

Older Adult Narrative of the Experience of Cardiac Surgery

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Boston College

William F. Connell School of Nursing

OLDER ADULT NARRATIVE OF THE EXPERIENCE OF CARDIAC SURGERY

a dissertation

by

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Abstract

OLDER ADULT NARRATIVE OF THE EXPERIENCE OF CARDIAC SURGERY

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Cardiac surgery is frequently performed as a surgical intervention within the United States; but there is little known about how the older adult (70 years of age or greater) experiences cardiac surgery and recovery over time. This qualitative research study utilized narrative methodology to interview 13 older adults to inform understanding of the older adult's cardiac surgical experience. The purpose of this study was to describe the story of the older adult both coming to surgery (preoperative period) and during the transitional time of the acute recovery period following cardiac surgery (up to 8 weeks after cardiac surgery). The primary research question asked was "What stories do older adults tell of their experience of cardiac surgery from the preoperative period through the first 2 months postoperatively?" Using narrative analysis of participant discourse, consisting of both structural (re-storying of narrative content) and thematic analysis of interview content, there emerged an overarching story of older adult experience of cardiac surgery which can be described thematically as: *Moving toward healing: engaged in and appreciating life while conscious of time passing amidst the primacy and struggle of the symptom experience*. Knowledge gained from this study can help to broaden the understanding of the experience and the trajectory of older adult recovery after cardiac surgery, and also serves

to inform nursing education and practice models, nursing interventions, instrument development and innovative models of care designed to support the perioperative care of older adults.

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CHAPTER ONE

Introduction

Cardiac surgery is a frequently performed surgical intervention within the United States and affects approximately 250,000 adult patients annually (De Frances, Cullen & Kozak, 2007). Over 100,000 of these patients are 75 years of age or older (DeFrances et al., 2007). A large number of older adults have cardiac surgery, but there is little known about how the older adult (70 years of age or greater) experiences cardiac surgery and recovery over time. This qualitative research study utilized narrative methodology to analyze participant discourse in order to inform understanding of the older adult's cardiac surgical experience beginning with preoperative care through the acute recovery period.

Background

As the population of the U.S. ages, the demographic of persons who undergo cardiac surgery is shifting to include a large proportion of older adults (Etzioni & Starnes, 2011). There are multiple factors which shape these changing demographics. In the United States, as well as throughout the world, society is rapidly aging. Increased life expectancy and the aging of a large cohort of adults born between 1946 and 1964 (the baby boomers) continue to increase the growth of the older adult population. In 2030, it is expected that approximately 72 million people living in the United States will be 65 years of age or older (Federal Interagency Forum on Aging-Related Statistics, 2010).

Additionally, the number of adults living in the United States above 85 years of age is expected to triple between 2008 and 2050, from 5.7 million to 19 million with women and men who survive to 65 years of age living 19.9 and 17.2 more years, respectively (Federal

Interagency Forum on Aging-Related Statistics, 2010). It is anticipated that as the population ages there will be an increase in the number of older adults seeking surgical interventions including coronary artery bypass and cardiac valve replacement. This finding seems contradictory because as less invasive surgical procedures have evolved, including percutaneous coronary intervention (PCI), placement of drug eluting coronary stents, and advances in medical management, the overall trend is that fewer adult patients are having open heart surgery (Etzioni & Starnes, 2011). The rate of cardiac bypass surgical procedures in persons greater than 65 years of age has steadily decreased from 94.1 per 100,000 persons in 1999 to 60.9 per 100,000 in 2007 (Hall, DeFrances, Williams, Golosinskiy & Schwartzman, 2010; Popovic, 2001). However, this trend is not the case for adults over 75 years of age. In fact this cohort is more likely to require bypass repair via coronary artery bypass surgery than PCI due to the fact that multivessel and diffuse coronary artery blockages that develop with age are not amenable to treatment with PCI (Booth et al., 2008; McKellar, Brown, Frye, Schaff, & Sundt, 2008). Also, cardiac valvular disease is more common in those aged 65 years of age and older and currently heart valve repair and replacement predominantly necessitate open heart surgery (OHS) (Mirabel et al., 2007; Varadarajan, Kapoor, Bansal, & Pai, 2006).

Advances in surgical techniques and supportive technologies have resulted in improved morbidity and mortality for older adults with coronary artery disease (CAD) following PCI interventions such as atherectomy and cardiac stent placement, as well as after OHS (Alexander et al., 2005; Graham et al., 2002; Zingone et al., 2009). Thus, despite the advent of less invasive procedures, the proportion of older patient having open heart surgery as remained steady over the past three decades and it is projected that surgical interventions will continue to

increase as the population of adults living in the United States ages (Etzioni & Starnes, 2011).

Outcomes of cardiac surgery. Evidence associated with the outcomes of older adults who have cardiac surgery is still unfolding, and at times the results of surgical interventions in older adults are conflicting. In the recent past, adults greater than eighty years of age and older have been excluded from large scale clinical trials comparing outcomes for three avenues of treatment of coronary artery disease: medical management, PCI and cardiac surgery (Jackson & Wenger, 2011). Consequently, there is a lack of high quality synthesized evidence to inform the type of treatment and related outcomes for older adults, particularly octogenarians and nonagenarians (Likosky et al., 2008). There is clear evidence to suggest that older adults face greater risks in surgery. Age is an important independent predictor of risk associated with cardiac surgery along with other known predictors of surgical risk including kidney function, comorbid conditions (diabetes and cerebrovascular disease), cardiac ejection fraction, and increased risk in women (Zingone et al., 2009).

In addition to surgical risk factors, there are other factors which impact the outcomes of older adults following cardiac surgery. These include the added assessment of formal measures of frailty, risk for delirium, or independent activity of daily living to estimate the accuracy of outcomes predictors related to recovery and/or cardiac surgical risk. Frailty in older adults undergoing cardiac surgery places these individuals at an increased risk for multiple adverse health-related outcomes, such as nursing home admission or death (Bergman et al., 2007; Hastings, Purser, Johnson, Sloane, & Whitson, 2008). Additionally, the prevalence of delirium following cardiac surgery has been estimated to range between 30 to 50 percent in adults 60 years or older and is associated with increased morbidity and mortality (Bakker, Osse,

Tulen, Kappetein, & Bogers, 2012, Tan et al., 2008). It is well understood that there are many poor outcomes associated with delirium, up to and including, death. Recent attention has focused on the 30 and 60-day hospital readmission rates, for older adults on Medicare, and, the poor outcomes of patients who have experienced delirium (Leslie, Marcantonio, Zhang, Leo-Summers, & Inouye, 2008).

A review of quality of life measures suggest there is significant symptom burden impacting patient quality of life during recovery from cardiac surgery (see Appendix A). Multiple measures of quality of life have been used to characterize the recovery of men and women following cardiac surgery and current evidence suggest that women have disparate quality of life measures after cardiac surgery when compared with men (Barnason, Zimmerman, Anderson, Mohr-Burt & Nieveen, 2000; Lindquist et al., 2003). Both physical and psychological symptoms have been described in the postoperative period, with a nadir of quality of life experienced at one month to six weeks after surgery (Myles et al., 2001; Lindquist et al., 2003; Hunt, Hendrata & Myles, 2001). Older adults have increased length of hospital stay, may require more lengthy postoperative institutional care and the overall care of older patients is associated with increased costs of healthcare (Chee, Filion, Haider, Pilote, & Eisenberg, 2004; Gelsomino et al., 2011). As a results, identifying the ‘best’ treatment choice (i.e. medical treatment, cardiac surgery or PCI) for older adults requiring treatment for cardiac problems may not be a readily apparent due to the emerging, conflicting and variable evidence on health outcomes of older adult patients following surgical intervention.

Qualitative exploration of experience after cardiac surgery. Qualitative research that has examined the experience of adults who have had cardiac surgery uses primarily qualitative

descriptive approaches. A review of 22 qualitative research studies that explored the experience of cardiac surgery patients between 2000 and 2010 indicated that of these, six studies reported interviewing octogenarians (See Appendix B). A summary of findings from these studies is presented in the review of the literature in Chapter 2 of this proposal and in Appendix B. Only one study (Lindsay, Smith, Hanlon, & Wheatley, 2000) interviewed patients prior to and following cardiac surgery. In this study septuagenarians were interviewed but the sample did not include octogenarians. There were no studies found that utilized narrative inquiry to follow the recovery experience of older adults during the time period prior to and after cardiac surgery.

Gap in Knowledge

The current increase in surgery for older adults is recent and knowledge about the health care experience of older adults following cardiac surgery is still developing. To date, there are no reported studies examining the experiences of older adults from the preoperative phase through the first two months of recovery. It is known from prospective and retrospective studies that older adults face greater risks preoperatively and postoperatively, with compelling evidence that frailty and delirium impact patient outcomes. What is not known is the patient's perspective and experience over this time period. It is therefore imperative to further a more in-depth understanding of the peri operative experience and recovery of older adults undergoing cardiac surgery.

The phenomenon of the older adult experience, particularly over the trajectory from preoperative care through recovery deserves study and recognition of the unique physical, psychological and developmental needs of the older adult. Shifts in age distributions have resulted in a new cohort of patients who are now experiencing cardiac surgery in age groups

referred to as the middle old (75-84) and 'old-old' (85 years and older) (Neugarten, 1974).

Because the shift to performing surgery on older adults is recent, there is a gap in understanding of the experience of middle old and old old adults. This knowledge is essential to providing care that is responsive to anticipating health care outcomes of older adults who have had cardiac surgery. Nursing as a discipline and a profession is vested in developing knowledge and understanding of individual responses in health and in illness over time. This nursing research brings forward the disciplinary view of a particular patient centered experience to generate new knowledge that can serve to inform the care of older adults that have cardiac surgery.

Problem Statement

The phenomenon of older adults having cardiac surgery is a new one; but to date there is a lack of extant knowledge about the older adult experience. Little is known about older adults' firsthand accounts of the experience of cardiac surgery, the trajectory of their postoperative recovery and its relationship to outcomes such as physical and mental health and patient satisfaction. A clear understanding of the older adult experience prior to and throughout post operative recovery and follow up is needed to inform patient care including assessment, diagnosis, and treatment of symptoms as well as informing measures of quality of life and reducing symptom burden in older adults. By virtue of their age alone, older adults are at increased risk for poor surgical outcomes. Nursing is well positioned to anticipate the responses of older adults to surgical events, to support healing and recovery and attend to the physical and psychological responses of older adults.

This study utilized a qualitative approach to address the gap in knowledge needed to inform the health care of older adults that have cardiac surgery. Nursing science is informed by

qualitative research methods which rely on less structured, more open ended research approaches to garner holistic understanding of patient experience (Jones, 2007; Newman, Sime, & Corcoran-Perry, 1991). While quantitative descriptive studies that explore older adult recovery after surgery inform understanding, quantitative approaches do not convey a holistic unscripted picture of the experience of older adults.

Qualitative research describing patient experience of cardiac surgery to date has had limited exploration of the older adult experience. The disciplines of psychology, sociology, nursing and anthropology have used narrative analysis of patient stories as a means of promoting human understanding, however to date no studies were found that explored the narrative accounts of older adults and cardiac surgery. The older patient's story of cardiac surgery needs to be brought forward, recorded and explored and attended to by the systems of care that surround the patient. Nursing as a practice based discipline is well positioned to listen to and describe the patient story of cardiac surgery prior to and after cardiac surgery. Nursing as a discipline focuses on holistic knowing and caring for patients. This knowledge will inform nursing care of patients and foster understand of the meanings of health and illness to older adults as well as to their physical, psychosocial and spiritual needs (Jones, 2007; Newman, Smith, Pharris & Jones, 2008; Willis, Grace, & Roy, 2008). Nursing science informed by this inquiry of the older adult experience can generate new knowledge that will inform structure and processes of nursing care that support patients both prior to surgery and in their recovery after surgery.

Disciplinary Perspective of Nursing

The life processes of older adults include developmental and physiological changes of aging, and

call for expanded understanding of the concerns, needs and meanings of surgery and recovery to older patients throughout the process of recovery. Nursing science is grounded in the relationship with patients and is well positioned to hear participant narrative and bring participant narrative forward to inform health care.

This research study is guided by nursing's disciplinary perspective that holistic person-centered care is central to the practice of nursing (American Nurses Association, 2010; Newman et al., 2008; Willis et al., 2008). Nurses are integral members of the health care team, bringing a distinct disciplinary perspective that informs health care delivery across the developmental growth of human beings (Institute of Medicine, 2010). There is consensus in the discipline of nursing that this holistic, dyadic, relationship based care encompasses meta-paradigmatic concepts of nurse, patient, health and environment and caring (Jones, 2007; Newman et al., 1991; Watson, 1979, 1985, 2002).

In particular, the impetus for this research study is informed by the theoretical work of Watson (1985, 2002). Watson (2002) characterizes transpersonal caring as the enactment of a nurse's intentional relationship and caring consciousness with a patient. Nurses' transpersonal caring creates an environment of healing through interaction (Watson, 1985, 2002). Integral to the process of transpersonal care of patients, are the core principles of care which include "...[e]ngaging in genuine teaching-learning experience that attends to wholeness and meaning, [and] attempting to stay within the [patient's]...frame of reference" (Cara, 2003, p. 2). The guidelines for enacting transpersonal caring are referred to the "caritas principles" and include:

1. Practicing loving-kindness and equanimity within context of caring consciousness.

2. Being authentically present and enabling, and sustaining the deep belief system and subjective life world of self and one-being cared for.
3. Cultivating one's own spiritual practices and transpersonal self, going beyond ego self.
4. Developing and sustaining a helping-trusting, authentic caring relationship.
5. Being present to, and supportive of the expression of positive and negative feelings.
6. Creatively using self and all ways of knowing as part of the caring process; engaging in artistry of caring-healing practices.
7. Engaging in genuine teaching-learning experience that attends to wholeness and meaning, attempting to stay within other's frame of reference.
8. Creating healing environment at all levels, whereby wholeness, beauty, comfort, dignity, and peace are potentiated.
9. Assisting with basic needs, with an intentional caring consciousness, administering 'human care essentials,' which potentiate alignment of mind-body-spirit, wholeness in all aspects of care.
10. Opening and attending to mysterious dimensions of one's life-death; soul care for self and the one-being-cared for; "allowing and being open to miracles. (Cara, 2003, p.2.; Watson, 2008)

From the standpoint of Watson's (1985, 2002) work and the continued person centered disciplinary focus of nursing, it is important to explore the particular experiences of persons in health and illness and the meanings that are attached to those experiences. This research study utilizes narrative methodology to engender holistic understanding of persons; learning from personal narrative is essentially a way of knowing a whole person, as that person wishes to be

known, through the telling of their unique story. Exploration of the older adult story of cardiac surgery can inform care delivery and assist clinicians in anticipating and addressing older adult responses during the perioperative period. Data from this study can be used to develop understanding of the experiences of older adults by providing knowledge that can inform conceptual models, measures, interventions and models of care designed to facilitate the nursing care of older adults.

Significance of this Research

The need for understanding of the process of recovery for older adults who have cardiac surgery is heightened by the shortened length of hospital stay of adults after surgery, the multiple transitions of care during recovery and the lengthy process of healing from the surgery (Barnason, Zimmerman, Nieveen, Schulz, & Young, 2012). Initial assessment of the patient may take place in the outpatient setting, such as a physician's office; while in hospital, the patient may enter multiple systems of care such as medical services (Cardiology) and surgical services (Cardiothoracic Surgery). The length of in hospital postoperative stay has been shortened, from an average of 11.8 days in the hospital in 1978 to less than 6 days in 2005 (Pokras, 1982; De Frances et al., 2007). In the United States, currently hospitals are targeting a 5-day postoperative stay in hospital after cardiac surgery regardless of age, comorbid conditions or functional status. This shortened length of stay has shifted patterns of recovery after discharge and increased the use of post-acute care service (PAC) use (e.g. skilled nursing facilities, intermediate rehabilitation facilities and home health care) following hospitalization for cardiac surgery. After surgery, patient postoperative care is provided by the patient's cardiac surgeon, cardiologist and primary care provider. The constant denominator throughout these care systems is the patient

himself/herself and his/her experience of care as he/she interacts with different systems of care. Knowledge of what is meaningful and important to older adults can inform relationship based care of patients and also build recognition of the responses of older adults and suggesting strategies that will anticipate and prevent complications to patient progress. Both patient satisfaction and quality of care stand to be informed by knowledge generated from this study. Building understanding of the older adult experience of cardiac surgery has the potential to inform targeted interventions that will promote healing and recovery as well as reduce readmissions and decrease cost. The unscripted open ended nature of qualitative inquiry allows the participant to bring forth previously unrecognized aspects of the recovery experience as well as informing understanding of the known physical challenges of symptom burden during the acute recovery period.

