transition from hospital care back into their home environment. During this period of transition, older adults and their caregivers discussed several factors affecting their readiness for discharge including: relief of symptoms, the importance of caregiver support and their expectations of the discharge process. Though most participants felt well prepared for discharge and did not experience any complications in the early post-operative period, those who did provided insight into how early complications affect how older adults and their caregivers experience the transition home after early discharge following TAVI.

***Readiness for discharge*.** This sub-theme explores how different factors shaped participants' comfort and willingness to be discharged early. All participants experienced relief from their pre-operative symptoms and often expressed feelings of surprise at how quickly they were able to recover. Many patients acknowledged that their early discharge and successful transition home from the hospital would not have been possible without the support provided by informal caregivers. Finally, though the vast majority felt ready to be discharged home in the 72

hours following TAVI, those who expressed concerns did so within the context of what they had expected from the discharge process. These categories will be further explored to help understand the sub-theme readiness for discharge.

Relief of symptoms. Many participants who underwent TAVI reported feeling an almost immediate relief of their symptoms following the procedure, most commonly a relief in their shortness of breath. One older adult reflected on the immediate relief he felt after waking up after surgery: "When they're doing their work, you're out cold, but when you wake up you come right to. And I looked around and my hands were pink, my spirits were up, and it was like turning on a light switch" (Participant 8, Interview # 4). These feelings of early relief of symptoms were often associated with expressions of surprise at the immediate difference they felt. Participant 30 reflected on the early post-operative period after TAVI as "incredible". He stated: "and it was like a big elephant had been lifted off my chest. Even after that, I could already feel the…I was able to breathe. It was incredible. I've never experienced anything like that" (Participant 30, Interview # 3).

Informal caregivers also had similar experiences in the early discharge period, expressing gratitude and feelings of disbelief at how well their loved ones were recovering. One TAVI patient's wife stated: "We're just thrilled with the procedure. So are our…daughters. They just couldn't believe the change in him and how well he is doing" (Informal Caregiver 3, Interview # 3).

The speed of recovery was also frequently commented on in the early post-operative period and provided many participants with their reason for recommending TAVI to others in the future. One participant reflected on how undergoing TAVI in comparison to open heart surgery resulted in a shorter recovery and less symptoms of pain: "Recovery time is so much quicker

than going through the chest. Why go through the agony of cracked ribs and the whole nine yards? Myself I would recommend the TAVI procedure at any time" (Participant 29, Interview # 3). The early relief from symptoms while still in hospital resulted in all older adults, with the exception of participant 24, reporting feeling ready for discharge home often as early as the next day. A 92-year-old female stated:

> Researcher: did you feel like you were ready to leave the hospital on Sunday?
>
> Participant 25: Yes I did.
>
> Researcher: can you tell me how you felt ready? You felt physically ok?
>
> Participant 25: Oh yeah. I felt really great. (Interview #3).

Overall, all but one TAVI patient expressed feeling prepared for discharge after TAVI based on feeling physically ready due to relief of their pre-operative symptoms. Older adults and their caregivers articulated feeling surprised and pleased by how quickly they saw or experienced relief both in hospital and after their transition home. Though the early relief of symptoms helped support a perceived readiness for discharge, participants also felt that this readiness was dependant on the presence of informal caregivers to help ensure a safe transition home.

Importance of caregiver support. Many older adults undergoing TAVI acknowledged that they felt safe being discharged within 72 hours due to the availability of support from caregivers to assist during this transition from hospital to home. Caregivers provided instrumental support such as cooking, cleaning and driving and also acted as monitors during the post-operative period looking out for complications and acting as a back-up in case assistance was required. In addition to the informal caregivers interviewed for this study, those who underwent TAVI often received additional support from their adult children who did not live with them. Many supplementary caregivers took time off work and from their own families to

stay with their older parents and provide support during the transition home after TAVI. Participant 28 described how his children had helped in the early post-operative period by providing support for both himself and his wife:

> Well one of them had to get back to work pretty fast. She was here for a few days. And the other one stayed actually a couple of weeks after I got home. She could keep my wife handy if there was anything needed (Interview # 3).

Some participants expressed an ability to manage their own care for the most part but still depended on their caregiver being present to help ensure their safety. Participant 31felt that he was able to manage his convalescence for the most part but described how his wife acted as a second layer of support "My wife was always on hand and there was no need for anybody to do anything really, other than make sure I was alright" (Participant 31, Interview #3).

During the early recovery period caregivers acted in the role of observer for older adults who had transitioned home after TAVI. Caregivers acted as sentinels for their loved ones to ensure that their needs were met but in the event of complications, caregivers moved from passive observers into action to ensure the safety of their loved ones. An 86-year-old female patient described how the presence of her daughter in the post-operative period helped her manage worsening health status after early discharge:

> She [P24's daughter] came over from [city 15] and stayed with us for three days. And she is a general practitioner. She's a medical doctor. And it's a good thing she was because it was she who, the next day, observed that I was not doing well and was monitoring me and was anxious about my lungs. (Participant 24, Interview # 3).

Though most patients and informal caregivers felt prepared for discharge following early discharge, one set of caregivers (Informal Caregivers 9 and 14) expressed that discharge would

have been impossible without them taking their loved one home to stay with them in the post-operative period. The need to unexpectedly take on a more involved caregiving role in the post-operative period was driven by these caregivers' beliefs that Participant 25, who lived in a different city from them would be unable to safely manage the transition home independently. They expressed their lack of preparation for this role and a feeling of helplessness like this:

> But yes, it's one thing, "I have friends that will look after me" meaning [Informal Caregiver 9] and I, but we didn't really have anything in place for her. We didn't have a choice but to have to bring her to our home because she could not have gone back home to [city 19] because she lives on her own, and there was no care put in place…I mean had [Informal Caregiver 9] and I been unable to spare time with her after, I don't know what would have happened. I don't know, I mean what would they have done? Would they have just sent her home on her own (Informal Caregiver 14, Interview # 3).

In this unique case, we see that one set of caregivers felt some pressure to accommodate the program needs for early discharge despite feeling unprepared for their role. Exploring the sub-theme "readiness for discharge" shows us that this perceived readiness was supported by the presence of informal caregivers to provide instrumental support, act as observers to ensure safety and to act in case of complications. The dependence on informal caregivers to provide care to facilitate early discharge was highlighted by Informal Caregiver14. Both the challenges of early discharge for TAVI recipients who live alone and away from caregivers as well as the need to adapt to unexpected or perceived care needs were highlighted in this case. Though not common to the participant group as a whole, it is important to identify these challenges early and develop strategies in conjunction with older adults and their caregivers to help ensure those who undergo TAVI are prepared at the time of early discharge.

Expectations of the discharge process. Though the majority of caregivers and older adults felt they were ready to be discharged home in the 72 hours following TAVI based on relief of symptoms and the presence of caregiver support, both Participant 24 and Informal Caregivers 9 and 14 expressed that they did not feel prepared at the time of discharge. These feelings seemed to be driven by their expectations of this discharge process following TAVI. For Participant 24 who was discharged the afternoon following her procedure, her concerns about early discharge were related to information regarding length of stay that she had received from the TAVI program:

> I was in great shock when they told me the day after the procedure that I was going home, because I had read their books, and I read that you usually went home on the third or fifth day following the procedure, and I had that stuck in my mind…So when they said I was going home the next day I couldn't believe it. Although I felt fine, I said "oh" I said "I thought it was the third or fifth day." The nurses said "oh no, you're well enough and we need the bed so we are sending you home" (Participant 24, Interview #3).

For this patient, despite feeling physically well after her TAVI, her expectation that she would be staying for at least three days following her procedure, affected her readiness for discharge.

For the Informal Caregivers 9 and 14 who provided care to their 93-year-old friend in the post-operative period, their expressed lack of readiness for discharge also did not relate to the physical state of their friend. Their concerns were due to a lack of support in preparing for discharge and the gaps they identified in the care required post-operatively. They expected to have more time to prepare for discharge to allow them to communicate with the physicians and allied health professionals before discharge. They expressed this need by saying "she and we needed that extra time – even just a day – just to speak to somebody and get some things figured

out you know?" (Informal Caregiver 9, Interview #4). Informal Caregiver 14 expressed the need to speak to the social worker to help set up the supports that they believed were required for a safe transition home for their loved one.