The patient's story can uniquely inform relational care by providing an understanding of the patient experience in context over time. Narrative analysis is uniquely suited, as a qualitative method, to understand the temporal aspects of recovery in older adults (Holstein & Gubrium, 2012). Narrative is a method that specifically addresses chronology, which is essential to understanding recovery from open heart surgery. Hall & Powell (2011) define narrative as a "means of communication that reflects time-ordered events with a discernible plot and cast of characters and that imparts personal and cultural information from the teller to the audience in a coherent whole" (p. 2). Narrative analysis illuminates the complexity of illness and promotes understanding of the patient's perspective (Frank, 1998). The goal of narrative inquiry is to elicit the voice of the individual and to allow an unfolding of the individual's story. Participant stories are analyzed as crystallized wholes and then related to other stories to uncover what is shared or

different between stories. This narrative study brings to the fore the voice of the individual experience which will inform and enhance the understanding and care of older adults who have cardiac surgery. Because narrative is, in essence, the purposeful sharing of what an individual wishes to be known about himself or herself, narrative analysis of participant's stories can further understanding of participants and the process of their recovery.

Research Aim/Purpose

The purpose of this study was to describe the story of the older adult as they come to surgery (preoperative period) and the story during the transitional time of the acute recovery period (up to two months postoperative). It is hoped that knowledge gained from this research will be integrated with what is currently known about this patient population and improve the nursing care of this patient population.

Research Questions

To address the primary aim of this study, the following research question was asked:

- What stories do older adults tell of their experience of cardiac surgery from the preoperative period through the first 2 months postoperatively?

The narrative process allows each person's story to unfold. While each participant experience is unique and subjective, there exists a commonality of participant experiences over time that can lead to an understanding of participant shared experience. Therefore, a secondary aim of this study was:

- To describe the shared themes of older adult stories from cardiac surgery from the preoperative period through the first 2 months postoperatively.

Summary

There is a paucity of knowledge about the experience of older adults (>70 years of age) over the trajectory of recovery from cardiac surgery. Because the event of older adults having cardiac surgery is relatively new, little is known about the particular experience of older individuals as they await cardiac surgery, and the trajectory of acute recovery. This research study brings forward the unscripted narrative experience of older adults in order to directly inform understanding of the meanings and concerns of older adults who undergo cardiac surgery. Knowledge generated from this study can inform the assessment, management and health promotion of older adults who have cardiac surgery.

CHAPTER TWO

Review of the Literature

Background

This review of the literature will initially provide background to contextualize the understanding older adult experience undergoing cardiac surgery within the context of changes in the health care delivery in the United States. The background topics covered will include: current theoretical understanding of adult development and aging, the experience of living with coronary artery disease (CAD), angina and heart failure, and the evidence base for treatment options for older adults.

After providing background, a systematic review of the literature will follow which will focus on what is known about the experience of older adults recovering from cardiac surgery including:

- Awaiting cardiac surgery: the preoperative experience
- Postoperative experience including acute recovery while hospitalized and recovery post hospital discharge

Current theoretical understanding of adult development and aging. The definition of aging and what constitutes old age has evolved with the increasing life span of persons in developed countries. Neugarten (1974) originally coined the terms young old (ages 55-75) and old old (ages 75 and older) and distinguished the young-old by the life transition of retirement from employment. This conceptualization of age has evolved to refer to three groups within the older population in developed countries, the young old (65 to 74), middle old (75-84) and the old old (85 years and older) (Neugarten, 1974). These shifts in age distributions along with the

increase in adult life span have resulted in a new cohort of patients who undergo surgical interventions than in the past: older adults experiencing cardiac surgery are in age groups referred to as the middle old (75-84) and old-old (85 years and older).

With the trend of increased longevity there is an increasing recognition that the developmental needs of older adults continue to change with age, just as they change during the lifespan from birth to adulthood (Neugarten, 1979; Tabloski, 2010). Erikson's (1959) influential psychological theory of the development of identity postulated eight successive stages of development from infancy to end of life. According to Erikson (1959), middle adulthood was characterized by the crisis of generativity versus stagnation in which a person measures successful passage through this stage by their ability to make productive contributions to future generations. The final stage, navigated as an older adult (>65 years of age), is termed the crisis of integrity versus despair in which a person has conducted a life review, and through this introspection develops meaning and an integrated understanding of their life (Erikson, 1959). Later research suggested that the stage of generativity persists throughout the older adult period and that this continued generativity is an important part of successful aging (Erikson, Erikson, & Kivnick, 1986).

Biological theories on aging, taking a mechanistic approach, have postulated two major explanations of aging including a) changes in organism function at the cellular and tissue level due to influences of the environment and b) changes in genetic programming of cellular function (Jin, 2010). Recent psychological and sociological theories of aging have focused on dynamic concept in the aging process such as adaptation, compensation and plasticity and there is

recognition that the emotional well being of adults increases with age (Bengtson, Gans, Putney, & Silverstein, 2009; Carstensen & Lockenhoff, 2003).

Nursing grand theories and their core theoretical concepts (e.g. adaption, self care, transpersonal caring, health as expanding consciousness), inform nursing knowledge and practice and have strong applications for promoting health across the life span (Newman et al., 1991; Orem, Renpenning, & Taylor, 2003; Roy, 2008; Smith, 2011; Watson, 2002) The essential concern of grand nursing theory is focus on concepts that promote health through attention to patient responses and the meaning of health and illness to individuals and their families. One method of applying nursing grand theory to the care of older adults has been enacted by integrating borrowed findings from other disciplines on aging (e.g. biology, psychology, sociology), meshing this evidence with theoretical concepts of nursing care and applying these frameworks to the practice of nursing care (Rogers & Keller, 2009). In addition to grand nursing theory, a middle range theory in nursing describing successful aging was proposed by Flood (2005). Drawing on the Roy Adaptation Model, Flood (2005) postulated that the process of individual self appraisal in multiple dimensions (mind, body and spirit) is key to successful aging.

Across disciplines there has been a reconceptualization of what the nature of aging is, what constitutes being aged, as well as recognition of the importance of physical, intellectual and social engagement in the promoting the health of older adults (Hertzog, Kramer, Wilson and Lindenberger, 2008; World Health Organization Policy Framework on Active Aging, 2002). For older adults who have cardiac surgery, their experience is situated in a dynamic context of redefinition of what is considered “older” and what is considered health with increasing age.

The experience of living with cardiac symptoms and heart failure. Older adults who have cardiac surgery may have experienced living with cardiac symptoms over a period of time prior to their surgery. Persons with CAD and/or heart valve disease can experience a constellation of signs and symptoms caused by compromised heart function or heart failure. The prevalence of CAD and heart valve disease both increase with age. In fact, CAD is the single leading cause of heart failure due to ongoing ischemia to the tissues of the heart (Bui, Horwich, & Fonarow, 2011; Schocken, 2000). It is estimated that over 6 million Americans over the age of 18 have had or live with heart failure (Roger et al., 2012). Heart failure is the one of the leading cause of hospitalization in the United States, and a leading cause of repeated hospital admissions (Hall, Levant, & DeFrances, 2012).

Individuals awaiting heart surgery may experience from multiple symptoms associated with CAD including chest pain (or angina) as well as symptoms of heart failure (shortness of breath, fatigue) that are distressing and that decrease their health related quality of life (Pihl, Jacobsson, Fridlund, Strömberg, & Måtensson, 2005). In an integrative review (Welstand, Carson, & Rutherford, 2009) synthesized 18 qualitative studies that explored the lived experience of heart failure in adults. Welstand et al. (2009) described a process of patient identification of a “new self” as they come to face their diagnosis, the manifestations of heart failure, a changing perceptions of day to day life and changes in social roles. The authors (Welstand et al., 2009) conceptualize the patient utilizing this new self in order to “map a journey” and negotiating a complex path to adapting to their diagnosis and learning self care.

Synthesized evidence on help seeking behaviors of people with heart failure suggest that this process of “mapping the journey” described by Welstand et al. (2009) is a difficult one. In a

metasynthesis describing the help seeking processes of persons living with heart failure, Clark et al. (2012) described the stages of help seeking as: “ Living with an extreme unpredictable and confusing condition,...the challenge of recognizing the need for help, [and] ...selection of a source of help (p. 1581)” Clark et al. (2012) characterized the experience as follows:

Heart failure help-seeking was embedded in daily experiences of heart failure but ongoing symptoms were confusing, ambiguous and disruptive; little support was available from professionals to interpret the presence and significance of fluctuations in symptoms for help-seeking (p. 1582).

The experience of living with heart failure can be considered unpredictable and complex. This finding is corroborated by what is known about the trajectory of the illness of heart failure, which is characterized by declining function punctuated by exacerbations of the illness (Jaarsma et al., 2009). In addition to the uncertainty faced by the patient, the health of family caregivers is known to be effected by the stress of their family member’s chronic illness and hospitalization (Luttik, Blaauwbroek, Dijker, & Jaarsma., 2007; Iqbal, Francis, Reid, Murray & Denvir, 2010). In Macleod’s (2009) exploration of the experience of spousal caregivers of persons who had cardiac surgery; caregivers described challenges in coping, increased vigilance in facing the uncertainty of their partner’s illness, and finding information helpful in gaining control in the face of that uncertainty. The importance of the relational care role of the nurse engaging with the caregiver was found to enhance mutuality and transformative awareness of life of the caregiver (MacLeod, 2009). Should an individual require hospitalization, there is an increased mortality risk for the spouses/partners of those who have been hospitalized (Christakis & Allison, 2006).

Thus older adults and their families may have navigated a lengthy and unpredictable journey of chronic illness prior to having cardiac surgery.

Evidence guiding treatment options for older adults who have CAD. Within the medical literature there is considerable debate on what treatment options are best to treat coronary artery disease in older adults. While chronological age, in and of itself, is not a contraindication to cardiac surgery, age alone is an independent predictor of postoperative morbidity and mortality. In addition to age, the consideration of surgical risk for older adults includes not only risk associated with particular procedures (i.e. CABG versus valve surgery) but also consideration of patient comorbidities such as renal disease, diabetes and cerebrovascular disease (Wiedemann, Bernhard, Laufer, & Kocher, 2010). Complex scoring systems developed to guide the decision to recommend CABG versus PCI to patients (e.g. the SYNTAX II score) consider cardiac anatomy, as well as known predictors of risk including age, kidney function, female sex, and cardiac ejection fraction (Farooq et al., 2013). Exploring outcomes of septuagenarians, a large prospective case controlled study ($N = 9869$) found that patients more than 70 years of age had an a higher risk of increased ICU stay following cardiac surgery (OR 2.59, 95% CI 1.86 to 3.62) with associated significantly increased risk of postoperative complications and mortality (Rosenfeld, Smith, Woods, & Engel, 2006).

There are some indications suggesting that older adults who have CABG have outcomes that mirror the outcomes of PCI or medical treatment. McKellar et al. (2008) conducted a meta-analysis of 66 individual studies and compared short term (30 day survival) and long term outcomes (1, 3 and 5 year survival) for octogenarians who have had PCI to those who had CABG. McKellar et al. (2008) tentatively concluded that the outcomes were comparable

between treatment with CABG versus PCI but cautioned that, because of the variance of each group's pre-procedural risk, a synthesis of randomized controlled trials (RCT) would be needed to inform decision making. One RCT ($N = 244$) found there was no benefit to cardiac surgery versus medical therapy in adults with CAD and heart failure (defined as an ejection fraction less than 35%) (Velazquez et al., 2011).

Booth et al. (2008) conducted a randomized control trial ($N = 988$) in adults (mean age 62 years) and found a lowered mortality rate at 6 years post-CABG when compared to PCI (hazard ratio 1.66%, 95% confidence interval 1.08-2.55, $p < .022$). A suggested explanation for this finding was that CABG is a more effective treatment of diffuse coronary artery vessel disease; a pattern of disease which is characteristic of CAD in older adults, and in diabetics (Booth et al., 2008). Findings from Booth et al. (2008) support the current approach that CABG is a preferential therapy for cardiac revascularization of older adults with diffuse coronary artery disease.

Sheridan et al. (2010) retrospectively studied outcomes of PCI versus CABG in Medicare beneficiaries with multivessel coronary artery disease greater than eighty five years of in adults ($N = 10,141$) and concluded that at 3 years, CABG offered benefits over PCI based on endpoints of death, repeat revascularization, stroke, and acute myocardial infarction. This benefit was optimized when very elderly patients did not have significant comorbid chronic conditions, in particular, congestive heart failure, lung disease or peripheral vascular disease (Sheridan et al., 2010). More recently, a five year follow up study of an international randomized clinical trial ($N = 1800$) compared PCI and CABG in 3 vessel disease and left main coronary disease (Mohr et al., 2013). Based on the endpoint measures of major cardiac or cerebrovascular events, the

authors of this study recommended that CABG should remain the standard of care for patients with multivessel coronary artery disease (Mohr et al., 2013).

For patients who have valvular disease, surgical risk is higher than that for CABG alone. In general, surgical risk increases depending on the type of valve surgery and the number of procedures performed in surgery. In older adults existing comorbidities may preclude a patient from being considered for cardiac valve surgery. Currently, less invasive hybrid (involving both cardiology and cardiovascular surgery) procedures in valve replacement (specifically aortic valve surgery) are being evaluated for safety in patients who are not surgical candidates and are at high risk for death or stroke. The procedure referred to as transcatheter valve replacement (or TAVR) involves catheter deployment of an aortic valve over an existing diseased aortic valve via a femoral or apical approach.

An additional consideration in deciding a “best” avenue of treatment concerns the question of an individual’s frailty. Emerging understanding of the phenomena of patient frailty in the context of cardiac surgery is taking place in the setting of ambiguity of the concept of frailty in the research literature (Van Kan et al., 2008). There is general consensus that the meanings and consequences of frailty are multidimensional and complex and that while frailty can be associated with aging, chronological age alone does not infer frailty exists. Pel-Littel, Schuurmans, Emmelot-Vonk, and Verhaar (2009) note: “Although the symptoms of frailty are diverse, the most common symptoms are deterioration of activities of daily living...mobility, nutritional status, cognition and endurance “(p.390).

Lee, Buth, Martin, Yip, and Hirsch (2010) retrospectively studied cardiac surgery patients ($N = 3826$) at a single center and found frailty independently predicted in-hospital

mortality (OR 1.8, 95% CI 1.1-3.0), as well as predicting institutional discharge (OR 6.3, 95% CI 4.2-9.4). Gait speed assessment (Afilalo et al; 2010) has been shown to be a predictor of mortality and major morbidity in older patients undergoing cardiac surgery and has promise to be used as a screening tool for preoperative assessment of frailty.

Current consensus recognizes that “the core feature of frailty is increased vulnerability to stressors due to impairments in multiple, inter-related systems that lead to decline in homeostatic reserve and resiliency” (Bergman et al., 2007, p. 731-732). Because negative health outcomes such as institutionalization, and increased morbidity and mortality are associated with frailty in the elderly there has been a growth of multidisciplinary research work describing, measuring and intervening to prevent the poor health outcomes associated with the syndrome of frailty

Review of Older Adult Experience of Cardiac Surgery

This section provides a review of the older adult’s experience of cardiac surgery. Special attention will be given to findings that inform an understanding of older adult experience of cardiac surgery. The review was based on the methodology of Whittemore & Knafl (2005) and identified the topic of interest, literature search, data evaluation and analysis and presentation. Advances in surgical techniques and postoperative care can limit the usefulness of literature on patient postoperative experience prior to 2000. The current review focused on qualitative research articles that were written from 2000 to 2010. One study that was published prior to 2000 was included because it was often cited as an early study and resulted in a grounded theory of recovery in adults who have had CABG surgery (Keller, 1991). The search terms for the review included recovery, trajectory, cardiac surgery, cardiac surgical procedure, cardiovascular surgical procedure, postoperative, qualitative, lived experience, phenomenology, interpretive, naturalistic,

grounded theory, descriptive, narrative and ethnography. Multiple combinations of these terms were used and retrieved article references were used to identify relevant research (ancestry method).

Review topic and inclusion and exclusion criteria. The sampling procedure consisted of purposive sampling of peer reviewed qualitative research articles that were relevant to the experience of recovery after cardiac surgery. Articles were included that examined gender experience and cross-cultural experiences in order to broaden the perspective of the review and acknowledge the complexity and particularity of the recovery experience. Articles were excluded that did not inform the recovery experience with direct participant quotes, were not in English, non- research articles, duplicate publications, and articles that were not qualitative in approach. Based on recommendations of Sandelowski & Barroso (2003), in the conduct of this review no qualitative articles were excluded on the basis of methodological flaws; however, articles with problematic qualitative design were noted.

Categories and themes of research. The 22 studies that were reviewed on the topic of the older adult experience of cardiac surgery showed an overall temporal pattern with grouping of studies noted to fall in one of three categories of patient experience: preoperative (3), intensive care (2), and postoperative (17). (See Appendix B for a list of articles reviewed). Within the postoperative category, seven studies were found that focused on the experience of women after cardiac surgery. These were examined as a separate category in the review presented. The review presented international perspectives of the adult experience of cardiac surgery, including the United States and Canada, as well as Finland, Norway, Denmark, Scotland, Ireland, Australia and Taiwan. It is notable that only one study interviewed patients both preoperatively and

postoperatively (Lindsay et al., 2000). Of the 22 studies reviewed, six reported interviewing octogenarians (See Appendix B). Consistent with a naturalistic approach, the reviewed studies explored patient experiences, developed concepts and developed theory related to patient experience before and after surgery.

Preoperative experience. Outside of the United States, wait times for surgery can be prolonged, sometimes lasting over one year. This review found these experiences described in three studies. See Table 1 for summary findings of study thematic content.

Table 1

Thematic Findings: Preoperative Experience

Author/Year/Country	Study Topic	Thematic Findings
Fitzsimons, Parahoo, & Stringer (2000) Ireland	Waiting for *CABS	Major themes: uncertainty, anxiety and symptom distress Secondary themes: powerless, dissatisfaction with treatment, anger/frustration, physical incapacity, reduced self esteem, altered family and social relationships Inductive model proposed
Lindsay, Smith, Hanlon, & Wheatley (2000) Scotland	Perceptions of health prior to and after surgery	Preoperative themes: Dependency (functional, relational and pharmacologic) and a sense of “impending doom”, Expectations of freedom, independence, years to life and life to years, and hope, uncertainty and chance.
McCormick, Naimar, & Tate (2006) Canada	Waiting for *CABS	The psychologic effect of symptoms, psychologic effect of waiting and uncertainty as opportunity

*CABS = coronary artery bypass surgery

Fitzsimons, Parahoo, & Stringer (2000) studied the experience of “waiting for coronary artery bypass surgery” of 70 adults in Ireland (ages 39-72, mean age 59) and inductively developed a

model of awaiting surgery based on three emergent study themes (uncertainty, chest pain and anxiety) with anxiety proposed to be the central feature of the model. The authors' suggested that these findings show that patients need more information during the waiting periods prior to surgery and that nursing interventions were needed to address anxiety and pain management.

Lindsay et al. (2000) interviewed 214 adult patients (Ages 39.9-79.3, mean age 58.2) preoperatively and postoperatively (average time period after surgery 16 months) on their expectations of health both prior to and following OHS. Preoperative themes of anxiety ("impending doom") and uncertainty emerged from interview data as well as participant concerns about dependency (functional, relational and pharmacologic). Themes also emerged around patient expectations from surgery that included freedom from illness, and the expectation of additional years of life with improved quality of life. Findings from this study have implications for improved pre operative counseling of patients on expectation of benefits related to surgery.

In a mixed methods analysis, McCormick, Naimark, & Tate (2006) conducted telephone interviews of 42 adults in Ireland (mean age 64) who were awaiting CABG to explore the interrelationships of anxiety, symptom distress, uncertainty and functional status. Citing Mishel's (1990) theory of uncertainty, the authors suggested that participants in the study viewed uncertainty on a continuum i.e. uncertainty can be viewed as a positive experience that provides an opportunity or in a negative light as a danger or a threat. As in the study of Fitzsimons et al. (2000), McCormick et al. (2006) found that preoperative symptom distress was strongly associated with both uncertainty and anxiety. Implications of this study suggested that nurses needed to be cognizant of the patient experience during waiting periods and positioned to assess

patients at regular intervals. Findings also indicated more research was needed to define parameters related to clinically significant deterioration of patient status.

In summarizing these three studies, this review suggests that the experience of an individual anticipating cardiac surgery could be characterized by themes of uncertainty, anxiety, dependency, changing functional status, expectations and symptom distress. The preliminary conceptual model proposed by Fitzsimons et al. (2000) suggested that there is an interaction of physical and psychological symptoms that merits further study. These three studies emphasize the impact of symptoms on patient experience, including patient perceived functional ability. Implications for nursing care include the need for vigilant patient assessment, patient education, counseling and support, and interventions to address anxiety. It is unclear from these studies what structures or processes of care were in place to support patients preoperatively, but study results point to the need for more support and nurses being positioned in a role to deliver that care particularly during periods when patients experience symptom exacerbation. While some older adults were included in these investigations, the particular experience of older adults awaiting surgery was not explored.

Postoperative experience. During the postoperative period, this review identified two studies which explored the intensive care unit experience of adults who had had cardiac surgery and seventeen studies which examined adult experience in the time period ranging from one week to seven years after cardiac surgery. Within the postoperative category, seven studies were found that focused on the experience of women after cardiac surgery; these were examined as a separate category in this review.

Intensive care unit patient experience. Two studies were found that examined in detail the intensive care unit (ICU) experience, one of these studies also followed further postoperative experiences of study participants. See Table 2 for summary findings of study thematic content.

Table 2

Thematic Findings: Postcardiac Surgery ICU Experience

Author/Year/Country	Study Topic	Thematic Findings
Gardner, Elliott, Gill, Griffin, & Crawford (2005) Australia	Patient experiences after CABS**	Theme: Impressions of the *ICU
Schou & Egerod (2008) Denmark	Experience of mechanical ventilation	Themes: general phenomena (physical discomfort, impaired communication) psychological phenomena (loss of control, loneliness) existential phenomena (losing track of time and human interaction)

*ICU = intensive care unit ** CABS = coronary artery bypass surgery

Gardner, Elliott, Gill, Griffin, & Crawford (2005) interviewed 8 participants (ages 29-85, median 75) six months after surgery and uncovered six emergent themes, one of which was “Impressions of the ICU”. The authors reported that some patients had vivid memories, and reported positive experiences, such as the comfort of a nurse’s physical touch, as well as patient’s experiencing of fear and physical pain (Gardner et al., 2005). Based on these findings, the authors suggest that there is a need for improved communication of information to patients in the ICU as well as the need for individualized holistic patient assessment and a continuum of psychosocial support over the recovery period (Gardner et al., 2005).

A second qualitative descriptive study (Schou & Egerod, 2008) interviewed 10 adults (ages 35-84, mean age 65) about their experience during mechanical ventilation after open heart

surgery and found 3 themes: general, psychological, and existential (see Table 2). Patients characterized the breathing tube as uncomfortable, strange and unpleasant and felt frustrated, afraid and embarrassed by the inability to communicate (Schou & Egerod, 2008). Patients also reported the experience of feeling alone, the importance of family contact, feeling disoriented to time, and the feeling that, at times, “time stood still” (Schou & Egerod, 2008, p.175). The authors recommended “caregivers give timely, reliable, accurate and unambiguous information, respect the patients’ domain and individual time frames” (Schou & Egerod, 2008, p. 178). Nurses are well positioned to attend to the concerns of patients in the ICU setting; however, some patients describe nurses as distant or preoccupied with tasks (Schou & Egerod, 2008).

In summary, patients characterized the ICU experience as painful and uncomfortable and accompanied by feelings of fear, vulnerability, uncertainty, loneliness and disorientation. Family and nurses are described as key support persons to patients in the ICU. While older adults are at increased risk of a lengthened ICU stay in hospital (Rosenfeld et al., 2006), the particular experience of older adults was not explored.

Adult postoperative experience. (Table 3 summarizes adult postoperative thematic findings). Keller (1991) derived a grounded theory of “seeking normalcy” from interviews conducted with 9 adults (8 men, 1 woman) in the period after cardiac surgery. Keller (1991) conceived of the postoperative process as stages of 1) surviving (with subthemes of fear of dying, fear of mistakes and worthwhile suffering) 2) restoring (with subthemes of doing what’s right, valuing support) and 3) normalizing (being lucky, being fixed, and seeking other explanations). Keller (1991) describes the hallmark features of seeking normalcy as “...moving

forward, enduring a range of suffering and lifestyle changes in an effort to return to a familiar lifestyle” (p. 177).

Lindsay et al. (2000) interviewed 214 adult patients (Ages 39.9-79.3, mean age 58.2) post operatively on their expectations of health following cardiac surgery. Following data analysis, the authors reported four themes that included: the enormity of the experience, the importance of laypersons, and removal of a death sentence and freedom of choice. In this study, many patients verbalized feeling unprepared for how traumatizing the surgical experience was for them and how contacts they established in hospital with other patients as well as family encouragement provided them with the necessary social support they needed during their recovery (Lindsay et al., 2000). This study was unique among reviewed literature in that it explored patient experience both prior to and following surgery. The authors noted a disconnect between patient expectations of health benefits such as from cardiac surgery and what is generally known about postoperative outcomes such as and suggest that assessment and exploration of patient expectations is an important part of support during the preoperative period (Lindsay et al., 2000).

Raholm conducted two studies exploring spirituality in patients having cardiac surgery (Raholm, 2002; Raholm & Eriksson, 2001). The studies suffer from methodological flaws in that there is a lack of congruence of the study design (phenomenology) with the methods used (written surveys and focus groups). Raholm & Eriksson (2001) interviewed seven adults (4 men, 3 women) after cardiac surgery and conceptualized that patient suffering is part of the experience of OHS, likening spiritual dimensions of the experience to a ‘sacred journey’ that also encompasses themes of inner space, belief and serving in love. Raholm (2002) based his conceptualization of spirituality on the experiences of 564 adults who were surveyed post-CABG

and reported that spirituality involves action (finding meaning by gaining a new appreciation of life and health), relational (an inner strength through love and faith) and ontologic (becoming through suffering and desire) domains. Doering, McGuire, & Rourke (2002) interviewed 89 (ages 44-71) patients by phone at one week and 6 weeks postoperatively. The authors (Doering et al., 2002) reported four emergent themes from their investigation: not being cared for, physical needs unmet, information needs unmet, and being satisfied. While some patients expressed themes of satisfaction with care, others reported a sense of ‘not being cared for’ and depersonalization. The study authors concluded: “Patients want nurses and doctors to provide a smooth transition to home, recognize the patients as individuals, prepare them honestly for their experiences with specific information, and manage pain and sleep” (Doering et al., 2002, p. 333).

Theobald & McMurray (2004) interviewed 30 adults (average age 65 years) and their caregivers at four to five weeks and at one year after their cardiac surgery to explore the range of patient discharge concerns. Major themes reported were the patient experience of CABG as a huge personal shock, patient financial concerns as well as lifestyle and physical adjustments. Pain was still a significant problem for participants when interviewed one year after surgery (Theobald & McMurray, 2004). All participants interviewed suggested “strengthening discharge planning with more accurate information about what to expect during recovery, to help them anticipate fluctuations in health and wellbeing” (Theobald & McMurray, 2004, p. 483).

Gardner et al. (2005) interviewed 8 adults (ages 29-85, median 75) after cardiac surgery and found seven emergent themes: impressions of the ICU, comfort/discomfort, being sick/getting better, companionship/isolation, hope/hopelessness, acceptance/apprehension, and changes in life outlook. Six months after surgery patients reported they still struggled with both

physical and psychological challenges from their surgery and had not regained full function. Because of the complexity of the recovery process, the authors suggest there is a need for 1) improved sharing of information with patients across all time points of hospitalization as well as after discharge and 2) individualized postoperative follow-up and holistic assessment of patient psychosocial and physical needs (Gardner et al., 2005).

In a qualitative arm of a study focused on a nursing telehealth intervention 10 adults (39-67 years, mean 59.3 years) were interviewed (Hartford, 2005). The results of this study suggested that physical symptoms and affective concerns (particularly that of anxiety) predominated in the first week after discharge (Hartford, 2005). By day 7 patients began to shift their outlook to the future, (such as focusing on beginning to gradually increase activity levels) and by 7 weeks after discharge participants were beginning to resume normal activities (Hartford, 2005). In the face of physical symptoms such as pain, shortness of breath and wound healing, Hartford (2005) found that some patients expressed anxiety about how quickly they were discharged from the hospital and also verbalized they did not find the benefits to surgery that they had expected. Results from this study suggest patients need the support of health services given the abbreviated length of hospital stay and that a nursing telehealth intervention is able to provide health promotion information adjusted to individual patient needs over the recovery period (Hartford, 2005).

Tolmie, Lindsay, & Belcher (2006) interviewed 62 patients (ages 42-81, mean age 68) about their experience of well-being seven years after their heart surgery. Four major themes emerged from this analysis that included: recovery and rehabilitation, seven years on, maintaining a positive approach and health behavior change. Within these themes, the authors

(Tolmie et al., 2006) noted a wide range and complexity of responses to cardiac surgery and suggested that:

...there is a need to acknowledge the more variable longer-term effects of CABG operation in order to appropriately inform patients and their families of the challenges they may encounter throughout the extended rehabilitation period. There is also a need to emphasise [sic] to patients the chronic nature of cardiac disease and the benefits of maintaining a positive healthy lifestyle.... explanations should be unambiguous, condensed and tailored to the individual patient (p. 234).

Dunckley, Ellard, Quinn, & Barlow (2007) studied the perception and trajectory of recovery of 8 patients (average age 70 years) and 13 health care professionals eight months after surgery. Four themes were reported in this study: definition and timeline of recovery, preparation for surgery including information provision, attitude to surgery and confidence in staff, clinical factors and the inpatient experience (Dunckley et al., 2007). The authors noted "...both health professionals and patients define recovery as returning to normal functioning" (Dunckley et al., 2007, p. 205). Prior to surgery, patients recognized CABG as a major serious operation, tried to put trust in their caregivers, and recognized the importance of information about what they would experience. In hospital, patients reported lack of appetite and sleep disturbances as barriers to recovery (Dunckley et al., 2007). Another finding of this study was that the authors identified the need to enhance patient and carer understanding of the 'normal' trajectory of recovery for patients after cardiac surgery because patients reported not knowing if their post operative symptoms were expected or required medical attention (Dunckley et al., 2007)

Lapum, Angus, Peter & Watt-Watson (2010) utilized narrative methodology to describe patient (ages 59-85) stories of recovery from OHS; the authors explored the patient story structure in the postoperative period (at 4 days, 2 weeks and 4-6 weeks) and found themes of "surrender of agency to technology" and "regaining of self-sufficiency". During the acute

recovery period, patient stories suggested that they viewed surgery as a technological fix and they were conscious of the technological aspects of healthcare that surrounded them, feeling “plugged in” and surrendering themselves to machinery and technology that sustains life. The authors suggest that while patients were hospitalized they were passive because they felt that they had given over control during this period and patients viewed this as a necessary part of becoming well. Over time, and with the removal of equipment (catheters and wires), patients “resumed authorship” of their story and began to share stories of regaining self sufficiency. The authors suggest that as patients recover from surgery clinicians play a key role in supporting a patient’s sense of control and engaging patients in an active role in their recovery.