> I just think we would have felt so much more comfortable having the ability to speak to a social worker or somebody about having something in place rather than just sort of being put out on the street "Now okay well here you go. You deal with it" (Informal Caregiver 14, Interview #3).

In both of these cases, the participants' expectations surrounding the discharge process were not met, resulting in expressions of a lack of readiness for discharge.

Though most study participants felt ready for discharge based on a relief of symptoms, the sub-theme "readiness for discharge" also explores the importance as well as the dependence on informal caregivers to provide care and support to facilitate early discharge following TAVI. In addition, despite feeling physically well, in a few cases, unmet expectations surrounding the discharge process led to some participants expressing a lack of readiness for discharge. These feelings were further compounded by those who experienced complications in the early post-operative period.

***The effects of early complications*.** Most older adults who underwent TAVI and their caregivers expressed feeling well informed and supported during their transition home after early discharge. Conversely, those who experienced complications in the early post-operative period expressed more concerns about the discharge process, had a need for more information and made requests for support from the TAVI program and the care teams in hospital. Though only two older adults experienced early complications, it is important to explore these experiences as they

may highlight gaps in the existing care processes that need to be addressed to ensure the safety of others transitioning home following early discharge after TAVI.

Satisfaction with the length of stay. As reviewed in the sub-theme "readiness for discharge" many participants felt prepared for discharge home as early as the next day. Those who expressed concern about the length of stay following TAVI were those who experienced complications in the early post-operative period. A 94-year-old caregiver expressed concern regarding the short length of stay in response to his wife's need to return to hospital very early in the post-operative period:

> My wife was discharged from [hospital 1] the day following the TAVI procedure. Perhaps this very short stay should be reconsidered. Forty-eight hours after discharge, she had to be taken by ambulance to [hospital 2] where she spent the next five days with fluid on her lungs. At the time of admissions, she suffered both breathing difficulties and angina like pain (letter written by Informal Caregiver 12 – as read by Participant 24, Interview #3).

In light of post-operative complication, both Participant 24 and her informal caregiver expressed concerns regarding the short length of stay after TAVI. They felt that being in hospital longer may have allowed them to avoid a hospital re-admission as well as the anxiety that came with experiencing an early complication following TAVI.

*Desire for more information***.** Older adults who did not experience early complications following discharge reported feeling well informed regarding how to care for themselves and their loved ones after the transition home. None provided suggestions for how discharge instructions and preparations could be improved. Participant 28 described how he incorporated the information provided to guide his transition home: "Yeah, I just sort of followed the

instructions and they seemed to be so very simple and straightforward." (Interview # 3). Participant 7 reported being happy with the discharge experience based on the information provided by the TAVI program:

> Oh, I mean I got booklets on when you go home from the hospital and after the care and that kind of thing. Yeah I've had a lot of it…So I think it's a very good system what they have (Interview # 3).

In contrast, those who experienced early complications voiced concerns regarding challenges accessing information and a lack of communication with staff. Participant 25 experienced bleeding complications in the early post-operative period including nose bleeds and hematomas in the weeks following discharge. Participant 25's caregivers expressed frustration surrounding their experience of discharge as they had been concerned regarding Participant 25 being on multiple blood thinners but they had been unable to discuss this concern with the TAVI team:

> So I mean it was frustrating just for the fact that we really didn't want her coming out as quickly as she did, we didn't have any communication with anybody…you couldn't get any answers with regards to her meds, another reason we wanted to speak with a doctor just to get it nailed down. "Okay these are her meds and this is what she's going to take." And of course, when we had a question, nobody could answer the question. Why is she taking all of these blood thinners? (Informal Caregiver 14, Interview #3).

A desire for more information when experiencing early complications highlights that although the information provided to older adults and their caregivers may be sufficient to manage an uncomplicated transition home, further support may be required when experiencing unexpected outcomes. Whether this support could have been facilitated with improvements in the discharge

teaching information is not clear from the interview transcripts; caregivers tended to request access to health care professionals in the early post-operative period to navigate complications.

Requests for support. Older adults and their caregivers who did not experience early complications did not make any requests for further support from the TAVI team or other health care providers. They felt prepared to manage the transition home with just the support of their informal caregivers. In contrast, when those who experienced complications reached out to the TAVI team after discharge, they expressed concern that they were not able to contact anyone:

> [We called] to let her know what had happened, because I think the paperwork they sent home said if there's any need to admit her to emergency, then contact the TAVI team and let them know. So I did contact [Hospital 1, Staff 8] and let her know what happened, but after that we never heard from anybody (Informal Caregiver 14, Interview # 3).

Some participants were able to access more support from the TAVI team, including participant 31 who reported that the TAVI physician provided him with a direct phone number to call if he had concerns in the days after discharge (Participant 31, Interview #3). Participant 28 recalls the experience of a "fallback" in the early post-op period where he was able to talk to the TAVI team who provided him with advice:

> Yeah. And then I think I added a little bit every day [to his walk]. But then all of a sudden, I had a bit of a fallback. And I phoned Dr. whatever-his-name-was…anyhow, I phoned the hospital and they said "well just slow down a bit. You're obviously doing it too…getting ahead to fast." So I just slowed it down, and that took care of it and now I'm absolutely back to normal (Participant 28, Interview #4).

The experience of being able to speak with the TAVI team and be given advice helped this older adult navigate his transition home as he began to increase his activity level. This support was

helpful in transitioning home after TAVI and a desire for someone to contact for information and assistance was echoed by a caregiver who was not able to access this assistance:

> Informal Caregiver 9: I mentioned earlier, I send an email to [hospital 1, staff 8] questioning the medication. I said "who do I speak to?" She forwarded it over to [Hospital 1, Staff 2] and basically said "would you look after this or look into this?"
>
> Researcher: There was no follow-up okay.
>
> Informal Caregiver 9: No, nothing. No, nothing. And I don't want to sound unkind towards [Hospital 1, Staff 2]; I know she has a huge workload. But there should be somebody that can assist or send information (Interview # 3).

The sub-theme "effects of early complications" highlights how the occurrence of a post-operative complication can affect the experience of early discharge for older adults and their informal caregivers following early discharge after TAVI. Though only a small number of participants experienced complications, their occurrence revealed that further support may be required to help those who experience unexpected complications navigate the transition home.

Figure 4. Research Findings: Longer-term Recovery

Longer-term recovery – adjusting to life after TAVI. As older adults who experienced early discharge after TAVI moved beyond the initial phase of recovery, we see how their expectations of the TAVI procedure which were cultivated in the pre-operative and early recovery periods colour their experience of transitioning home and adjusting to a new normal. Those whose expectations were met expressed feeling grateful for their continued relief of symptoms in the longer-term recovery period and this led to positive feelings about the procedure itself as well as their ability to manage at home independently during longer-term recovery. When older adults and their caregivers experienced dissonance between what they had been told to expect during their longer-term recovery at home and what they were actually experiencing, they worked to reconcile this mismatch by attempting to manage their expectations of recovery. Though older adults reported being told to expect a significant improvement in symptoms after they underwent TAVI, some had not experienced the relief they were expecting and this in turn coloured their experience of transitioning home during longer-term recovery. To manage the discord between expectation and reality, older adults and their caregivers tried to make sense of their longer-term recovery in the context of comorbidity and advancing age. This process of reflection to understand and reconcile their experience was necessary as the individual factors affecting recovery after TAVI was something that was not discussed with health care professionals in the pre-operative and early recovery periods.

Feeling grateful. Many older adults continued to experience a relief of their symptoms in the longer-term recovery period. Those who had their pre-procedure expectations of recovery met expressed the ability to get back to activities that they were not able to do prior to their TAVI procedure including being able to take longer walks, engage in social activities such as shopping with friends and being able to start gardening again. Participant 7 reflected on the many benefits of undergoing TAVI that he had experienced:

> Well I've run into a couple of people that might be lined up for it [TAVI], and I say "go for it." Well when you come right down to it, you know, if you look at it it's that or oblivion…so there's not much of a choice. But given the choice, it's painless and so beneficial you just can't believe. No, anybody I talk to, I say "well look, here I am. I'm out putting fertilizer in the lawn, and I'm driving down to the store and going to the bank. I certainly didn't feel like that beforehand" (Participant 7, Interview #4).