The experience of stress for patients (ages 39-76) following cardiac surgery and their caregivers was explored by Robley, Ballard, Holtzman, and Cooper (2010). The authors (Robley et al., 2010) interviewed 19 adults two weeks to one month after hospital discharge after CABG and described broad categories of: manifestations of stress, causes of stress and coping with stress. In their interviews, patients describe shock and disbelief when coming to terms with their diagnosis, fears of becoming a burden to their family or partner, stress related to not having received thorough information to guide them and stress related to their images of what it is like to have heart surgery (Robley et al., 2010). The postoperative causes of stress included pain and discomfort, while coping mechanisms included being informed, trusting caregivers, setting stress aside and getting through the surgery itself. The authors (Robley et al., 2010) point to the crucial link between coping with stress and communication with health care providers; providers need to offer honest informative information to patients and their caregivers. See Table 3 for summary findings of study thematic content.

Table 3

Thematic Findings: After Cardiac Surgery

Author/Year/Country	Study Topic	Thematic Findings
Keller (1991) United States	Experience of CABG surgery	Grounded theory: Seeking normalcy (surviving, restoring, being fixed)
Lindsay, Smith, Hanlon, & Wheatley (2000) Scotland	Perceptions of health prior to and one year after cardiac surgery	Themes: The enormity of the experience, the importance of laypersons, expectations of removal of a death sentence and freedom of choice.
Raholm & Eriksson (2001) Finland	Exploring the dialectic of suffering and desire in spirituality	Themes: Sacred journey in spirituality of explicit suffering concealed unrevealed suffering, the inner space, belief, serving in love.
Raholm (2002) Finland	Conceptualizing spirituality in open heart surgery patients	Themes: new appreciation of life and health, inner strength through faith and love, inner strength through suffering and desire.
Doering, McGuire & Rourke (2002) United States	What patients want caregivers to know about recovery from CABG	Four emergent themes with twelve subthemes: Not being cared for (depersonalized, expectations not met, not being listened to, staff behavior unprofessional) physical needs unmet (sleep, pain, complications, physical environment) information needs unmet (needing more/different information), and being satisfied (a positive experience, getting information).
Gardner, Elliott, Gill, Griffin, & Crawford (2005) Australia	Patient experiences after CABG	Seven themes impressions of ICU, comfort/discomfort, being sick/getting better, companionship/isolation, hope/hopelessness, acceptance/apprehension, life changes

Author/Year/Country	Study Topic	Thematic Findings
Hartford (2005) Canada	Telehealth intervention after cardiac surgery with qualitative arm of study	Three major themes with subthemes: physical (energy, wound healing, pain & discomfort, shortness of breath, fluid retention, sleep disturbance, medications, gastrointestinal) affective (anxiety re discharge, fear of angina, depression, worry about partner burden) and lifestyle changes (diet changes, smoking, cholesterol medication, family history)
Tolmie, Lindsay, & Belcher (2006) Scotland	Experience of well-being after CABG	Four major themes identified: 'Recovery and Rehabilitation', 'Seven Years On', 'Maintaining a Positive Approach' and 'Health Behavior Change'.
Dunckley, Ellard, Quinn, & Barlow (2007) United Kingdom	Patient and clinicians' view of recovery after CABG	Themes: definition and timeline of recovery, preparation for surgery including information provision, attitude to surgery and confidence in staff, clinical factors and the inpatient experience
Lapum, Angus, Peter,& Watt-Watson (2010) Canada	Discharge experiences and transitions, the impact of technology	Themes: authorial voice of technology (technological fix, plugged in), re-anchoring of authorial voice (resuming authorship with technological consciousness, self-sufficiency)
Robley, Ballard, Holtzman, & Cooper (2010) United States	Experience of stress after CABG	Themes: manifestations of stress (feeling overwhelmed: shock and disbelief, worry about family, becoming a burden) causes of stress (physical: having discomfort, lack of information: not knowing, interruption of life, image of heart surgery) coping mechanisms for stress (getting honest answers, being in their hands, setting it aside, getting through it)

In summary, many adult patients experience cardiac surgery as a life changing event that was overwhelming and difficult to prepare for properly. The patient postoperative experience can be characterized as prolonged and multifaceted which can encompass complex physical,

psychological, social and spiritual processes. The studies reviewed noted a broad array of reported symptoms for patients both prior to and following surgery. Processes that are essential to the recovery and well being of patients after cardiac surgery include attention to the physical needs and psychological supports to patients, and recognition of the social and relational needs of patients as they interface with family, caregivers and health providers. Recovery as perceived by the patient involves fundamental changes in function over time and changes in symptoms experienced and can be promoted by information, education, and physical and psychosocial support. While some of these studies included patients that were 70 years of age and older, none of studies focused primarily on the experience of older adults who have had cardiac surgery.

Women's experience after cardiac surgery. Seven studies in this review explored women's experience of recovery from open heart surgery. (See Table 4 for a summary of findings on women's recovery). Plach & Stevens (2001) examined the postoperative recovery experience of 13 women (ages 51-66, mean of 59) two years after either coronary angioplasty or cardiac surgery. The authors found an overarching theme of paradox, which encompasses contradictory (both negative and positive) experiences of the women as they "...tried to regain footing in their daily lives" (Plach & Stevens, 2001, p. 207). These experiences centered around five themes: expectations about heart disease, perceptions of well-being, lifestyle changes since diagnosis, impact on relationships and roles, and feelings about heart disease (Plach & Stevens, 2001). Because women function in different roles (e.g. wife, daughter, mother, grandmother) they may or may not be able to resume these some aspects of these roles after surgery. The authors suggest that there is a need for improved clinician understanding of the social context of

women who have had heart surgery and in providing anticipatory guidance to women after cardiac surgery (Plach & Stevens, 2001)

Allen and Wellard (2001) utilized a phenomenological approach to study the experience of four older women (69-79) undergoing sternotomy and six themes emerged from their investigation: being invaded and scarred, the younger generation and body scarring, being prepared, knowing, need for conversation, and being in hospital. In exploring patient body image concerns about the appearance of scarring after sternotomy; participants expressed they were shocked when they saw their incisions (Allen & Wellard, 2001). The theme of knowing was related to the women's need to be more fully informed prior to surgery (Allen & Wellard, 2001). In addition, women participants voiced concerns about the need for more open and honest communication with family as well as with providers prior to surgery, in order to facilitate planning (e.g. wills). One woman in this study who had stayed in a mixed gender hospital room felt a loss of dignity from the experience. An implication of this study was that it suggests a key need is preparation of women for surgery with clear information about the surgical approach, location of incisions, and what normal recovery from the sternotomy will entails (Allen & Wellard, 2001).

Using an ethnographic approach, Angus (2001) described the "social and material predicaments" of three women (ages 75, 50, 53) who have had heart surgery. Based on the experiences of these three women after cardiac surgery, the author suggested that women's social role at home impacts their postoperative caregiver support, financial support and assistance in the home (Angus, 2001). In particular, "Eva", an older woman in this study, reflected on her experience and challenges of caring for her husband while, at the same time, she was recovering

from cardiac surgery. Findings from this study suggest the meaning of being at home changes for women after heart surgery, including the sense of being ‘at home’ in their bodies (Angus, 2001).

Robinson (2002) described the experience of twelve older women (Ages 57-77, mean 69 years of age) living alone during periods from 6 months to 2 years after open heart surgery. This study was unique in that the sample was comprised of older women, who self-identified as having recovered from open heart surgery. Robinson (2002) characterized the thematic findings of their recovery experience as survival relief, going on, living in a contracted world and regained independence; “[lost-recovery meant restoring the identity the women had known before surgery together with actualizing the value of self-reliance (p.124). It was noted that even though these women functioned with a heightened sense of perceived vulnerability “...there was a remarkable lack of interest in modifying lifestyle to reduce cardiac risks” (Robinson, 2002, p. 124).

Three studies reviewed focused on the experience of pain of women following cardiac surgery. Findings included that pain is disruptive to sleep, performing housework and general activity in the first two weeks after cardiac surgery (Leegaard, Rustøen, & Fagermoen, 2010) and that women generally did not remember information about pain management and required individualized counseling to self-manage pain (Leegaard, Nåden, & Fagermoen, 2008). In addition to postoperative incisional pain, women described unexpected back, neck and shoulder pain (Leegaard & Fagermoen, 2008). See Table 4 for summary findings of study thematic content.

Table 4

Thematic Findings: Women's Experience after Cardiac Surgery

Author/Year/Country	Study Topic	Thematic Findings
Plach & Stevens (2001) United States	Midlife women's experiences recovering from cardiac surgery	Themes: expectations about heart disease, perceptions of well-being, lifestyle changes since diagnosis, impact on relationships and roles, and feelings about heart disease
Allen and Wellard (2001) Australia	Older women's experiences with sternotomy	Themes: being invaded and scarred, the younger generation and body scarring, being prepared, knowing, need for conversation, being in hospital.
Angus (2001) Canada	Experiences of women after OHS at home	Theme: Women's social role impacts their care support at home, financial support and assistance once home.
Robinson (2002) United States	Older women living alone after cardiac surgery	Themes: survival relief, experienced as awe and gratitude; going on, described as an obligation; living within a contracted world, structured by a sense of vulnerability; and regained independence, characterized by affirmation of self-worth and personal freedom
Leegaard & Fagermoen (2008) Norway	Experience of pain for women at home after surgery	Themes: Descriptions of pain after surgery :expected versus unexpected pain, desire to avoid taking pain medications
Leegaard, Nadel & Fagermoen (2008) Norway	Postoperative pain and self-management: women's experiences after cardiac surgery	Theme: Need for individualized information on pain management after discharge
Leegaard, Rustoen, & Fagermoen (2010) Norway	Interference of pain on daily life after early discharge from cardiac surgery	Themes: pain as disruptive (sleep, housework, general activity)

Women may have several unique indicators of their recovery process which center on body image, symptom presentation and adjustment to changes in their social roles, which impact their recovery. In addition, older women who considered themselves “recovered” from surgery also recognized functional limitations in the time period of 6 months to 2 years postoperatively (Robinson, 2002). Two studies reported interviewing older women who were octogenarians. A study which interviewed a large percentage of middle old to old old women participants found significant physical and psychological challenges to functioning that persisted six months after surgery (Robinson, 2002).

Review Summary

The findings from this review suggest that for adults there are major physical and psychological challenges that impact function and that recovery from cardiac surgery is a prolonged process. There is little known about the experience of older adults, particularly those 80 years of age and older, who have had heart surgery. There is a need for particular, contextual, temporal understanding of the trajectory of preoperative through postoperative experience in older adults.

This study proposes the research question: “What is the older individual’s story of the experience of cardiac surgery?” Asking this question may lead to understanding the patient’s story, how is it constructed and how it evolves. It may inform understanding of facilitators and challenges to an older individual’s pre op preparation through 3 months recovery, and when and how older adults define their recovery. It also could inform how an older adult would construct a tailored support for this trajectory of recovery for themselves. This study may also inform the question of whether an older adult could share this story with his/her care providers along the

way and how this would inform and promote care over the trajectory. A first step in a program of research concerned with these issues is to explore unscripted older adult experience. Hence, there is a need for serial narrative interviews and a construction of the story of older adults who have had heart surgery.

Chapter 3

Methods

Research Aim/Purpose

The purpose of this study was to describe the story of the older adult experience of cardiac surgery beginning with the preoperative period and during the transitional time of the acute recovery period (up to 2 months postoperatively). To address the primary purpose of this study, the following research question was asked:

What stories do older adults tell of their experience of cardiac surgery from the preoperative period through the first 2 months postoperatively?

The primary aim of this research study was to describe the stories of older adults who experience cardiac surgery. A secondary aim of this study was to describe the shared themes of older adult stories of cardiac surgery from the preoperative period through the first two months postoperatively. Based on the methodology of Bold (2012), this study utilized an analytic process consisting of both structural (re-storying of narrative content) and thematic analysis of participant narrative.

Rationale for Narrative Research

Cardiac surgery is a procedure that is performed frequently on older adults but the experience of older adults who have cardiac surgery is a poorly understood phenomenon in terms of the stories that individuals narrate about this type of event within the context of their unfolding lives after cardiac surgery. Qualitative research methods in general are useful to get a fuller sense of life experiences and processes than can be captured by quantitative research designs and measures that propose salient concepts at the outset of the research. Narrative

inquiry research is used to explore in depth the life stories and events and experiences of human beings as their lives unfold and, subsequently, inform the iterative process of developing a conceptual and theoretical understanding of the older adult experience of cardiac surgery. While there are studies that have sought to characterize the adult experience of cardiac surgery qualitatively, they fail to capture a holistic perspective of the life experience of the older adult patient from their unique perspectives during the preoperative period up to two months after cardiac surgery. No studies reviewed focused on understanding the experience of older adults (70 years and older) during the preoperative period and postoperative period (See Appendix B).

The open-ended exploratory approach of qualitative research works to free the research participant to drive the data generation process in partnership with the researcher through dialogue and narrative methods do not impose a priori concept identification nor conceptually structured constraints, as in quantitative research approaches. Qualitative research methodologies, such as narrative analysis, are important because they elicit an individual's subjective experience and help promote understanding of personal meanings and responses to an experience. Nursing is concerned with the meanings and responses of individuals in health and illness and seeks to understand these experiences in order to promote wellbeing and provide care. Narrative inquiry can inform person centered, relationship based nursing care by extending nursing knowledge of how patients construct meaning of interrelated experiences and how patients make sense of these experiences. In this way, a qualitative research approach, utilizing narrative methodology, can directly generate and refine nursing knowledge. This knowledge can inform nursing practice and nursing's understanding of the meanings and responses of older adult experience of cardiac surgery.

Background on methodology of narrative analysis. The goal of narrative inquiry is to elicit the voice of the individual and to allow an unfolding of the individual's story. The focus of narrative analysis is the story itself and the purpose of narrative analysis is "...to see how respondents in interviews impose order on the flow of experience to make sense of events and actions in their lives" (Riessman, 2002, p. 218). Participant stories are analyzed as crystallized wholes and then related to other stories to uncover what is shared or different between stories. The personal narrative of the story is a reflection of the individual's constructions, meaning and identity; Riessman (1993) explicates these ideas saying:

Human agency and imagination determine what gets included and excluded in narrativization, how events are plotted, and what they are supposed to mean. Individuals construct past events and actions in personal narratives to claim identities and construct lives (p.22).

Ricouer (1973) made seminal contributions to the philosophical basis of narrative inquiry. Ricouer (1973) viewed discourse (or linguistic usage) as worthy of analysis because it occurred at a particular point in time and was the product of a particular person thus, he contended, that an individual's identity (narrative self), and personal meanings are conveyed by and revealed through that discourse (Ricoeur, 1973).

The foundational methods of narrative inquiry are interviewing and observation; this method of inquiry is used by multiple research traditions including anthropology, psychology, sociology, and nursing (Frank, 1998; Polkinghorne, 1996; Marshall & Rossman, 2006). Methodological traditions of narrative analysis constitute a broad spectrum of approaches; they include structuralist, thematic, dialogic, and visual approaches to analysis (Reissman, 1993).