As stated by Participant 7 above, he appreciated that undergoing the TAVI procedure has allowed him to be alive at this point in addition to the other benefits of the procedure. This sentiment was echoed by Participant 22: "Well, I think the TAVI, if I hadn't had it, I wouldn't be here now. No, I'm really thankful with the TAVI" (Interview #4).

Where the expectations of recovery were met, older adults experienced a positive transition home that continued throughout their longer-term recovery. As discussed in the theme "preparing for TAVI and planning for discharge" these expectations were shaped by the interactions older adults had with health care providers including the TAVI team during the pre-operative period. These expectations focused on a relief of symptoms and a return to "normal". No participants discussed how they themselves or healthcare providers understood or discussed this recovery with reference to age or existing co-morbidities. During longer-term recovery,

those whose expectations of recovery were not met had to work to manage their expectations of recovery.

Managing expectations of recovery. Though many TAVI recipients experienced improvements in their functional status after TAVI, this improvement was at times viewed within the context of unmet expectations of recovery. Some expressed feeling hopeful for more and reported feeling discouraged. Many also sought to manage their expectations of recovery within the context of their other co-morbid conditions. Finally, other older adults were able to view their recovery within the context of their advancing age which helped them manage their expectations of recovery as they adjusted to life at home after TAVI. This was a journey that was undertaken alone or with their families. No participants mentioned discussing these experiences with their health care provider or the TAVI team.

Wishing for better. Despite echoing the experience of feeling grateful for improvement after TAVI and still being alive, some older adults felt discouraged when their expectations of recovery were not met in the several months following TAVI:

> Well right now I've been up and down quite a bit lately and I've got swelling in my feet, which is water eh? And I'm a little disappointed because I figured after three months I was going to be a little bit better than I am right now. But you know the thing is, I'm still walking. You know I'm still alive and that's the thing that matters to me (Participant 29, Interview #4).

Though Participant 29 is grateful that she underwent the TAVI procedure, we see how unmet expectations of the recovery process affected the experience of transitioning home after TAVI. Though some older adults experienced disappointment that they had not recovered as well as expected, many remained hopeful that with time, they would continue to improve. In the months

following TAVI, Participant 22 stated “I’m not as steady on my feet as I’d like to be, but that’ll improve too” (Interview #4). For Participant 3, though he reported feeling satisfied with the TAVI procedure as he was breathing and sleeping better he reported “but I still haven’t got too much energy yet” (Interview #3). In this case, though Participant 3 is somewhat discouraged by his unmet expectations of the TAVI procedure, his caregiver expresses a different experience and seeks to clarify the improvements in her husband in the post-operative period:

> That operation that he had made the world of difference to him…and this business of not having a lot of energy, well, he can go for walks now that he couldn’t do before. I mean, there isn’t a whole lot of energy yet, but he’s got to build that up” (Caregiver 3, Interview #3).

Here we see a disconnect between the experience of the individual who underwent TAVI and those providing their care in the post-operative period. Though this was not a common finding throughout the transcripts it does highlight how the expectations of others may influence how older adults manage their expectations of recovery while at home after TAVI. These unmet expectations of recovery may also have been shaped by both the age and co-morbid burden of the older adults who underwent TAVI.

Recovery in the context of co-morbidity. In addition to unmet expectations colouring the experience of recovery after TAVI, the older adults interviewed also experienced their longer-term recovery within the context of their other comorbid conditions. Some were challenged to differentiate between complications from TAVI or a new comorbid condition. Participant 22 experienced limited energy during her longer-term recovery as a result of low hemoglobin but was unclear of the cause:

> Well, you know, with being low in iron and red blood, I haven't got the energy that I…I'll get up in the morning and have breakfast feel great, and then shortly after I have to have a little nap – and usually the same in the afternoon…yeah, we don't know why and they don't know why I am [anemic]…they did a scan of the pelvic area where they started the TAVI to see if there was any leakage there, but everything was clear (Participant 22, Interview #4).

Where Participant 22 was unsure if her lack of energy was a result of TAVI complications or a new diagnosis, other older adults attributed limitations in their longer-term recovery to their co-morbid conditions. For example, Participant 31 was also experiencing less energy during longer-term recovery after TAVI but felt this was related to a new treatment for his cancer.

> I can breathe better, that's one thing that's for sure, but I just started on a new medication for my cancer thing here and it makes you drowsy, so it's hard to sort of say where're you're at, you know? I mean I feel drowsy quite a lot, but I don't think that's because of the procedure, I think that's because of the horse pill that I'm taking (Participant 31, Interview #4).

In addition to co-morbidities affecting energy levels, older adults who experienced early discharge after TAVI also expressed how pre-existing functional limitations affected their experience of longer-term recovery after TAVI. Participant 24 describes the effect of an old injury on her mobility and limited ability to socialize:

> Well, no, nothing to do with the procedure. No, it's because of my mobility to walk and get around because I do have this problem. I didn't mention that. In 2009, I got a ruptured disc in my spine. It was terribly painful, extremely painful. So that restricted me. I have trouble standing to this day, and I can't walk very far (Participant 24, Interview # 4).

The presence of pre-existing limitations to mobility had affected this patient's experience of recovery as she has not been able to increase her level of socializing after TAVI. One caregiver explains how the presence of other co-morbidities have coloured the experience of recovery after TAVI for their loved one:

> You see, she has some other issues as well, that are draining mentally for her. Her eyesight is her biggest thing. She's losing her eyesight and she suffers terribly with macular degeneration…and then she also suffers with skin cancer…So it's all the health issues that are emotionally draining for her. As a result, she tends to be a little depressed from time to time. Well I know that the procedure [TAVI] hasn't depressed her at all. If she didn't have all these other issues, she would be wonderful (Informal Caregiver 9, Interview # 4).

Co-morbidities help shape how older adults and their caregivers begin to manage their expectations of recovery in the months after undergoing TAVI. They began to reconcile themselves to the fact that the residual challenges of low energy, limited mobility or depressed mood may not be related to recovery from the TAVI procedure but in fact be a result of their co-morbid conditions. The focus placed on these realities for older adults and their caregivers who experience early discharge after TAVI highlights the importance of addressing the effects of existing co-morbidities on recovery. It may be important to engage with patients and their family members in the pre-operative period to help manage expectations to allow participants to understand how their individual health challenges and co-morbidities may affect how they experience their transition home after TAVI. This discussion was not present in the interview transcripts and uncovered a gap in discharge planning and teaching for older adults and their caregiver who are discharged early after TAVI. Addressing how comorbidities may affect

longer-term recovery when patients are introduced to the TAVI program may help mitigate the effects of unmet expectations on the experience of early discharge after TAVI.

Perceptions of advancing age shaping expectations. Some older adults sought to manage their expectations of recovery within the context of their advancing age. Many appreciated the limitations of recovery through this lens which allowed them to feel more positive about the changes they have experienced after TAVI. Participant 7 explains how she has managed her expectations of recovery within the context of her advancing age:

> …accept the fact that you can only do so much and then you just…but then other people at my age are exactly the same. It's age. I think age does say something. You are…you just can't do what you would like to have done (Participant 7, Interview #4).

While acknowledging how age has limited her recovery and shaped her expectations, Participant 7 highlights the need to continue to push for improvement:

> I think you have to sort of think positive and keep yourself going. I mean, don't sort of say "Oh, I'm so tired," but I try to make myself do things. Sometimes you have to push yourself to do it. Some people just give up." (Participant 7, Interview #4).

Some older adults expressed feelings of pride when discussing how well they were doing in the post-operative period despite their age:

> I haven't gotten back to what I was when I was 37 but I'm up and around…I don't think I'm every going to get back to what I was 30 years or so ago, but for my 93 years, I'm doing pretty darn well (Participant 8, Interview #4).

Though the older adults interviewed in this study seemed to understand how their perceptions of advancing age may alter their experience of early discharge during longer-term recovery this

again was not discussed with health care professionals in the pre-operative period. Though age may be a factor in how the transition home in longer-term recovery is experienced, it is important to acknowledge the differences or heterogeneity present within the population of older adults who undergo TAVI and how this could alter the experience of discharge.

During longer-term recovery older adults who underwent TAVI and their caregivers began to adjust to life after the procedure. Many expressed feeling grateful for the relief of symptoms that persisted after the early post-operative period and well as for still being alive. Participants began to manage the expectations of recovery by wishing for better when expectations of recovery were not met and by framing expectations of recovery within the context of co-morbidity and advancing age. These expectations were shaped by individual's interactions with the health care team but no participants expressed having discussed their recovery with the team within the context of their individual health challenges, co-morbidities or age.

Conclusion

In this chapter, the research findings were presented to help understand how older adults and their caregivers experience the transition home after early discharge following TAVI. To illustrate and highlight how this transition was experienced over time, the research findings were presented through the lens of three different time periods: preparing for TAVI and planning for discharge, early recovery – transitioning home (2-4 weeks) and longer-term recovery – adjusting to live after TAVI (2-4 months). Though this organizing framework, we saw that during the pre-procedure period there was limited planning for recovery after TAVI and most of the information that was provided or sought out by participants pertained to what to expect from the procedure as opposed to how to prepare for the transition home. During the pre-procedure period we were also

made aware of how the unpredictable nature of surgical procedure timing as well as the challenges of preparing from out of town led to feelings of frustration and uncertainty for the study participants. During the early recovery period, the majority of older adults who were discharged early felt physically ready and adequately prepared for their transition home. Despite feeling prepared, older adults and caregivers alike acknowledged that early discharge would not be possible without the presence of caregivers to provide support and ensure safety during this transition. Though the majority of participants reported positive transitions between hospital and home, the experience of those who had early complications helped to highlight the gaps in care that exist for those who do not follow an uncomplicated path to recovery. When complications were experienced, participants recommended longer lengths of stay, requested access to the TAVI team for support navigating the transition home and finally highlighted that the discharge information, though adequate for those who did not experience complications, was insufficient for those who did. Finally, during longer-term recovery, though all participants felt grateful to be alive and for the continued relief of symptoms, many had to reconcile their expectations for recovery within the context of unmet expectation, other co-morbidities and advancing age. This provides the clinician with some insight into how best to inform older adults and their caregivers when preparing for and adjusting to life after TAVI.

This study provides insight into how older adults and their caregivers experience the transition home after TAVI following early discharge. It is unique, in that it highlights how this experience is shaped by where participants are in the illness trajectory as well as their other co-morbidities and aging process. Though most participants had positive experiences and did not have any recommendations to improve the post-operative care, the concerns raised by those who experienced early complications the impact of comorbidities, unmet expectations and advancing

age could help provide some direction in how best to further develop care processes to facilitate safe and effective early discharge after TAVI.

Chapter 5: Discussion

Increasing scrutiny and interest in the patient and caregiver experiences of undergoing TAVI has resulted in increased research looking at this phenomenon but current published literature specifically looking at early discharge after TAVI has not addressed patient or caregiver experience instead, the published literature has focused on the safety and feasibility of implementing early discharge (Barbanti et al., 2015; Durand et al., 2015; Noad et al., 2016) or the development of interdisciplinary pathways to support early discharge following TAVI (Lauck et al., 2016; Noad et al., 2016). The higher risk for adverse events experienced by older adults in hospital (Admi et al., 2014; Long et al., 2013; Rothschild et al., 2000) helps support a movement toward facilitating safe and early discharge for this patient population but this must be done while addressing and acknowledging the heterogeneous and often complex needs of older adults transitioning home after hospital stays. While qualitative studies have been published which explore the experience of coping with severe aortic stenosis while waiting for TAVI (Olsson et al., 2016), factors influencing the decision to be assessed for TAVI (Lauck, Baumbusch et al., 2016) and the experience of undergoing TAVI one-year post procedure (Baumbusch et al, 2017), no studies have examined the experience of early discharge for older adults and their caregivers.

The purpose of this project was to explore the experience of early discharge after TAVI for older adults and their informal caregivers to help guide recommendations for safe and effective early discharge which could be integrated across the continuum of care. Participants in this study experienced the transition home after early discharge as temporally linear, where their priorities, experiences and concerns were shaped by where they were in the trajectory of recovery after TAVI: pre-procedure, early recovery or longer-term follow-up. While waiting for

TAVI, older adults and their caregivers focused on what to expect from the procedure itself with limited attention paid to how to prepare for the transition home. During the period of early recovery, the majority of older adults in this study reported good experiences transitioning home and felt safe, supported and well informed to manage their recovery with the assistance of their informal caregivers. In contrast, those who experienced early post-operative complications expressed a desire for more information, requested support from the TAVI team and were concerned about shorter lengths of stay. Finally, during longer-term recovery, although all participants expressed feeling grateful for having undergone TAVI, some experienced a mis-match between their expectations of recovery and their actual experience. Due to the paucity of literature exploring the experience of early discharge after TAVI, the implications of these findings will be examined within the context of existing literature from other areas.

This chapter will explore three main interpretations of the findings within the context of the published literature including (1) lack of pre-operative discharge planning (2) challenges associated with early complications and (3) recovery in the context of comorbidities. This study adds to the TAVI literature by providing insight into the experience of early discharge after TAVI for older adults and their caregivers. This will be followed by a discussion of the limitations of this study and its implications for future research and clinical practice.

Lack of Pre-Operative Discharge Planning

During the pre-operative period described by this study as “preparing for TAVI and planning for discharge” I found that patients and their caregivers focused mostly on what to expect from the procedure itself, as opposed to planning for their transition home. During this period, participants sought information from multiple sources including written and online materials and from health care professionals directly to understand and plan for their upcoming

procedure. The overwhelming sentiment expressed by older adults and their caregivers was one of uncertainty surrounding both the timing of the procedure as well as what to expect after discharge home. As discovered in the category *playing it by ear*, this uncertainty of what to expect led many to forgo planning for their transition home and place more focus on the actual procedure of TAVI itself. This waiting period was described by participants as anxiety provoking, forcing them to place their life on hold and resulting in a desire to have the TAVI completed to "get back to normal."

Waiting for surgery. The feelings of uncertainty experienced while waiting for TAVI by the participants in this study are common throughout the literature looking at people waiting for other types of interventions including orthopedic, cardiac, oncology and bariatric surgeries (Banner, 2010; Chan, Kan, Lee, Chan, & Lam, 2012; Drageset, Lindstrom, Giske, & Underlid, 2011; Gregory, Newhook, & Twells, 2013; Olsson et al., 2016). Similar to the findings of this study, the reported feelings of uncertainty were a result of several factors including uncertainty surrounding the timing of their procedure (Banner, 2010; Gregory et al., 2013; Olsson et al., 2016), a desire for information about what to expect from the surgical procedure itself (Banner, 2010; Chan et al., 2012), and uncertainty about what to expect from their discharge home (Chan et al., 2012; Gregory et al., 2013).

Uncertainty of timing. The challenges surrounding the uncertainty of the timing of their procedures often led study participants to feel as though they needed to put their lives on hold while waiting for intervention. During the pre-operative period they reported how this led to feelings of frustration and desire to have the surgery completed. A grounded theory study examining the experience of women waiting for coronary artery bypass graft surgery (CABG) done by Banner (2010) reported that participants experienced the time waiting for CABG as

disruptive where they felt their lives had been put on hold and limited their ability to plan for the future. A study by Drageset et al. (2011) looking at the experience of awaiting breast cancer surgery also found that participants found the uncertainty around waiting for surgery difficult to tolerate and expressed a desire to have the surgery completed quickly so they could "get on with their lives" (p. 1944). Similar to the results of this study, we see that individuals waiting to undergo surgery are preoccupied by the timing of surgery itself and experience feelings of anxiety as their lives are often put on hold waiting for necessary interventions. To manage the anxiety of uncertainty surrounding the timing of the procedure, some participants from this study chose to contact the TAVI program to enquire where they were on the waitlist. A study looking at patients waiting for bariatric surgery reported that participants stressed the importance of receiving more information surrounding the waitlist process as well as a designated contract person during the waiting period to help manage the anxiety of waiting for surgery (Gregory et al., 2013).