Structuralist approaches use specified formats to analyze narrative; they focus on how language is spoken to uncover meaning in narrative. For example, Labov and Waletzky's (1967) seminal structural approach to analysis is based on the plot elements of an individual's story that includes: an abstract, an orientation, complicating action, evaluation, resolution and coda. Another structural approach analyzes oral discourse for meaning based on the linguistic elements of oral language including patterns and rhythms of speech (Gee, 1991). Dialogic analysis focuses on who is in the narrative and the performances that are key to the story. Images from artwork and photos, and other media, are used to inform a visual approach to narrative analysis.

Thematic analysis focuses on the transcribed content of participant interviews focusing on what is spoken; methods similar to open coding in grounded theory research or content analysis of participant narrative are used to develop themes that reflect participant experience (Bold, 2012). Thematic analysis methods are distinguished from qualitative descriptive content analysis because participant's stories are analyzed in their entirety via restorying (i.e. ordering of narrative events over time) prior to analysis of content (Bold, 2012; Holloway and Freshwater, 2007). In this way, the narrative structure of the participant story over time remains intact and is not fragmented when text is coded and synthesized thematically.

Procedures

Study design and analytic process. Based on the methodology of Bold (2012), this study utilized an analytic process consisting of both structural (re-storying of narrative content) and thematic analysis of participant narrative. The focus of this study was to elicit and describe the story of the older adult experience of cardiac surgery beginning with the preoperative period and during the transitional time of the acute recovery period (up to 2 months postoperatively).

Because there are varying analytic processes available that constitute different methodologic approaches to narrative analysis, Bold (2012) recommends tailoring the analytic method to the research question that is posed. This qualitative study followed the recommendation of Bold (2012) using an analytic process based on the tenets of narrative methodology that would best serve to answer the primary research question and aims of this study. The primary aim of this research study was to describe the stories of older adults who experience cardiac surgery. A secondary aim of this study was to describe the shared themes of older adult stories of recovery from cardiac surgery.

Following the narrative inquiry approach described by Bold (2012), this research included: 1) re-storying of participant data, 2) content analysis of individual participant narratives and 3) synthesis of shared thematic content across participant stories. As thematic content of each individual story was generated, common shared narrative themes across participant stories were identified and summarized as broad narrative themes of the stories older adult participants told about their experiences during the preoperative period and during the first two months after cardiac surgery.

Because there is little known about older adult stories of the experience of cardiac surgery, utilizing a purely structuralist approach to data analysis (e.g. coding participant narrative into an abstract, an orientation, complicating action, evaluation, resolution and coda) was not chosen because of the potential to oversimplify, constrain or reduce participant stories. Thematic analysis of narrative content was chosen for this study in order to allow a less structured, more open ended approach to the emergence of thematic content.

Steps in the narrative analytic process. The first step involved collecting participant's stories through interviews. This study consisted of thirty one interviews with thirteen older adults who had open heart surgery; the first interview took place during the preoperative period while the participant was hospitalized, the post operative interviews were conducted at 1) four to six weeks and 2) eight to 10 weeks after surgery. The rationale for choosing those interview time frames was as follows:

1. The preoperative interview situated the participant's narrative prior to the experience of cardiac surgery and allowed for contextualization of the person and their experiences as he or she prepared for cardiac surgery. This interview helped to construct an understanding of the participant experience prior to surgery as well as to allow participant narrative to identify what was important to the participant during the time period awaiting cardiac surgery.
2. Because evidence from quality of life studies suggested that a particularly difficult time in the recovery period is at one month after surgery (See Appendix A), the second interview was set at one month after cardiac surgery in order to allow participant narrative to characterize the acute recovery experience. The rationale for choosing this one month time frame was that qualitative exploration of patient narrative at this point could inform detailed understanding of the difficulties participants faced at this juncture in their postoperative recovery.
3. The rationale for conducting the third interview at two months after cardiac surgery was to elicit narrative on the time frame that participants would be entering or contemplating enrolling in a cardiac rehabilitation program.

The inclusion of three interviews was to enrich narrative content of each participant. Hall et al. (2009) suggest that “Multiple interviews provide depth, comparisons of story versions, a prospective view over the interview period, and credibility” (p. 377). In addition, at each follow up interview (one month and two months postoperatively), there was an opportunity to perform “member checking” with the study participant e.g. to review narrative content that had been shared by the participant by re-reading of key points in narrative with the author of the story.

The next sections of this chapter will describe the population of interest in this study, the recruitment plan, inclusion and exclusion criteria as well as the steps followed in the protections of human subjects.

Target population. The target population for this study was older adults (persons greater than or equal to 70 years of age) who planned to have cardiac surgery. The rationale for targeting adults over seventy years of age was based on evidence that suggested age greater than 70 years is an independent risk factor for surgical morbidity and mortality (see Chapter 2). Because the literature review pointed to a particular lack of knowledge on the cardiac surgery experience of octogenarians, purposive sampling (the deliberative selection of participants for the purpose of informing the research questions) was used to ensure that adults eighty years of age and older were represented in the sample. All of the study participants were persons who were scheduled to have cardiac surgery including coronary bypass surgery and/or heart valve surgery (both replacement and repair), with or without bypass support for the procedure. Recruitment for this study focused on enrolling hospitalized persons who met study inclusion and exclusion criteria and who were inpatients awaiting cardiac surgery in a 500 bed teaching hospital located in

Northern New England. The demographics of the population of persons in the locale of the study are illustrated in Table 5.

Table 5

Demographics of Proposed Study Site

Census data 2010	Percent of population
White persons	96.9
Black persons	2.6
American Indian/Alaskan native	0.5
Asian persons	3.1
Hispanic persons	1.5
Native Hawaiian/Pacific Islander	0.1
Persons reporting two or more races	1.0

Inclusion criteria and exclusion criteria. The inclusion criteria for participation in this study were as follows:

- Hospitalized adults ≥ 70 years of age
- Adults having cardiac surgery including coronary bypass surgery and/or heart valve surgery (both replacement and repair), with or without bypass support for the procedure.
- Adults willing to consent to participate in this study

The exclusion criteria for participation in this study were as follows:

- Adults not conversant in English

- Adults with a diagnosis of dementia or with a diagnosis of cognitive impairment
- Adults who were hemodynamically unstable or not interactive due to the severity of their illness.

Participant recruitment and retention. Institutional Review Board approval for the study was obtained from the both the medical center site of participant recruitment and at Boston College prior to participant recruitment. A multifaceted process for participant recruitment was implemented. As part of the process for hospital IRB approval, physician directors of cardiac surgical services and cardiology were apprised of the research study and signed off their approval of the research plan. As part of the process for IRB approval, each nursing director of the four potential clinical recruitment sites was contacted, informed about the study and gave approval of unit participation in the project. The principal investigator (PI), Kathleen Keane, was solely responsible for participant recruitment. The clinical units were given a binder that was placed on the unit to serve as a resource to staff and which contained contact information for the principal investigator (PI), Kathleen Keane, if staff had questions about the study. In addition, the PI provided in-service education about the study to interested clinical staff at the participating recruiting sites.

A release to perform informational reviews on potential participants who met inclusion criteria (called a review preparatory to research) was approved by the IRB. Prospective participants were identified by the PI by reviewing the scheduled cardiac surgery cases for each week. The PI identified potential study participants by chart review for inclusion and exclusion criteria and then participants were directly approached by the PI for invitation to participate in this study. While in-hospital awaiting surgery, patients had up to the time they had surgery to

consider if they wished to participate in this study. Patients had the choice to not participate in the study, or once enrolled, they could withdraw from the study at any time without compromised care. Prospective study participants awaiting cardiac surgery included patients who were awaiting functional assessments, the effects of anti-platelet therapies to wear off prior to having cardiac surgery, diagnostic screenings or admitted for glucose control or those who had stabilized angina and were awaiting surgery.

After obtaining a written informed consent, the PI set up the first interview (preoperative) with the participant at a date and time convenient for the participant. A quiet private room on the hospital floor was secured as a meeting place for the preoperative interview setting in case if this was preferred in lieu of meeting in the participant's hospital room. During the first interview contact and demographic information was collected, followed by the preoperative interview using a semi structured interview guide (See Appendix C). At completion of each interview, the following interview was scheduled for approximately four weeks after the participant's surgery. Permission was obtained to contact the participant or the participant caregiver with a reminder phone call prior to the next interview. Follow up interview times were flexible and could be rescheduled at a time that was convenient for the participant's daily schedule.

Setting. The approach to choosing a setting for the interviews was guided by concerns around participant burden, sensitivity to intrusiveness, and recognition that recovery from surgery is a prolonged process that may impact the mobility and energy level of participants. The first interview with hospitalized participants who consented to participate in the study was a face-to-face interview. The PI worked with each participant to plan a convenient time for the hospital interview. In addition, the PI worked with the participant and their bedside nurse to

avoid disrupting the plan of care in the hospital. The initial interviews in hospital lasted approximately 15-40 minutes. The lengths of the interviews were tailored to the participant tolerance and interview time was shortened to respond to participant fatigue or expressed desire to terminate the interview. If feasible, a private interview room was reserved for the face-to-face preoperative interviews with study participants on their hospital unit. Each interview began with an introduction period of 10-15 minutes during which time the PI gathered demographic data and participant contact information (see Appendix D Demographic Questionnaire). The participant's story was then elicited, see Preoperative Interview Guide (Appendix C) and Postoperative Interview Guide and Phone Script (Appendix E). Lastly, there was a closing period to summarize the content of the first interview with the participant and to encourage participant feedback on the interview process. The second and third interviews were conducted following the same interview structure and took place with participants by phone interviews. (See Appendix E Postoperative Interview Guide/Script).

Sampling and attrition. Sampling methodology was purposeful; "...individuals and sites for study [were selected] because they [could]... purposefully inform an understanding of the research problem and central phenomenon in the study" (Creswell, 2007, p. 125). Each participant narrative was analyzed individually and enrollment of participants continued until thematic saturation of broad thematic content across participants was obtained. Based on findings on thematic saturation on a similar study of narrative content (Lapum et al., 2010), it was projected that a sample size of 10 to 15 participants would be needed to achieve thematic saturation. It was understood by the PI that sampling would continue until thematic saturation occurred. Each story was analyzed individually for thematic content and then themes were

considered across all stories. The endpoint of the data collection process relied on saturation of broad thematic content across participant narrative.

Given that the study consisted of three interviews that occurred over approximately eight weeks time, it was anticipated that not all participants would complete the entire study. Data from participants that did not complete the study due to attrition at different time points were still used in analysis, but the data set was noted as incomplete. In order to mitigate study attrition, a remuneration of participants in the form of a gift card worth twenty five dollars was given to study participants at the completion of the first interview (i.e. face to face interview) or mailed to the participant at the completion of each follow up interview (i.e. phone interview).

Protection of human participants. Prior to data collection, the PI applied for and received Institutional Review Board (IRB) approval from both the IRB affiliated with the hospital recruitment site and Boston College. The process of informed consent was provided to all study participants by the principal investigator (PI), Kathleen Keane. The PI provided complete information to participants, including risks of participation in the study and also consented all participants prior to their first interview. Participants were free to choose to participate, not to participate, or wait and reconsider participation at the first interview. No data was collected on participants without their informed consent. Participants were specifically informed that they could withdraw at any time from the study and that withdrawal would in no way affect the delivery of their health care. All electronic data such as transcribed interviews was kept on a password protected computer that was protected with up to date anti viral and anti-spyware software.

Risks and benefits to participants. The study posed minimal risk to participants. The major risk to participants was the risk of loss of participant confidentiality. Confidentiality of participants was assured by storing digital audiotapes of each interview and participant demographic data in a password protected computer. Pseudonyms were assigned to all participants in interview transcripts to protect identification by name. All identifying data was deleted from all transcripts. The codebook linking participant identifiers to transcribed interviews was kept apart from all de-identified study data and was secured electronically via password protection. The laptop computer that was used to store data was kept in a locked secure location when not with the PI and had up to date anti viral (McAfee 8.7i) and anti spyware (Malwarebytes Anti-Malware) software installed.

A potential risk of participation in this study was that a patient could become emotional upset when recounting a cardiac surgical experience that was part of their narrative. In hospital if a patient became emotionally distressed, the PI had a plan to contact the patient's bedside nurse and attending physician and notify them of the patient's response and need for additional support. When conducting phone interviews after surgery, if a patient experienced emotional distress, the PI had a plan to assist the patient in contacting his or her primary health care provider.

When the discussion of experiences of surgery resulted in questions about their medical condition, the PI redirected participant health questions to the health care provider. If multiple questions arose, the PI assisted the participant in making a list of questions for their health care provider. In one instance during a preoperative interview I assisted in helping the participant to

write down his questions for his provider, the list was shared with the participant's bedside RN who brought forward these questions to the participant's medical provider.

Recognizing that the interview may place an added burden on participants' illness experiences, concerted efforts were made to minimize inconveniences including: a) the scheduling of interviews at a place and time that was convenient for the participant b) following up with a phone interview at the second and third interviews in lieu of face to face interviews which would involve traveling c) offering to close the interview and rescheduling or shortening interview length if the participant complained of or displayed fatigue during the interview process. There were no known benefits to the participant for participation in this study

Data collection. In narrative inquiry, the process of interviewing and collecting data is a reflexive one; there is recognition that data is co constructed by the participant and researcher in that the narrative collected is the product of a unique point in time and the interaction between the researcher and participant (Riessman, 2008, Mishler, 1986). Accordingly, I attended to creating an atmosphere for the interview through focused and attentive listening, providing an environment that was comfortable for the participant, and reflecting participant discourse to evoke detailed descriptions by the participants (Riessman, 2008).

Each participant interview was digitally audio-recorded and the intended topical area was participant stories of their experience of cardiac surgery. Each participant story consisted of three interviews, a preoperative interview, and two postoperative interviews (at one month, and at three months after surgery). Observational field notes were made during (if unobtrusive) and after the interview to record impressions of the interview. Observational field notes consisted of detailed recounting of empiric contextual data such as the setting of the interview, situational and

interactional contexts such as the presence of family members or a recent visit/phone call from family or friends, the time of day and environmental influences (noise, weather) that informed analysis of the interview.

Based on the method of Bold (2012), reflective notes after each interview were kept and these involved my conscious attempt to sustain reflective thinking and to understand my assumptions, biases, and emotional responses to working with the participant. Each interview began by explicitly recognizing the participant as the expert in the in interview process. The time allotment of each interview was approximately thirty minutes, with extra time allocated if the participant wished further discussion time. Considerable attention and sensitivity was given to limiting interview periods due to concerns of contributing to participant fatigue and burden. No interviews lasted more than 45 minutes.

Observational and reflective field notes were generated following each interview. Thematic, theoretical and methodologic memoing were conducted throughout the analysis of the study. Data collection forms consisted of an interview guide (See Appendix C for a sample interview guide for the preoperative interview), and template of form for participant demographic data (age, sex, planned cardiac surgery procedure, health concerns).

Data Analysis

Assumptions and potential bias. The use of qualitative inquiry as a research method requires the research to explicitly recognize and state assumptions of the methodological approach as well as potential biases of the researcher. The discussion to follow describes pertinent assumptions of narrative methodology as well as potential biases of the researcher. The assumptions inherent in utilizing narrative methodology include the following:

- In the conduct of conducting narrative research, the researcher is involved in interacting and constructing data with the participant while listening to and transcribing participant stories of their experiences (Bold, 2012; Richards & Morse, 2007). In utilizing narrative methodology, and gathering the participant story, the author of the story is the participant and the role of the researcher is to bring forward the authorial voice of the participant.
- In narrative methodology, the participant's experience is brought forward in the participant's story. What is important in the story is the subjective experience of the participant and how the participant experienced the situation. So, the question of an objective "truth" of the story is left aside, that is the context of understanding the participant story is set firmly in the subjective experience of the participant and the context of the participant experience.
- Older adults were assumed to be willing to verbalize their stories of their experience of cardiac surgery from the preoperative period up to 2 months after cardiac surgery.
- Each older adult will have unique responses, perceptions and meanings during their experience of cardiac surgery over time. Additionally, because of the commonality of some aspects of the cardiac experience over time, older adults may have shared dimensions of experience during the preoperative period throughout the first 2 month postoperatively.