From the existing literature we see that the feelings of frustration and anxiety related to the uncertainty of procedure timing tend to dominate the preoperative period independent of the type of surgery. As was the case in this thesis project, participants tended to focus on having the procedure completed as opposed to planning for their transition home. The suggestion for a designated contact person recommended by the participants in the study conducted by Gregory et al. (2013) could help ease some of the anxiety of waiting for surgery while also providing an opportunity for further contact with the TAVI program to help older adults and their caregivers begin to identify and plan for their future needs following early discharge after TAVI.

Uncertainty surrounding the surgical procedure. Both older adults and their informal caregivers included in this study tended to focus their search for information around what to

expect from the TAVI procedure itself. Some engaged with the written documents provided by the TAVI team, while others engaged more actively by seeking out information online including watching videos of the surgery being performed. The women waiting for CABG who were studied by Banner (2010) had the opportunity to participate in an education session that included written information, a video outlining what to expect from surgery as well as the opportunity to discuss questions or concerns with health care professionals. This experience significantly helped reduce the anxiety felt in the preoperative period. A systematic review of patients' experiences of preoperative communication also found that the information they received in the preoperative period helped decrease their fear of the unknown and helped them know what to expect when they arrived for surgery (Chan et al., 2012). The importance of preoperative information surrounding what to expect from a surgical procedure is important to help manage the anxiety related to what to expect. The participants in this study reported feeling well informed about what to expect from the procedure itself through their communication with the care team, written materials provided and online searches for information.

Uncertainty of what to expect from transition home. Participants in this study did not engage in advanced planning for their transition home following early discharge after TAVI. Many expressed that this was the result of uncertainty surrounding their care needs in the post-operative period. Rather than actively seeking out information as they did to understand what to expect from the procedure itself, only one participant reported seeking out information to understand what to expect from his transition home. The category *playing it by ear* from this study explored how participants dealt with this uncertainty by hoping for the best and assuming they would be able to organize support after discharge if it was required. In contrast with the findings of this study, the examined literature looking at the experience of waiting for other

surgeries shows that the participants in these studies often felt more anxiety related to what to expect from their transition home and requested information from health care professionals to manage their transition. The systematic review of preoperative communication by Chan et al. (2012) reported that patients, especially those undergoing orthopedic surgeries, wanted structured information regarding their post-operative recovery including expected discharge date, how to increase mobility safely as well as information regarding postoperative pain. This information was best delivered in both verbal and written formats with a focus on individualized recovery information (Chan et al., 2012). This discrepancy could be related to the fact that TAVI is a minimally invasive procedure in contrast to most of the surgical procedures studied. The perceived and real differences in post-operative care needs may have led TAVI patients and their caregivers to experience less anxiety and thus desire less information about their transition home as they prepared for TAVI.

The literature looking at successful discharge planning for older adults and their caregivers highlighted the importance of developing a comprehensive care plan through collaboration between care professionals, the patient and their caregivers to identify and address an individual's discharge needs (Bauer et al., 2009). Effective communication with health care professionals and a need to be actively involved in the discharge planning process were identified by older adults and their caregivers as essential to a successful transition home (Andreasen et al., 2015; Hvalvik & Reierson, 2015). In addition, caregivers often expressed feeling unprepared to take their family member home after hospitalization as a result of poor communication regarding what to expect and lack of understanding of their roles and responsibilities at home (Slatyer et al., 2013). Though participants in this study reported making few plans for their transition home, the majority were able to transition successfully and felt that

the information provided to them by the TAVI program was adequate to facilitate a safe and early discharge following TAVI. Those who expressed similar concerns to those identified in the above literature will be examined in the next section: challenges associated with early complications.

Congruent with other literature examining patients waiting for surgery in the community, TAVI patients tended to focus on the timing of their procedure and the TAVI itself. In contrast, participants tended to focus less on preparing for their eventual transition home, hoping to *play it by ear* and access services as required. Though many did express uncertainty surrounding their expected care needs, this did not dominate the narrative in the preoperative period. The program structure at the TAVI site may have led to a larger focus on the timing of the procedure and the procedure itself. Prior to their TAVI, patients and their caregivers have only one in person meeting with the TAVI team which occurs at the time of their eligibility assessment. During this meeting the patient does not know if they will be accepted for the procedure and the interaction is focused on testing (cognitive, functional and medical imaging) to determine their eligibility for TAVI. As they have not yet been accepted for the procedure, they may be thinking less about the recovery process and their questions were more focused on the procedure itself and how it could relieve their symptoms of aortic stenosis. Significant functional and social information is gathered at this initial visit with the TAVI team and could be used to help identify patients who are at risk for a more complicated transition home after TAVI. Further contact with the team after the patient is accepted for TAVI could help shift the focus from the timing of the procedure itself to providing the information and support that may be necessary for a successful transition home. Those who experienced early complications highlight some of the challenges associated with a more complex transition home, this second main interpretation will be explored next.

Challenges Associated with Early Complications

During the period of early recovery, TAVI patients and their informal caregivers navigated the process of transitioning from hospital to home. Overall, the majority of participants had a positive experience reporting early and significant relief of their AS symptoms, the provision of adequate information to safely transition and felt well supported by their formal caregivers to manage this period of transition. Though only two older adults who underwent TAVI experienced early post-operative complications, their experiences, and recommendations highlight the gaps in care that exist when the transition home is complicated by an unexpected recovery trajectory. Older adults and their caregivers who experienced early complications expressed a desire for more information and for a higher level of support from the TAVI team.

Managing uncertainty. Participants who experienced early complications reported difficulties in managing the uncertainties of their transition home following early discharge after TAVI. These challenges manifested in recommendations to address perceived lack of preparation for discharge as well as requests for access to the TAVI team for support. The requests for more information and access to health care professionals found in this study was also common in the reviewed literature examining the experience of discharge after day surgery which will be revisited in the following sections.

Lack of preparation. The perceived lack of preparation for discharge centered on a desire for more information as well as improved communication with the healthcare professionals encountered during their hospital stay. Participants in Boughton and Halliday's (2009) qualitative study exploring the experience of patients and caregivers discharged after day surgery reported similar findings. Their participants reported feelings of uncertainty and insecurity related to lack of information surrounding what to do if they were to experience complications

after discharge (Boughton & Halliday, 2009). They reported that the written information provided was inadequate as it was at times difficult to understand and also did not provide enough information regarding the normal recovery trajectory, including what to expect with regards to pain and healing (Boughton & Halliday, 2009). The grounded theory study conducted by Mottram (2011) exploring the discharge experience following day surgery also reported that participants felt ill prepared to manage the transition home. Again, participants reported a lack of information regarding what to expect in terms of their physical recovery and were left unsure of how to respond in the face of what the author described as "unexpected occurrences" such as decreased energy levels or bleeding (Mottram, 2011). Participants were left feeling anxious when they couldn't distinguish between a normal occurrence and the development of a post-operative complication (Mottram, 2011). These feelings of uncertainty related to lack of preparation were also expressed by the participants in this study who experienced early complications.

Lack of preparation affecting the perception of readiness for discharge was also interpreted by study participants as a result of breakdowns in communication with the care team while in hospital. For example, the informal caregivers for Participant 25 reported significant stress and anxiety as a result of their inability to communicate with both physicians and social work prior to discharge with regards to the anticoagulation regime as well as the need for additional home supports to facilitate the transition back to the community. Concerns regarding lack of communication with healthcare professionals during discharge planning is commonly reported in the contemporary literature looking at the discharge experience following hospital admission for older adults and their caregivers (Bauer et al., 2009; Bragstad et al., 2014; Dilworth et al., 2012). Bragstad et al. (2014) reported that informal caregivers of older adults were often not involved in the discharge planning process and had to become actively engaged as

they “struggled to gain influence” through communicating the discharge needs of those in their care to health care professionals. Older adults interviewed by Dilworth et al. (2012) also experienced a lack of communication with health care professionals leading up to their discharge which led to feelings of “being left out” and in turn having their preferences and needs ignored. Finally, a literature review undertaken by Bauer et al. (2009) also found that older adults and their caregivers need to communicate with care providers to help facilitate a safe and effective discharge after hospitalization.