Furthermore, when conducting narrative analysis, the researcher is expected to reflect on potential sources of bias that he or she brings to the analytic process. As a qualitative researcher, I recognized that I am involved in co-constructing and transcribing participant stories in narrative

analysis. The following are potential biases I recognized in reflecting on prior to and while engaging in data analysis:

- While I have recognized that evidence based care and standardized care may improve health outcomes, I also have recognized that patient information gleaned from the health care record is factual and illness focused and not person focused. As a bedside nurse I have felt that there is a need for listening to the individual's voicing of his/her story in the delivery of health care; and my belief is that it is this context that humanizes the nursing care of patients, promoted recognition of human dignity, and facilitates healing and recovery (Willis et al., 2008).
- In my experience as a bedside critical care nurse, I have believed that there is a strong potential for building an understanding of patients through understanding of participant narrative and that this process facilitates the nursing care of individuals, contributes to knowing the patient and improves the delivery of patient-centered care.
- During my tenure as a critical care nurse, I have seen the shift in performing cardiac surgery on older adults and have seen that older adults may not recover from surgery despite prolonged intensive care stays.
- Prior to initiating this study, a close family member became very ill and had urgent cardiac surgery and a gradual recovery from surgery over the period of a year.
- With a clinical expertise in cardiac surgery; my role as a nurse researcher needed to be aware of and reflect on the potential bias of filtering participant discourse through the lens of clinical assessment and intervention.

Being aware of the biases, assumptions and intuitions I bring to this study, I made every effort to be aware of and leave behind these biases and assumptions. By being open to the experience of each participant and allowing the data to speak for itself. I tried to be open to the experiences of participants at each interview period. I engaged in reflection about the processes of interviewing, data analysis and interpretation and reflective notes were used to increase my awareness of the potential for researcher bias in analyzing and interpreting participant narrative. In order to aid in this reflexive process, I debriefed with committee members as way to develop awareness of and reflect on potential biases that could influence the interpretation of narrative or the interview process, for example, to clarify my understanding of my role as a nurse researcher as opposed to nurse clinician.

Analytic process. Based on the narrative methodology of Bold (2012), the analytic process used in this study draws upon a family of narrative analytic approaches to individualize the process of analyzing and interpreting interview data. Bold (2012) notes that one “can benefit from examining and drawing on other researcher’s methods, but ... [one does]... not necessarily have to apply them in exactly the same way” (p.124). Bold (2012) recommends developing an analytic process that is consistent with research questions being asked and the type of analysis, in this case, thematic analysis. Key to the process of thematic analysis is examining the relationship between people and contexts over time (Bold, 2012). Bold (2012) states:

A thematic analysis focuses on the content of the narratives, the events that occur, the experiences that people have and the meanings that emerge through finding a set of themes within the data (p.141)

Data analysis began with professional transcription of the audiotaped interviews. Then each transcription was checked against the recorded audiotape by the PI to ensure accurate transcription. The analysis of each participant story began with a review of the research questions (Lapum et al., 2010). Text that pertained to the overall gestalt (or the unified whole) of narrative used by older adults to describe their experiences of cardiac surgery was retained for analysis (Bold, 2012; Riessman, 2008; Riley & Hawe, 2005). Each participant story consisted of three interviews, a preoperative interview, and two postoperative interviews (one at one month, one at two months). All three interviews were combined for analysis and listened to absorb an overall gestalt of the story.

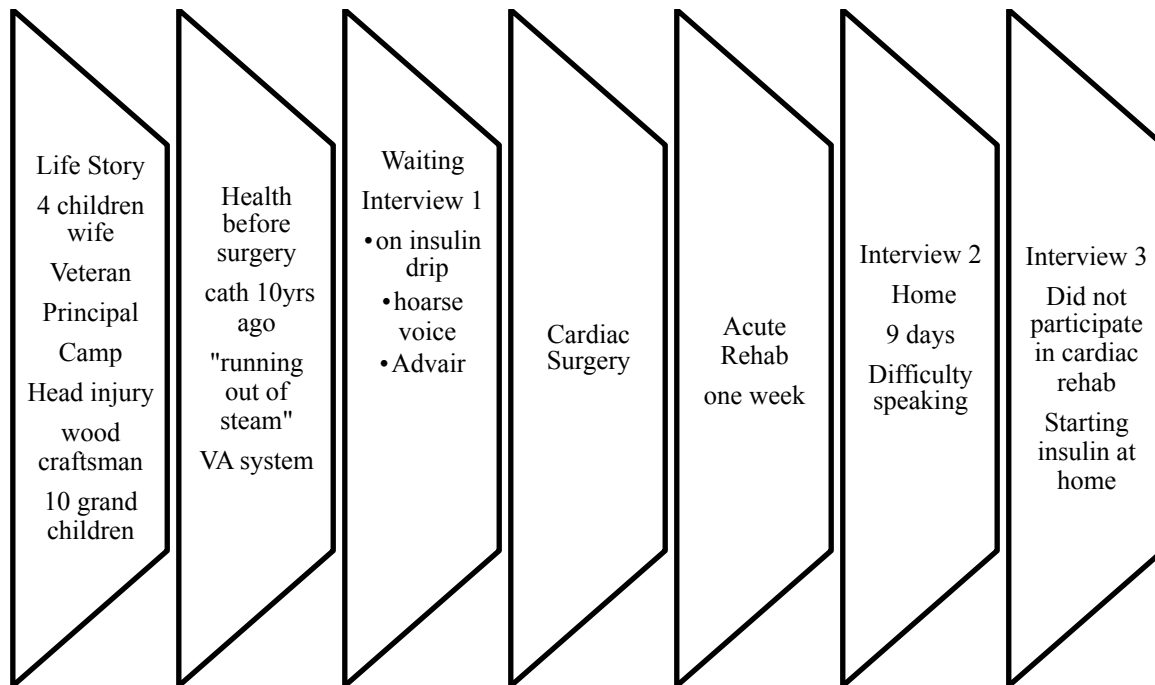
Because study participants do not always describe chronological events in sequence when they relate their experiences, part of narrative analysis involves rearranging the content of each story (or “restorying”) into a beginning, middle and an end based on the chronology of the participants’ story. This process of restorying is unique to narrative analysis in that the analysis of participant experience is grounded in a chronological evolution over time (Bold, 2012; Creswell, 2007).

In narrative methodology, placing a participant story in chronological sequence (i.e. restorying) is an essential part of beginning data analysis (Creswell, 2007). Drawing upon a heuristic approach utilized in narrative analysis, chronologic mapping was used to illustrate key events of participant narrative and place them in sequence over time. The process of chronologic mapping allowed participant narrative to drive the structure of the stories that were related instead of imposing a structure on the story initially. The use of visual mapping of narratives has been recognized as useful in the narrative analytic because visually mapped life chronologies can

assist in restorying of the participant narrative and understanding the trajectory of the participant story (McAdams & Bowman, 2001; Thomas & Hall, 2008). A sample of the chronologic mapping of one participant's story is illustrated in figure 1.

Figure 1

Example of Narrative Mapping



The restorying of narrative content across each participant resulted in a sequence of story events that began where the participant chose to begin their story until the period at two months after surgery. Table 6 outlines time story points that were related by study participants as well as the experiential content within those time frames.

Table 6

Narrative Chronology

Chronology	Experiential Content
Life Story	Childhood, young adulthood
As an older Adult	Current life experience
Health needs before surgery	General health at home
Precipitating events	What brought the participant to acute care
Hospitalization	Includes content on decision making, waiting for surgery, participant preoperative focus, current symptoms
Rehabilitation in a Skilled Nursing Facility	Stay in rehabilitation prior to discharge home after surgery
Readmission	Two participants were readmitted after discharge from the hospital
Home	Home experience (after hospitalization or rehabilitation facility)
Cardiac Rehabilitation	Participating in or contemplation of enrolling in a cardiac rehabilitation program.

Once narrative content of a participant was restoried, in vivo coding of the narrative content of each story time period was performed. Interview text was analyzed and assigned code categories based on a high degree of relevance (or referential adequacy) between the coded text and the assigned code category (See Table 7 for an example of content coding). The content of each participant's story was analyzed within the chronology of their experience of cardiac surgery over time. The coding of participant narrative situated within the context of their story allowed participant unique stories to emerge and for content themes to emerge within each participant's story.

Bold (2012) recommends drawing on methodologic approaches suitable to the research question and analysis of narrative data. Throughout this analysis thematic, theoretical and methodological notes were kept as a heuristic for recording ideas during the analytic process (Rossman & Rallis, 2003). The rationales for utilizing detailed memoing procedures were to enhance the process of building understanding of the contextual influences on narrative, draw connections between narrative accounts and maintain an audit trail of decision making in coding and interpretation of data.

Methodologic notes pertained to ideas about how to code in vivo interview text using content analysis methodology or articulated a question about how the text should be coded. Theoretical notes pertained to ideas on how interview text reflected themes or theory noted in the review of the literature and noted how themes related to theory from other disciplines such as sociology or psychology. Thematic notes related to how codes might synergize to reflect an emerging theme across participant stories or, in contrast, reflect a unique experience for that participant. Reflective notes were kept to aid in understanding any personal bias or experience I brought to co- construction of the interview (Bold, 2012).

The analytic approach then followed an iterative process that consisted of a) reading each individual narrative to identify significant meanings by means of attention to evaluative clauses, verbal emphasis, and use of metaphor and word repetition and b) comparing one narrative account with another to identify similar and dissimilar meanings c) noting text that was evaluative (or imbued with meaning) and ensuring that it was coded within the chronology of the story (Riley & Hawe, 2005). This iterative process supported the analysis of individual story content as well as the synthesis of thematic content across participant narrative.

As each successive story was coded, codes between stories were contrasted and compared and codes with similar content were clustered together in subcategories and then larger categories. A qualitative software analysis program was used to facilitate the analysis (Hyper Research). Saving the initial coding of each participant story ensured an audit trail. As each story was coded, and as like subcategories and distinct subcategories emerged, narrative themes emerged across stories. Table 7 illustrates a sample of the coding process:

Table 7

Sample of Coding Process

Chronology	In vivo unit	Sub category	Category	Descriptive Theme		
Life as an older adult	“I was working very hard”	<u>Working</u>	<u>Keeping Busy</u>	<u>Engagement: working and being busy</u>		
	“I couldn’t stand not working”					
	“I’m a good worker”					
	“I keep busy, working in the hills”					
	“Been doing and doing for a long, long time”	<u>Doing a lot</u>	<u>Diverse Responses of aging</u>	<u>Conscious of aging and time passing</u>		
	“We’re really doing everything”					
	“My body doesn’t cooperate. Inside it says, you’re young yet”					
	“I’m probably one of the oldest [working at my job]”					
	“Well, I’m very old”	<u>Being older</u>				
	“Being my age, everything seems to be going backwards”					
“Of course, I don’t consider myself old”						

Chronology	In vivo unit	Sub category	Category	Descriptive Theme
Health needs before surgery	“Something’s wrong, I haven’t got that momentum”			
	“I just noticed I was running out of steam”			
	“I started slowing down”	<u>Slowing down</u>	<u>Getting worse</u>	<u>Noticing changes</u>
	“And the last year or so I’ve noticed some degradation in my ability to do things”			
Hospitalization, Rehabilitation, Home	“The hardest thing for me was I couldn’t eat”	<u>Lack of appetite</u>		
	“I felt depressed. Everything was going wrong”			
	“I was feeling very depressed”	<u>Depressed</u>	<u>Postoperative symptoms</u>	<u>Living with the burden of symptoms</u>
	“I have been going crazy”			
	“I was out of it...I was trying to break out of there”	<u>Confusion</u>		
	“My bowel’s weren’t working”			
	I don’t know why it wasn’t easy for me...My bowel’s hadn’t moved”	<u>Constipation</u>		

Descriptive themes that emerged from the data were analyzed within the context of the participant story as a whole to identify themes that were contiguous within the chronology of the story. For example, the overall experience of symptoms included descriptive themes such as the prodromal changes in health of participants prior to surgery. There were acute changes in symptoms that led to hospitalization and descriptions of symptom experience dominated participant discourse after surgery. Comparison of content across individual stories was used to inform the development of themes that were shared by participants and to evaluate for thematic saturation of broad narrative themes across participant narrative (Bold, 2012). Select extracts of

interview text were chosen in order to illustrate the themes that emerged from thematic analysis (Bold, 2012)

Elements reflecting of broad thematic saturation began to emerge with content coding of four participants stories. Saturation in major content categories appeared complete with content analysis of ten participant stories, thereafter; three more participants were enrolled without emergence of new broad thematic content.

Trustworthiness

In the qualitative paradigmatic approach to research, trustworthiness is defined as the extent to which the research brings forward an accurate representation of the participant experience (Speziale & Carpenter, 2007, p. 460). The overall trustworthiness of this study was addressed by through attention to the individual criteria of Lincoln and Guba (1985) that support the trustworthiness in qualitative research.

Credibility. Credibility, according to Lincoln and Guba (1985), refers to ‘truth value’ of the data, or ‘...how can one establish confidence in the “truth” of the findings of a particular inquiry for the subject (respondents) with which and the context in which the inquiry was carried out? (p.290). Multiple methods, including prolonged engagement, persistent observation, analytic memoing , triangulation and internal and external member checks were used to support the credibility of this research study. Lincoln and Guba (1985) state:

Prolonged engagement is the investment of sufficient time...learning the ‘culture’, testing for misinformation introduced by distortions either of the self or of the respondents, and building trust (p. 301).

The use of multiple interviews in this study design contributed prolonged engagement with participants and thus enhanced the credibility of study findings. The approach allowed by allowing for the principal investigator to revisit key points in narrative with participants during multiple interviews. This provided opportunities for detailed exploration of narrative with participants and to allow for member checking (i.e. reviewing key points of narrative) with participants. The use of multiple interviews also supported the process of persistent observation which involved focusing in detail on the narrative content that was emphasized by participants (Lincoln & Guba, 1985).

Field notes, reflective notes, and analytic memoing (thematic, methodologic, and theoretical) added to the credibility of the findings because they contributed to an auditable trail of analysis. Field notes also provided detailed descriptions of the setting and other contextual variables that took place during the interview processes. The process of writing reflective notes informed understanding of the personal experiences and biases I might bring to the analytic process.

While in the process of developing the study proposal for this research, a close family member had cardiac surgery. By acknowledging the differences between my family member's experience and study participant experience and acknowledging these differences as a potential source of bias this allowed a study participant driven process of co-construction of narrative.

Thematic notes were specific to defining the content codes assigned to text and elucidated possible connections between subcategories and categories of codes that clustered together. Methodologic notes were made to provide a clear auditable decision making process on how content codes were defined and how decisions were made to collapse codes or recode items.

Theoretical codes related coded content to previously published theory and noted when a participant's text was congruent or incongruent with published theory on this content.

Data was triangulated utilizing content analysis, chronological restorying, and by referring to field notes (observational and reflective) as an additional source of information. This process ensured contextualized interpretation of data. In order to obtain rich detailed narrative, the design and development of the interview guide was reviewed by expert clinicians prior to its use and the interview guide was piloted prior to its use in this study. Based on the work of Lincoln and Guba (1985), external checks of the analytic narrative method were instituted with dissertation committee members to ascertain if there were factual or interpretative errors and to bring forward methodologic questions (Lincoln & Guba, 1985).

External member checks were conducted with nurses and physicians that are clinical experts in care of older adults who have cardiac surgery. These member checks provided information on how the sample cases might representative or be atypical of the study site and whether the cases might be missing important contextual or factual data (Lincoln & Guba, 1985). Engaging clinicians who were not involved in the direct care of participants assured confidentiality.

Comprehensive member checking with study participants further supported study credibility. Shared data collection with study participants, such as a re-reading of key points in narrative with the author of the story was used to support the credibility of this study. This member checking preceded the beginning of each of the second and third interviews, and gave participants an opportunity review their previous interview text and clarify, expand upon or correct narrative.

Fittingness/Applicability. Lincoln and Guba (1985) indicate that applicability refers to ‘How one can determine the extent to which the findings of a particular inquiry have applicability in other context or with other subjects (respondents)? (p. 290). Lincoln & Guba (1985) suggest that the researcher supplies descriptive data and that those seeking to transfer that knowledge need to seek contextual similarity of the phenomenon. Accordingly, I supported the applicability of the findings of this study by using prolonged engagement with multiple interviews, detailed observation, and thick description as well as demonstrating congruence of the research question to the research method (Creswell, 2007).

Auditability/Consistency. For Lincoln and Guba (1985) consistency refers to “How can one determine whether the findings of an inquiry would be repeated if the inquiry were replicated with the same or similar subjects (respondents) in the same (or similar) context?”(p. 290). I supported consistency in this study by keeping a decision trail that clearly illustrated how the design of the study grew and evolved with the data and engaged an external consultant as an auditor of the study process (Creswell, 2007). Audio taping of interviews, field notes and methodologic noted on coding decisions supported the consistency of this study. Systematic coding at each level of analysis provided an audit trail for the analysis and provided referential adequacy.

Confirmability/Neutrality. Lincoln & Guba (1985) refer to neutrality as “How can one establish the degree to which the findings of an inquiry are determined by the subjects (respondents) and conditions of the inquiry and not by the biases, motivations, interests, or perspectives of the inquirer? (p. 290). As the researcher, clarifying and understanding the bias and assumptions I brought to this study are essential to supporting the neutrality or

confirmability of the findings. By reflective memoing and dialoguing with clinical experts and dissertation committee members, I made more explicit potential biases and experiences that could influence the analytic process of this study. By making this process explicit via memoing and discussion, this procedure served to support a confirmable and neutral analytic process.

CHAPTER 4

Research Findings

The primary research question posed in this study was:

- What stories do older adults tell of their experience of cardiac surgery from the preoperative period through the first 2 months postoperatively?

The secondary question posed was:

- What are the shared themes of older adult stories of cardiac surgery from the preoperative period through the first 2 months postoperatively?

The initial research findings presented reflect the descriptive results of this study including participants' characteristics, sample attrition, and interview characteristics. The second section of this chapter will present the interpretive results of the narrative analysis with an overview of the study context, two narrative exemplars of older adult stories of cardiac surgery, brief thematic summaries for each participant case and thematic findings.

Descriptive Results

Participant Characteristics. Participants in this study consisted of older adults (70 years of age and older) who were in hospital awaiting cardiac surgery. Reasons for participant hospitalization prior to surgery included ongoing medical treatment (such as intravenous heparin administration) for stabilization of unstable angina or treatment after myocardial infarction, threatening anatomy (e.g. the patient had had a cardiac catheterization and had significant left main coronary artery disease), stabilization of blood sugars, optimization of kidney function prior to surgery, bridging anticoagulation from oral warfarin to intravenous heparin prior to surgery, and the need for additional diagnostic testing prior to surgery. All participants in this

study were interviewed in the hospital prior to surgery. A total of 21 patients were invited to participate in the study, of these 13 consented to participate (See Table 8 on Sample Attrition). The eight patients who declined to participate cited the following reasons: concerns about confidentiality, did not know how it would be after surgery, “plate too full”, daughter did not like the idea of participating in the study, patient did not want to be interviewed and having hearing difficulty. Thirteen participants were enrolled and of these, five were female. Participants ranged in age from 74 to 88 years of age; the mean age of participants was 80.8 years of age.

Table 8

Sample Attrition: Number of Participants Enrolled and Interviewed

Participants	Pre operative interview	One month after surgery	Two months after surgery
Total number of interviews	13	11	10
men	8	7*	7
women	5	4~	3*

Note. *participant lost to phone follow up ~ participant died after surgery in the intensive care unit

Of the 13 participants interviewed in this study, three participants were scheduled for a less invasive form of cardiac surgery, involving transcatheter replacement of their aortic valves. This procedure did not require a sternotomy incision or placement on cardiopulmonary bypass. These novel hybrid surgeries involve both interventional and cardiothoracic operating room teams and participants have an extensive work up prior to surgery to ascertain eligibility for the procedure. Of the remaining ten participants who required a sternotomy and cardiopulmonary bypass for surgery, seven had coronary artery bypass surgery; three participants had dual CABG and valve

repair or valve replacement surgery (See Table 9 for a description of study participants). In all, a total of 34 interviews were conducted for this study.

Table 9

Study Participant Characteristics

Pseudonym	Age	Type of surgery	Pre-op stay at outside hospital	Readmission within first sixty days	Stay in SNF/ARF prior to home	Enrolled in CR at two months
Harriet	octogenarian	CABG	Yes	*	Yes	*
Allan	octogenarian	CABG	No	*	Yes	*
Patty	octogenarian	CABG	Yes	No	Yes	Yes
Will	septuagenarian	CABG	Yes	Yes	Yes	Yes
Brad	septuagenarian	CABG	No	Yes	No	No
Tim	septuagenarian	CABG	Yes	No	Yes	No
John	octogenarian	CABG	No	Yes	No	Yes
AVR						
Ralph	octogenarian	TAVR	No	No	Yes	Yes
Jane	octogenarian	TAVR	No	No	Yes	No
Douglas	septuagenarian	CABG	No	No	No	Yes
Cynthia	septuagenarian	CABG	Yes	~	~	~
MVR						
Jill	octogenarian	TAVR	No	No	Yes	No
Stephen	octogenarian	CABG	Yes	No	Yes	Yes
MR						

Note: CABG coronary artery bypass graft AVR Aortic Valve replacement MVR Mitral valve replacement MR Mitral Repair TAVR Transcatheter Aortic Valve Replacement SNF Skilled Nursing Facility ARF Acute rehabilitation facility CR cardiac rehabilitation Program *participant lost to phone follow up ~participant died in hospital after surgery

Table 10 outlines an overview of the length and setting of each interview period.

Table 10

Setting Characteristics of Interviews

Interview	Interview method	Settings	Average length of interview (minutes)
Preoperative	Face to face, in hospital	In hospital	23 (17-33)
Postoperative 1 month after cardiac surgery	phone	Patient at home or in ARF/SNF	18 (6-24)
Postoperative 2 months after cardiac surgery	phone	Patient at home	26 (15-38)

Table 11 lists the average lengths of stay in the continuum of care prior to surgery until their return home based on participant report.

Table 11 *Range and Average Length of Participant Stays in Continuum of Care*

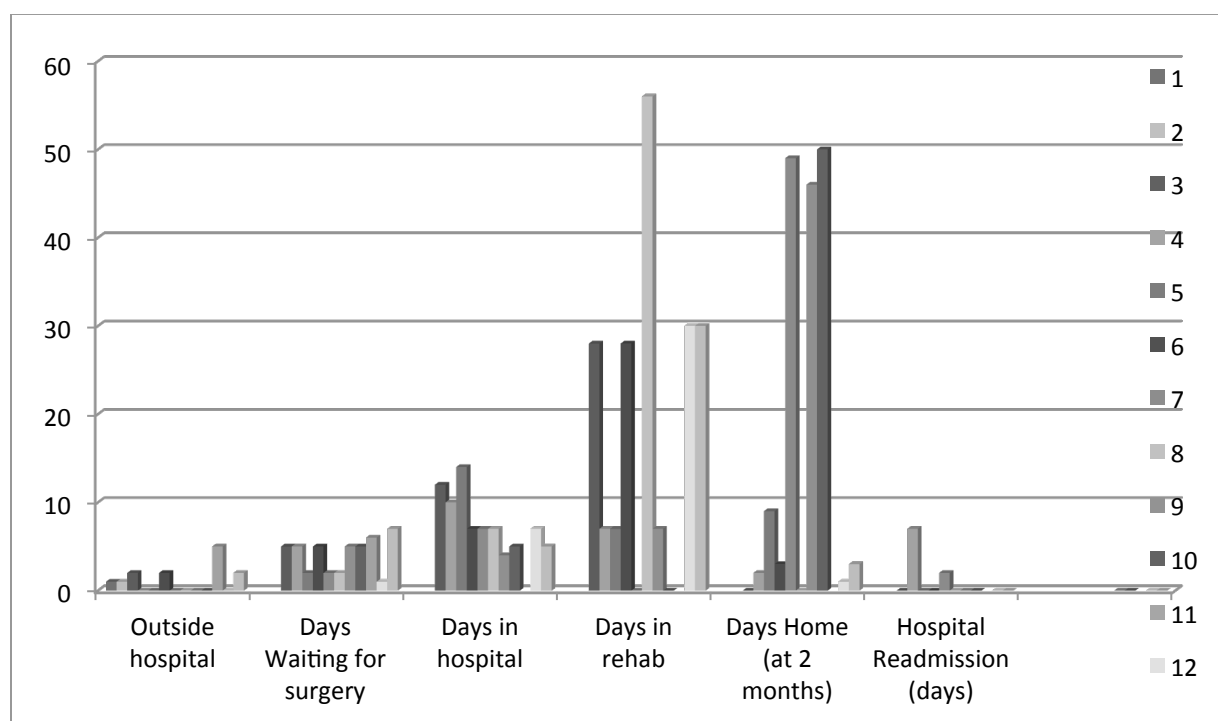
Length of stay (days)	Outside hospital	Waiting for surgery	In hospital after surgery	In ARF or SNF	Hospital readmission
Range	0-6	1-7	4-14	0-56	0-7
Average	1.8*	4	8.2	18.2**	0.9
% of total number of participants	46.1%	100%		77%	15%

Note. *average days waiting for those in community hospital preoperatively ($n = 6$) **average days in rehab for those who went to rehab ($n = 9$) ARF Acute Rehabilitation Facility SNF Skilled Nursing Facility

Figure 2 illustrates the self reported days each participant spent in different phases of care, including days awaiting surgery in community hospitals, days waiting prior to surgery and days spent in hospital, rehabilitation facilities and home.

Figure 2

Graph of Participant Reported Days Spent in Continuum of Care



Interpretive Results of the Narrative Analysis

Study context. Participant enrollment in this study began in December 2012 and continued through July 2013. This study took place in a nonprofit 600- bed teaching hospital and Level 1 trauma center in a city in the Northeastern United States. On a local level, during the study period, a new electronic health record system implemented in the study institution and

throughout health care systems connected to the center allowing healthcare professionals to view documentation across settings. In the hospital where this study took place, a system of navigation of transitions which provided support for all cardiac surgery patients after discharge was instituted in September 2012. The goal of this grant funded project was to decrease hospital readmission rates by facilitating the medical transition needs of the patient once discharged to home and to provide social support via a social worker for challenges assessed during the transition to home. Another cardiac service line hospital program was instituted that was designed to reduce admission rates by instituting a follow-up clinic at one week after discharge for cardiac surgery patients was begun in March of 2013.

Protection of Human Participants

During the conduct of this study, participants verbalized a range of emotions, and some participants were, at times, were tearful. Careful attention was given, as noted in the IRB study protocol, to minimize participant burden and to offer support to participants if needed. Two participants experienced a loss of a close family member during the course of the study, but, when asked, noted that they were well supported by family members during this time. Two participants reported that they felt they were grieving the loss of a spouse during the time they awaited and recovered from surgery, but when asked, noted that they were well supported by family members and/or church community members throughout this period. One participant reported feeling “low” after surgery during the period one month after surgery; I offered to assist the participant in contacting his primary care provider. The participant reported that he would be following up with his primary care physician within a few days. After this interview, I conferred with dissertation committee members because of my concern for this participant and as a

consequence, initiated a follow up phone call and did converse with this participant to ascertain he had seen his physician. In the follow up conversation, the participant reported that he had seen his physician, was doing well and feeling hopeful.

Narrative Exemplars

The primary purpose of this research study was to describe the stories of older adults who have cardiac surgery. In this study, each of the thirteen participants, while sharing similar chronology and experiences over time, nonetheless also brought forward a unique particular story of experiences, informed by personal history and circumstances.

The two participant narrative exemplars are presented in the results section of this study to illustrate a range of individual experiences shared in older adult stories of cardiac surgery. These two narrative exemplars reflect the shared general structure of the experience of participants in this study, encompassing a chronology of events over the preoperative interview and continuing until two months after cardiac surgery. The narrative exemplars selected are illustrative of content and thematic coding within each participant's individual story. While each participant's story had unique characteristics, the structure that participant narrative followed shared a similar chronology across participants, reflecting the temporal commonality of the shared experience of cardiac surgery. (See Table 6).

Exemplar one – Patty's story: Approaching difficulty with acceptance and resolve.

The overarching theme of Patty's story was "approaching difficulty with acceptance and resolve". Childhood experiences in which Patty had a lack of choice were reminiscent of her present situation of needing to have cardiac surgery as an octogenarian. Patty felt her decision to have cardiac surgery was really the only viable option given her health status and she related that

she did not feel “in control” in her postoperative experiences. Nonetheless, despite these feelings of lack of control, Patty’s story conveyed the sense that she was knowledgeable and actively participating in making decisions about her care. Patty also recognized the need to take a more active role in self care after her surgery as she learned to check her blood sugar levels at home. In her narrative, Patty reflected on her realization that stress and responsibility could have contributed to her illness.

Preoperative experiences. I interviewed Patty while she was awaiting cardiac surgery on a cardiology medical floor in the hospital. She had been admitted to her community hospital with chest pain, stabilized with medications and then transferred to the study hospital for a medical work up that took five days. In sharing her experience, Patty related detailed parts of her life story, including the loss of her father when she was a child. This event changed Patty’s life and resulted in her needing to accept that others knew best, as she coped with changing life situations as a child. Patty related that after her father died, her mother remarried and their family changed residences frequently. Patty describes this time in her life:

So, it was my mother making decisions about her life. And I was an only child, thank goodness for her to be, if you’re going to be left, better to be left with the 1 than 2 or 3. So, anyway, that started our trek away.... no matter where we happened to be, if it was, you’re supposed to be in school, she’d [my mother] put me there. I went to a lot of them. ...So I was then in high school, sophomore, guess, and at my aunt’s house in Dallas. And [my mother]... needed to go to California and meet my stepfather and he had some business there. So she asked her sister if she would keep me. [Patty laughing]. So she said, “Okay.” ...I was a person who just did whatever.... I didn’t feel as though I had any option. Certainly when you’re seven and eight years old you don’t. And you don’t much when you’re ten or eleven either. And at thirteen, I mean, you do whatever you have to do.

Patty related this childhood experience to her present situation of having to accept her illness and the plan for her to have surgery. She likened her acceptance of her present situation in hospital as similar to her childhood experiences, and in her present circumstances she was doing what she

had to do just as she had when she was a child. Her acceptance of the situation and focus is mirrored in her statement:

Well, I'm taking it day by day.... once the decision was made to have the surgery, I'm just following instructions. Just doing whatever they say, because I'm hoping for a good outcome. And so that's my main focus. And my family is supporting me and my husband is supporting me with this decision.

Patty also conveyed a sense of enjoyment and involvement in the life she lives in a small town in coastal Maine. While she related enjoying programs and entertaining, she also described an awareness of time passing, of her age, and the stress she felt regarding ongoing responsibilities. Patty reflected on her life as rich and full, but there were still responsibilities and decisions that needed to be made, and this caused Patty to worry. This is captured in this statement from Patty:

... you know my husband is not getting any younger either. He's a year and a half older than I am. He'll be ... [octogenarian] in March. And so, we, you know, you can't help but think, what am I doing? Why am I not making some decisions about changes in our lives, because we're still in our house, with all that responsibility, so that's, I guess I've been thinking about things like that. But not doing anything. And I think that, I have a lot of insomnia. And I think a lot of it is things running through my mind that I ought to be doing and I'm not.

Patty also reflected on the stress of the holidays, and how her angina may have been worsening over the time prior to going to the hospital:

It was Christmas Eve, I had a million things still to do for Christmas and I thought it was the stress, you know. But I had been managing it really pretty well, but it had been getting worse.