For the participants of this study who experienced early complications, their experiences were congruent with the literature looking at discharge experience after day surgery as well as the experience of discharge after hospitalization for older adults and their caregivers. Of note, participants who did not experience early complication reported feeling satisfied with the discharge process. They reported feeling well informed on what to expect from discharge and felt well prepared to manage their transition into the community. This experience may support that the current care processes are adequate to facilitate an effective discharge home after TAVI regardless of length of stay but that there are gaps in preparation and after care for those who experience complications.

Requests for support; The role of transitional care models. To manage the uncertainty of the transition home for those who experienced early complications participants requested access to the TAVI team to provide support and reassurance during the early recovery period. Participants who experienced early complications expressed a desire to be able to access the TAVI team for reassurance, direction or clarification to navigate their transition home following early discharge. Patients undergoing day surgery also commonly expressed the desire for access to a health care professional during the transition period following surgery to seek reassurance

that they were “doing the right thing” (Boughton & Halliday, 2009). A phenomenological hermeneutic study undertaken by Berg et al. (2013) reported that patients recovering after heart valve surgery also expressed the need for the support of health care professionals to navigate and interpret their symptoms and recovery in the early post-operative period. Those who were unable to access support felt lost and reported feelings of insecurity in how to manage their recovery (Berg et al., 2013). Participants in this study who were able to contact the TAVI team to manage their uncertainties during transition reported the experience of early discharge as positive, in contrast to those who were unable to access a health care professional for support when they experienced early complications.

The role of pre, post and transitional care interventions to help manage the transition between home and community after hospitalization are often examined within the context of reducing costly re-admission to hospital (Hansen, Young, Hinami, Leung, & Williams, 2011). The literature looking at early discharge after TAVI has shown that there is no significant difference in 30-day readmission rates for those who experience early discharge (≤ 72 hours) in comparison to standard discharge (≥ 72 hours) (Barbanti et al., 2015; Durand et al., 2015; Lauck et al., 2016; Noad et al., 2016; Sud et al., 2017). Though no difference exists based on length of stay, there remains a significant level of all cause re-admission after TAVI ranging from 10.7 % (Lauck et al., 2016) to 17.9 % (Kolte et al., 2017) which highlights the possible need to examine and address gaps in the care processes supporting discharge after TAVI regardless of length of stay. As noted by Lauck et al. (2016), one could argue that the lower comorbid burden of patients selected for early discharge should show a decrease in 30-day re-admission rates highlighting the need to improve outcomes in this population.

Several strategies to address the need for support expressed by study participants who experienced early complications during the transition home following hospitalization or surgical intervention have been studied in the literature. A systematic review of interventions to reduce 30-day rehospitalization conducted by Hansen et al. (2011) looked at 43 different studies and identified three main types of interventions studied to reduce hospital stays. They described a "taxonomy of interventions" which included (1) Pre-discharge interventions: patient education, discharge planning, medication reconciliation and scheduled appointments before discharge, (2) Post-discharge interventions: timely follow-up, timely communication with primary care provider, follow-up telephone call, patient hotline and home visit and (3) Interventions bridging the transition: transition coach, patient-centered discharge instructions and provider continuity. Overall, the authors concluded that they were unable to identify individual or bundled interventions that were able to consistently reduce 30-day re-admission rates (Hansen et al., 2011). Despite the identified limitations, Hansen et al. (2011) identified several promising interventions including follow-up telephone calls to facilitate the transfer of knowledge in addition to patient centered discharge information which provided individual discharge instructions tailored to the individual's care needs. Overall, interventions that supported patient engagement in discharge planning, individualized care plans and structured follow-up were deemed to be the most effective, but that this effectiveness was likely dependant on bundled interventions as opposed to stand-alone interventions (Hansen et al., 2011). Current recommendations for essential discharge elements after TAVI suggest ensuring pre-procedure medications are ordered, identified discharge location, post-procedure echocardiogram (ECHO) and electrocardiogram (ECG) as well as a scheduled clinic visit follow-up (Otto et al., 2017). Otto et al. (2017) also identify the importance of identifying family and social supports, ability to

perform activities of daily living (ADLs), transportation as well as patient education and instruction, but no recommendation is made to provide phone follow-up or support between discharge and the patient's follow-up visit.

High levels of 30-day readmission following TAVI as well as the expressed need for support during the early recovery period expressed by study participants who experienced early complications after TAVI highlights the need to implement evidence-based interventions to support patients and their informal caregivers as they transition between hospital and home. The majority of 30-day readmissions are from non-cardiac causes (61.8%) and are often related to patient's pre-existing comorbidities (Kolte et al., 2017). The 30-day readmission for cardiac causes made up 38.2 % of re-admissions with heart failure being the most common single cardiac cause for re-admission (22.5%) (Kolte et al., 2017). Based on these findings, it is less clear if supportive follow-up in the early post-operative period is best provided by the TAVI team or through primary care providers or speciality clinics managing individual patients' co-morbidities such as heart failure or chronic obstructive pulmonary disease (COPD). To help ensure a safe and effective transition home following early discharge after TAVI, identification of those at risk for early re-admission, development of patient specific discharge instructions and provision of telephone access to health care providers are three possible strategies to reduce early re-admission as well as to help manage the feelings of uncertainty and need for support expressed by those who experienced early complications after TAVI.

Recovery in the Context of Multiple Comorbidities and Advanced Age

The preceding review of the literature exploring the causes of 30-day readmission following TAVI highlighted the fact that those who undergo TAVI, do so within the context of their medical co-morbidities and current level of frailty. This helps contextualize one of the main

findings of this study where older adults and their informal caregivers worked on "managing their expectations of recovery" and reconciled themselves to the unmet expectations of recovery experienced within the context of co-morbidity. Though all patients during longer-term recovery were happy to have undergone the TAVI procedure, the experience of unmet expectations was commonly expressed by older adults who experienced early discharge after TAVI. A qualitative study looking at the experience of TAVI one-year post procedure conducted by Baumbusch et al. (2018) also found that older adults and their caregivers recovered in the context of comorbidity and struggled to reconcile their expectations of TAVI with the realities of their recovery. This study did not exclude patients based on length of stay after TAVI which highlights that for longer-term recovery the experience may not differ significantly between those who experience early versus standard discharge. Though the participants in this study often expressed feeling hopeful that their symptoms would improve with time, the results from Baumbusch et al. illuminate the fact that expectations of recovery often remain unmet at one-year post-procedure. This supports the importance of identifying those who may derive less benefit from TAVI based on pre-procedure comorbidities and integrate these findings into individualized teaching plans from early in the care trajectory to help support realistic expectations for recovery in the post-operative period.

TAVI outcomes, advanced age and quality of life. Many older adults have been denied surgical valve intervention based on the increased peri-operative mortality rate associated with advancing age including a 10% risk for those over 90 years of age (Alsara et al., 2014). Several studies have looked at the effects of advanced age on outcomes following TAVI (Alsara et al, 2014; Bekeredjian et al., 2010; Escárcega et al., 2016). Bekeredjian et al. (2010) found that those 80 years and older (average age was 86) experienced significant improvement in quality of life

using The Medical Outcomes Study Short Form 36-item Health Survey and reduced brain naturitic peptide levels (biochemical measure of heart failure) following TAVI. Escárcega et al. (2015) found that there was no significant difference in mortality at 30 days and one year for those over 90 years of age, and in fact they had lower rates of comorbidities including diabetes, prior CABG, hyperlipidemia and lower body mass index. Finally, a review of advanced age and clinical outcomes for TAVI patients found studies comparing outcomes based on age of TAVI patient found no difference in 30-day mortality, and all participants experienced significant improvement in functional status and quality of life (Alsara et al., 2014)). These findings support that patient's age may not be as helpful when developing individualized discharge teaching to help manage expectations of recovery.

Participants in this study also reported continued relief of their symptoms and as a result experienced improvement in their functional capacity and ability to re-engage in activities that they previously enjoyed such as gardening. This experience is congruent with the literature looking at the experience of TAVI one year following procedure (Baumbusch et al., 2018) as well as the literature reporting improvement in quality of life for older adults following TAVI (Elmalem et al., 2014; Fairbairn et al., 2012; Krane et al., 2012). Though the literature looking at quality of life universally reports improvement in patient reported quality of life, a narrative review of the literature by Horrocks, Closs and Astin (2014) highlighted the reality that the existing literature does not address the factors that cause some older adults to experienced improvements in their quality of life while others do not. Horrocks et al. concluded that the presence of co-morbidities may affect individual's experience of quality of life based on residual functional limitations as a result of existing co-morbidities. These findings are consistent with those of this study in that although participants reported improvement in their functional

capacity, the presence of comorbidities such as osteoarthritis, COPD and reduced ejection fraction coloured their experience of longer-term recovery and contributed to unmet expectations. For this reason, discussions surrounding what to expect after TAVI, must be individualized and consider existing co-morbidities which may limit or affect recovery post TAVI.

The role of frailty and comprehensive geriatric assessment. Eligibility assessment for TAVI now routinely includes a comprehensive functional assessment including assessment of frailty and disability, nutritional status as well as physical and cognitive function (Kolte et al., 2017). This information is gathered to determine eligibility and determine the risk of undergoing TAVI for individual patients (Kolte et al., 2017). As this information is gathered prior to the procedure, it may prove useful when developing individualized discharge plans as well as helping to manage the expectations of older adults and their families who may experience slow or incomplete resolution of their functional limitations after TAVI.

Studies have employed frailty assessments to help predict surgical risk and mortality following TAVI (Afilalo et al., 2017; Rogers et al., 2018) as well as to predict functional decline after TAVI (Schoeneberger et al., 2013). Rogers et al. (2018) used 5 markers of frailty (BMI < 29kg/m2, serum albumin < 3.5g/dL, Katz index of independence in ADLs score ≤ 4/6, low grip strength and a slow 15-foot walk time) to determine frailty of older adults undergoing TAVI which was defined as having three or more of the identified frailty markers. The authors found that frailty status was a significant predictor of both 30-day and one-year mortality (Rogers et al.). Afilalo et al. (2017) compared seven frailty scales including the Essential Frailty Toolset (EFT) which they have developed. The EFT provides a score of 0 (least frail) to 5 (most frail) using scores from a chair rise test, Mini Mental Status Exam, pre-procedure anemia and

hypoalbuminemia (Afilalo et al., 2017). The study showed through multivariate analysis that EFT scores had the strongest association with one-year mortality, and worsening disability for those undergoing TAVI. The authors argue that its strong predictive value, ease of use, high interobserver reliability and lack of specialized equipment make it an ideal tool to measure frailty for TAVI patients and to help with case selection and pre-procedure interventions such as exercise programs and nutrition interventions (Afilalo et al., 2017). Schoenenberger et al. (2013) used a frailty index of 0-7 where participants were assigned scores based on their Mini Mental Status Exam, Timed Get Up and Go Test, Mini Nutritional Assessment, Basic Activities of Daily Living and Instrumental Activities of Daily Living. Those who scored less than three points were categorized as non-frail and those who scored three or more points were deemed to be frail (Schoenenberger et al., 2013). The authors of this prospective study found that though few of the participants studied experienced a functional decline (20.8%), the frailty index served as the strongest predictor of functional decline for those undergoing TAVI. Schoenenberger et al. (2013) argued that the frailty index provided a good prediction of functional decline as they tend to identify patients who have impaired physiological reserves which may lead to a higher risk of deterioration after interventions such as TAVI.

Despite disagreement in the literature on the best ways to operationalize frailty and comprehensive geriatric assessments, the ability to identify frailty and stratify risk may allow health care providers the opportunity to plan interventions or predict risk (Rockwood et al., 2005). The presented literature supports the use of measures of frailty to predict both the risk of undergoing TAVI as well as the risk for functional decline after TAVI. To improve the experience of early discharge for older adults and their caregivers after TAVI, information gathered from comprehensive geriatric assessments and measures of frailty in the pre-operative

period could be used to help manage expectations of recovery and identify those who are more likely to have a more complicated long-term recovery following TAVI. Based on the similar findings of the one-year follow-up study for TAVI patients (Baumbusch et al., 2018) which did not exclude patients based on length of stay, the implementation of this knowledge could be integrated into discharge planning for all patients undergoing TAVI, regardless of estimated length of stay.

Older adults as caregivers. The majority of informal caregivers included in this study (67%) were older adults themselves and provided supportive care to their spouse throughout the care trajectory. Literature examining caregiving burden often does not explore the challenges unique to the older adults providing care but provides recommendations for interventions and practice change based on "family caregivers" which can include people of all ages and relation to the older adult receiving care (Oldenkamp et al., 2016). A meta-analytic comparison of spouses, adult children and children-in-law completed by Pinquart and Sörensen (2011) found significant differences in hours of care provided, perceived burden and health problems between groups. Older adult spousal caregivers reported worse levels of physical health, received less informal support, provided more caregiving hours and reported more depressive symptoms (which was found to be explained by the higher amount of care hours provided). In support of these findings, one quantitative study looking at subjective care burden for spousal and adult-child informal caregivers found that spousal caregivers (average age 73) experienced higher levels of overall subjective burden and reported more mental and physical health problems (Oldenkamp et al., 2016). Finally, a qualitative study looking at the experience of older adult spouses (mean age 82) providing care to a spouse with cancer found that participants spoke frequently about their concerns about their own health status (Wittenberg-Lyles, Demiris, Oliver, & Burchett, 2014).

These caregivers expressed concerns about their ability to provide care to their spouse in light of declines in their own health which they felt was related to advancing age as well as the strain of providing care (Wittenberg-Lyles et al., 2014). Though this section has focused on the unique needs of older adults acting as caregivers, it is also important to note that there are challenges for adult-children who provide care to older adults as well including the competing demands of balancing their work and family responsibilities with the care of older parents (Pinquart & Sörensen, 2011).

The results of this study did not reveal significant concerns or caregiver burden for older adult caregivers. This could be a result of the majority of caregiver interviews being conducted with their spouse in the room or on the phone with them, perhaps making them less likely to express their concerns regarding how their health has been affected. Another possible explanation is that the relatively fast recovery after TAVI as well as the relief of some symptoms and ability to take on more activities may have in fact lessened the caregiving responsibilities for older adult caregivers following the transition home after TAVI. As hours of care provided appears to be the most important factor when determining caregiver burden (Pinquart & Sörensen, 2011), a reduction or lack of increase in care hours may help explain the mostly positive experience of transitioning home after TAVI. More research to examine the unique experiences of older adults providing care for their spouses may help provide valuable insight into this unique category of family caregiver. As informal caregivers provide the majority of support during both early recovery and longer-term follow up it is important to assess patient care needs as well as existing or potential caregiver burden to help develop an individualized care plan to facilitate the transition home following early discharge after TAVI.

Limitations

The findings of this study are limited by the lack of generalizability of findings to broader populations due to the qualitative study design of interpretive description (Polit & Beck, 2012). Interpretive description acknowledges the individual, socially constructed and contextually dependant interpretation of a phenomenon grounded in clinical practice (Thorne, 2016). The purpose of this study was therefore not to develop generalizable findings but to generate interpretations from inductive reasoning and existing disciplinary knowledge to help provide recommendations for clinical practice (Thorne, 2016). Grounded in the study data and research literature, this interpretation of the findings led to the development of recommendations for research and clinic practice that will be further discussed in the implications section below.

This study was also limited by the use of existing data from a larger qualitative study to answer the outlined research questions. Though the TAVI study addressed the discharge experience after TAVI for older adults and their caregivers, it was not the main focus of the original TAVI study, which sought to understand the experience of undergoing TAVI as a whole. This could have led to certain elements of the experience of early discharge being missed. In addition, data collection for the TAVI study occurred between 2013 and 2014 when the movement toward minimizing hospital stays was starting to become a focus of TAVI teams. With the dynamic and changing nature of this procedure, length of stays as well as existing care processes have evolved to meet the evolving needs of this increasingly minimalist procedure. More contemporary patient experience may also have provided further insight into how current practices and length of stays are affecting the experience of early discharge for older adults and their informal caregivers following TAVI.

Implications

Further research. Several questions were generated from the research findings as well as the study limitations that would benefit from further evaluation. First, with evolving care practices inherent in a dynamic procedural program like TAVI, it may be beneficial to study more recent experiences of patients who experience early discharge after TAVI. With continuing reduction in length of stay after TAVI, it may now be feasible to interview only patients and their caregivers who are discharged the day after the procedure. The importance of pre-procedure discharge planning and education in this cohort is paramount as there would be very limited time for nurses to provide this education and address possible gaps within 24 hours or less.

The findings of this study revealed that those who experienced early complications after discharge expressed a need for support from the TAVI team in the early post-operative period to provide clinical guidance and reassurance. This was congruent with the literature looking at discharge after day surgery (Boughton & Halliday, 2009; Mottram, 2011). Though there is no consensus on the best way to provide support during transition from hospital to home to help reduce re-admission (Hansen et al., 2011) future research could trial a transitional care program for TAVI patients during the period of early recovery to provide support and reassurance during transition. This may prove particularly impactful for those deemed to be at high risk of complications or exacerbation of existing co-morbidities.

Finally, though the majority of older adults and caregivers interviewed felt that the information provided to them to facilitate discharge was adequate to support a safe transition home, those who experienced early complications requested more information in terms of what to do if complications occur. It would perhaps be beneficial to work with TAVI patients who experience complications or felt the need to reach out to care providers to understand how

existing education materials could be updated to address their concerns. This inquiry could take multiple forms such as a quality improvement project or a mixed methods study to help understand the type of information missing as well as patient and caregivers' recommendations for updating it.

Clinical practice. The main findings of this study explored in the discussion section highlight several clinic practice points that could be integrated along the care continuum of those navigating the transition home following early discharge after TAVI.

First, this study showed that during the preoperative period, older adults and their caregivers tended to focus on what to expect from the surgical procedure itself as well as the timing of their procedure as opposed to identifying possible care needs that may arise during their transition home. Part of this focus could be related to the structure of the TAVI program, where patients' and caregivers' only in-person interaction with the TAVI team occurs at eligibility assessment where patients, informal caregivers as well as the clinical staff are unsure if they will be candidates for the TAVI procedure. It would be difficult to begin to plan for and discuss possible challenges of transitioning home after the procedure when all involved are unsure if they will undergo TAVI in the future. With the hope of avoiding the expressed concerns of patients and their caregivers who experienced early complications, it may be worth considering another interaction with the TAVI team prior to their procedure to discuss what to expect from and how to prepare from their transition home. This could likely prove challenging to implement based on time constraints and may best be implemented in group education sessions as are often employed for people preparing for other surgical procedure such as joint replacement (Jorgensen & Fridlund, 2016; Uhrenfeldt & Hoybe, 2015). Unfortunately, the group

structure may not provide the individualized care plans that would address the heterogeneity of the TAVI population.

The collection of functional, cognitive and social information at eligibility assessment could also be used to help provide individualized teaching and care planning and help identify those at risk of complications following TAVI as well as to help manage the expectations of recovery within the context of comorbidity. Frailty scores have been shown to help predict functional decline after TAVI (Schoenenberger et al., 2013) as well as the likelihood of 30-day readmission (Ungar et al., 2018) or mortality (Rogers et al., 2018). Knowledge of patient functional status from eligibility assessment could be taken beyond the decision making for procedural eligibility and used to identify those at higher risk for complications or more limited recovery following TAVI. This knowledge, if applied and integrated into patient teaching in preparation for TAVI could be used not only to identify those who may require more support to plan for their eventual transition home, but could also be used when discussing what to expect from their recovery after TAVI. If these risk factors were identified and additional care planning was initiated, it may be possible to mitigate some of the challenges faced by the study participants who experienced complications in the early post-operative period. It could also help manage the expectations of recovery within an individualized patient specific context to help avoid the expectation reality mis-match experienced by many older adults in this study during long term follow-up.

Though the improvements to the discharge planning process generated from the findings and presented above may help reduce the requests for more information and support from the TAVI team that were expressed by those who experienced early complications, it may also be prudent to implement a simple transitional care model in the form of a hotline that patients can

call with cardiac or procedure related concerns in the immediate post-operative period. This may improve the experience of early discharge after TAVI both for those who experience complications as well as those who require reassurance and support during their transition from hospital to home. As discussed in implications for future research, this could possibly be integrated as part of a quality improvement project or pilot study to ensure that this would benefit the patients, caregivers and TAVI program as a whole.

Conclusion

The findings of this study help expand the current knowledge of early discharge following TAVI for older adults and their caregivers by looking beyond safety and feasibility to begin to understand the experience of the transition home. Discharge was experienced as a temporally linear process, where priorities, experiences and concerns were shaped by where participants were situated in the trajectory of recovery following TAVI. This led to the development of three main themes: (1) preparing for TAVI and planning for discharge, (2) early recovery – transitioning home and (3) longer-term recovery – adjusting to life after TAVI. This study adds to the TAVI literature by illuminating the experience of early discharge for patients and caregivers, while attending to the unique and often heterogeneous needs of the older adults who more commonly undergo TAVI.

During the pre-operative period, older adults and their informal caregivers focused on what to expect from the procedure and engaged in limited planning for their eventual transition home including possible care needs during this time. Review of the published literature found that this was common in patients waiting for other surgical procedures (Banner, 2010; Drageset et al., 2010). As participants transitioned into the early recovery period, most felt well informed and supported during their transitions home, with the exception of those who experienced early

complications. The patients and caregivers who experienced early complications requested more information, were concerned with lack of communication and requested support from the TAVI team to manage this transition. This highlighted how gaps in pre-operative preparation and teaching may have affected the experience of transitioning home for those who did not experienced an uncomplicated course. Finally, during longer term follow-up, older adults and their informal caregivers worked to reconcile residual functional deficits and comorbidities with their expectations of recovery from TAVI.

The findings of this study highlighted the importance of capitalizing on both the early encounters with patients and their caregivers as well as the potential of the large amount of functional, cognitive and social knowledge gathered during eligibility assessment. These early encounters and information could be used to help focus the pre-procedure period on identifying those at higher risk for complications or limited recovery and mobilizing resources to help create individualized care plans to address some of the concerns for those who experienced early complications as well as those who had a mis-match between their expectations and reality of their longer-term recovery. Moving forward, the findings of this study generated several recommendations both for further research as well as nursing practice. These included studying participants who experience next day discharge after TAVI as this has increasingly become the norm, thus placing further importance on the development and implementation of pre-operative care planning and education. In addition, research testing transitional care models to provide support in the immediate post-operative period, guided by the recommendations of TAVI patients who experience complications may also be beneficial. To integrate these study findings into practice, I would recommend considering ways to alter the current care processes to allow for more interaction with the TAVI care team both to help identify those at risk for challenges

during the transition home while developing individualized care and education plans as well as by providing support to manage complications and provide reassurance in the early post-operative period.

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Appendices

Appendix A: Study Participant Demographics

Table 1A

Patient Demographics

	Total Sample (N=10)
Age (years)	
Range	68-93
Median	85.5
Gender	
Male	5 (50%)
Female	5 (50%)
Proximity to procedure site	
Out of town (greater than 100 km)	4 (40%)
In town (less than 100 km)	6 (60%)
Living Situation	
Alone	2 (20%)
With spouse only	6 (60%)
With spouse and other family	1 (10%)
Other	1 (10%)
Length of Stay after TAVI (days)	
Range	1-3
Median	1.5

Table 2A

Caregiver Demographics

	Total Sample (N=9)
Age (years)	
Range	58-94
Median	73
Gender	
Male	4 (44%)
Female	5 (56%)
Working Status	
Retired	8 (89%)
Disability leave	1 (11%)
Relationship to patient	
Spouse	6 (67%)
Child	1 (11%)
Friend	2 (22%)
Living with patient	
Yes	6 (67%)
No	3 (33%)