In this time of waiting for surgery, Patty was resolved on her decision to have surgery and intent on having a successful outcome. Her resolve in the present was tempered by her reflections on the period before surgery that suggested that her health was worsening, though she did not fully recognize it at that time. In reflecting on her health before surgery, she also recognized that

stressors such as the demands of her house on her and her husband's age were contributing to her anxiety.

Experiences at one month after cardiac surgery in a skilled nursing facility. After hospitalization, Patty's stay in a skilled nursing facility (SNF) lasted for four weeks with setbacks such as a gastrointestinal virus and bad cough. But, she was also making progress in her functional recovery by exercising and weaning of off supplemental oxygen. Patty noted that she felt she had been "in stir" (i.e. being in prison) having been hospitalized for one week before surgery, then a week after surgery followed by care in a skilled nursing facility(SNF) for four weeks and all of this was around the Christmas holidays. At the time of the second interview, Patty was preparing to go home from the SNF. This interview was shortened due to Patty's fatigue and the hoarseness of her voice associated with her cough. As a result, the interview was of fifteen minutes in duration. During this time, Patty shared memories of her post operative intensive care experience ICU stay which she likened to a "blurred continuum":

... it's just kind of a blur. It's a continuum. You just take everything as it comes, which is kind of the way I am anyway. And so, you can't fight it, because you're helpless. And you've given over your [Patty laughing] control.

While Patty's approach was to accept events she could not control, it did not preclude her from being an active participant in her care and in the decision making process to have surgery. The following quote by Patty shows her acute awareness of the medical issues in her care and what her choices were as she reflected on her decision to have cardiac surgery:

...in my case I didn't feel as though I had much of a choice. What my cardiologist [said is] the stents were not in the cards for me. And that's his specialty, is stents. But he in my case, after he saw the cath-, and uh, it wasn't going to work, so what's the option? The bypass or just to live with the angina, which was getting worse? So it didn't make any sense not to do it (pause) after all they'd already increased my blood pressure medicine several times. And I suppose, I just, I don't know. I just think I'd have been

waiting for a heart attack. You know, when's it gonna happen?Because when I went to the Emergency Room I chewed two aspirin on the way. I had taken my Nitroglycerin and it didn't have an effect. And I tried resting, which normally worked, and it didn't work. So I don't know, what kind of life is that? So, we did not have a hard time making that decision....

When asked what she had found challenging thus far in her experience, Patty related the importance of trust in her caregivers, echoing the way she had placed trust in others as a child:

... you have to assume that ... [the health care team] know what they're doing. If you didn't have that faith, then I think it would be very, very hard to do. But everybody kept telling me that I'm in a very good place. I couldn't get better care. And so what more can you do?

Patty's wry sense of humor and this came across as she described the exchange she had with her surgeon prior to surgery, reflecting her conscious awareness about her age how that could be considered a contraindication to having surgery:

I mean, there are a lot of doctors that wouldn't even do... [surgery]... on an ... [octogenarian] old woman. In fact, I teased the surgeon. I said the reason is you just want to add this to your resume [Patty laughing]. Not that he needs anything to add to his resume because he's got quite a good one.

Patty's narrative was notable for the manner in which she expressed articulate thoughtful questions about her progress of recovery that was self evaluative in nature. She was interested in understanding if her progress was typical for someone of her age who had had cardiac surgery and she was aware of her age and that she, perhaps unlike other octogenarians, had had the opportunity to have surgery. Patty viewed events such as her respiratory infection and gastrointestinal virus as "set backs" and articulated questions about her progress asking what was usual for recovery for someone her age. She also expressed feeling that she was "lucky to be here" and remarked on the triple bypass, stating "It's amazing what they can do, isn't it?"

Experiences at two months after cardiac surgery. Two months after cardiac surgery, Patty had been home three weeks and described feeling "all healed up". She noted that she was

resuming enjoyable activities such as cooking for herself and her husband. Patty shared her realization that exercise was key regaining to her strength, but still found challenges due to fatigue and chronic back pain.

Well, it's good. I mean, I'm glad to be home. I'm not 100 % up to strength, I run out of it. [It's] an on-going problem. But, I can do things and I'm now past the point of being restricted as far as reaching and you know that sort of thing. I can pretty much do what I feel like doing. Except I'm not heavy lifting -- I don't know. But I'm all healed up. So it's just a matter of time and lots more exercise, I think, but I think exercise is going to be the answer, the walking and so on. I have to make myself do that when I'd rather sit down [Patty laughing] or lie down.

Patty had been considering cardiac rehabilitation, but did not feel ready. An obstacle to her participation in a cardiac rehabilitation was that it was a long drive (thirty five miles) to the facility and that Patty did not drive, so she would have to depend on her husband take her to classes.

Patty's outlook of "approaching difficulty with acceptance and resolve" spoke to both an acceptance about the need for surgery as well as acceptance of the difficulties and uncomfortable moments inherent in the experience. The loss of her father as a child had shaped her response to adversity as a child, and she related her acceptance of adversity to be a formative response to challenges in her life. Patty shared her strategies for dealing with the difficulties, "You just take everything as it comes", hoping, keeping faith in others and keeping a sense of humor about the process. Unlike her experiences as a child, as an older adult Patty had the ability to choose for herself treatment with an awareness of the challenges that faced her and her family played an instrumental role in supporting her in the decision making period.

In summary, Patty 's story encompassed both an ability to enjoy being engaged in the intellectual and social life she experienced in her community while also worrying about things

she was aware of, but not dealing with, which caused her stress. Along with the enjoyment of her life, Patty was aware of time passing, of her and her husband's age, and potential for changes in their lifestyle. Patty also related the importance of family support when making the decision to have cardiac surgery and the ongoing support of her husband, family and friends upon returning home from her stay in a skilled nursing facility. Patty's response to symptoms was a dominant theme throughout her preoperative narrative (including stress at home as well as managing episodic chest pain), in the ICU (with particular attention to the feelings of loss of control) and postoperatively (when fatigue and chronic pain were burdensome). Patty's voice in her narrative conveys that while she accepted the challenges she faced, she now was beginning to participate in actively making decisions about her care and managing her care at home with supportive services.

Exemplar two-- John's story: Trusting in God while practicing self nurturance.

The overarching theme of John's story was "Trusting in God while practicing self nurturance". Integral to John's approach to cardiac surgery was his belief and trust in Jehovah. This trust in God provided a basis for John's acceptance around the need for cardiac surgery and also provided him a sense of equanimity in the face of this challenge in his life. John's love of gardening stemmed from his childhood experiences of life on a farm, his appreciation for cultivating growth in a garden stayed with him as an adult, molding his outlook on his health and his life. As his experiences after surgery unfolded, John came to the self realization that while feeling restored to health following surgery,, he needed to continue to nurture himself in his recovery by modifying his activity level and not "pushing himself" as he had prior to surgery.

Preoperative experiences. In his preoperative interview, John described his life story as a “farm boy” growing up on a family farm in Massachusetts. He shared that he had a passion for gardening, as noticed the importance of his religious beliefs as a Jehovah’s Witness. John had made it a point to relate how important his faith was to him during his preoperative interview:

I believe in Jehovah God, and I just I pray to him all the time about the operation. I’m a little concerned about it. I’m not afraid about it. I’m trusting my Jehovah God that I love.

This faith was for John a solid foundation upon which he could rely and he related how his church community had been visiting him and supporting him as he awaited surgery. John’s wife, although not a Jehovah’s Witness, was also a source of support for John while he was awaiting surgery. John recounted how he had had polio as a child and described how the illness had impaired the use of his left arm. However, he also noted that this limitation had not stopped him from working as a car mechanic most of his life. John related that he considered himself a very active, dynamic person but he also noted that, over time, he had noticed changes in his physical symptoms prior to surgery:

I’ve been pretty good, pretty healthy. The last couple of years I’ve been noticing a change in myself. I was getting tired a little more. And I kept telling my wife, “I think something wrong here because I don’t have that momentum.” I’m always moving. I do things fast. That’s how my body is, I gotta keep going. But anyway I noticed last year I had to stop several times. I used to hoe two rows at one time back and forth down the row and come up, no problem at all. This year, this past year, I says, oh, something’s wrong, because I couldn’t do both rows anymore. I had to do one at a time. If I hoed six or seven plants, I had to stop and get my breath. Like, something is wrong here, you know?

Paradoxically, John appraised his health as “pretty good” but then described how over time he had noticed curtailing in his usual daily activities and increased shortness of breath. Despite noticing changes in his stamina, John waited to seek medical advice until the limitations became severe suggesting.

John had to wait two days for cardiac bypass surgery because of the need for preoperative testing. He shared his approach to waiting for surgery; John found his passion for gardening and nourishing life helped sustain him during his hospitalization and also provided a metaphor for growing towards regaining his health over time.

I try not to let ... [waiting] bother me, because I feel like, you know, like planting a garden. If you overdo something with a garden you're going to lose it. But if you sort of nourish it and take your time to make it to good health. I try to live according to that Zen, you know what I mean?

Experiences at one month after cardiac surgery. At the time of his second interview, John had been home for three weeks. John's postoperative experience was unique among all participant narratives, in that he recounted few problems with physical symptoms during the acute postoperative period while in hospital:

I felt like a champ. I felt like nothing happened. They asked me if I had any pain or anything like that I said, 'No. I just feel fine'.

John not only felt remarkably well physically but also experienced an encompassing sense of gratitude to the surgeon who had cared for him, as well as his other caretakers.

I really can't find words to really express about Dr. [X]. He did a good job. I really enjoyed all them nurses. They've got a hard job. I couldn't find words good enough to express myself about them people.

Initially when talking with John, he noted that he had had an uncomplicated recovery. However, upon further discussion, John revealed that he did have to be readmitted to the hospital after discharge because of problems he experienced with breathing. While this could have been

considered a severe setback, John accepted this challenge as part of his recovery process and thought it as a warning that perhaps, he had been overdoing things at home. At home after surgery, John was anticipating beginning a cardiac rehabilitation program and described it this way:

I'm doing a lot of walking gradually. I have [various help such as a physical therapist, nurse] coming over once a week...I feel like a brand new person, I really do. I can't wait to really get started [in the rehab program]. I'm not going to rush it because I don't want to end up going back to the hospital.

John's story did not focus on the profound impact of physical and psychological symptoms during his recovery. John's narrative could be uniquely characterized as transformative. His experience evokes a sense of awareness and renewal, a change so big that he feels "brand new", and almost a sense of euphoria. For John, the experience of cardiac surgery was a transformative one. His ebullience of spirit and spiritual sustenance, apparent on our first meeting, shaped his response to the experience. John became aware that his experience could be tied to the change in his symptom experience and overall response to surgery. He had had aortic valve replacement as well as cardiac bypass surgery and his preoperative symptoms had improved for him, by his accounts, dramatically postoperatively. At two months after surgery, John shared:

Oh, yeah, I've got all of my energy back. I was telling you earlier. I just don't want to overdo it and get into too fast you know. I'm good to go. I'm like a match. You light the match (pause) cause there's going to be fire [John laughs] it just wants to go and move. You know what I mean?....I'm trying to be active. I go on a walk in the morning. Sometimes in the afternoon I do more walking, and I exercise every day. This morning I didn't exercise. I just felt kind of lousy this morning.

John came to the realization that he needed to pace his activity level after surgery and noted his increased awareness of paying attention to his body's signals and modifying his activity level if he did not feel good. At this time in his recovery, John explicitly reflected on his

spirituality and faith and how it sustained him particularly in the period awaiting surgery. John also revisited feelings of trust in his physician and how his faith in Jehovah supported him in the process of having surgery:

Dr. X said, 'Before I operate, I want you to know your chances of dying.' I said, 'Well,' I says, "Well you (pause) the scriptures say that I don't take blood, you do the best you can. If I go then it's in God's hands. You have no wrong and no guilt or anything. I ain't putting the blame on you at all. And I'm sure I'm going to survive this. Well, I hope you're right,' he said, 'I'll see you later' [John laughing].

Experiences at two months after cardiac surgery. During the third interview, John's renewal for life was manifested in his passion for gardening and looking forward to the spring planting season:

That's my life out there. I do try to work in my garden, the flower beds and all that sort of stuff. I have a lot of work to do here. People can't believe I do this all by myself. I've got two big gardens, I've got beautiful shrubs, a row of trees, and oh, my goodness. I never thought about getting sick. I never planned to do that.

There is an awareness of the fragility of his recovery in John's storyline. In John's self appraisal of his progress he expresses a longing and hopefulness for a return of health as exemplified by the following quote:

I feel real deep down in my heart, I feel that in time that will be the way it is. I'll get up and move like the way I used to move. But I'm not going to rush it. I'm holding back a little bit. I'll go walk and get things out of my mind and then just walk and think about things or something and- I just don't want to fall back, you know. Fall back one more time and I'm in trouble, you know. It's like being crippled for life. I don't think I could live like that.

Even as John shared a narrative about his experience with relatively uncomplicated cardiac surgery as a positive life changing event, his account still reflects an awareness of the challenges he had faced throughout his story and a willingness to fully engage in his health and recovery. He noted recognizing his risk of dying in surgery without the option of blood

transfusions, needing to return to the hospital after discharge for difficulty breathing and now recognizing the need to be aware of pacing himself and his body during his recovery. Woven throughout John's narrative, was the importance of the sustenance of his faith as a Jehovah's Witness and the value of the active support from his church in the period before surgery as well as after surgery.

In his preoperative interview, John described his childhood history, his family tradition as farmers, and the impact polio had on his functional ability. Even though his function in one arm was compromised he did not let it limit his work as a mechanic. Before surgery, John focused on the changes he had noticed in his physical ability and his subsequent awareness that these changes may have been warning signs his cardiac condition was worsening. Postoperative experiences included John's feeling personal transformation and gratitude to his health care providers; this was reflected in his statements that he felt like "a champ" and like "a brand new person". This transformed sense of self was evoked by John in spite of the challenge of a post operative readmission to the hospital and a new found recognition of needing to limit his activity level. John remarked: "I feel like I don't want to push it anymore. I used to push it and...I ain't doing that anymore". John's sense of engagement and joy in his daily activities, particularly in gardening and staying active, was present throughout his story and he used gardening as a metaphor to explain his strategy of patience when dealing with adversity. John's sense of nurturance was focused not just on his passion for gardening but also directed inward, and his belief that his health could be nourished also.

Synopses of Participant Narratives

The narrative exemplars of Patty and John illustrated the unique nature and range of each participant's narrative. In addition to these two participant narrative exemplars, there were 11 other stories of participant experience that also serve to inform understanding of the particularity of individual experiences of cardiac surgery. The following synopses of the participant narratives from this study reflect the shared general structure of participant experience; encompassing a chronology of events beginning with the preoperative experience and continuing until two months after cardiac surgery. Each of the participant's stories brought forth distinctive dimensions of their experience in the process of their recovery.

Like Patty, Will also engaged in reflection and self evaluation about his progress. The theme that emerged across Will's story was "Seeking to heal over time while struggling with disappointment". Will's discourse both implicitly and explicitly conveyed that his expectations over the course of his experiences had not been met; both with waiting preoperatively, because of the need for reoperations and in his long term struggle to recover his physical strength after surgery. While grappling with his frustration, Will's strategies for recovery included reliance on his family, following a program of rehabilitation and considering additional exercise programs, trying not to think about what is difficult or not essential and waiting to see how things would progress over time.

The narrative theme that emerged from Brad's story was "Enjoying life as time passes while practicing self advocacy." Brad's narrative emphasized a sense of engagement and enjoyment of life activities prior surgery, a foundation in his legacy as an educator prior to retirement, as well as a sense of his condition having worsened over time in the recent past as he

“ran out of steam”. Brad shared some of his thoughts on the decision to have cardiac surgery while in hospital, as well as sharing particularly meaningful aspects of his life story as a young principal providing for a family of four children. Brad’s struggles postoperatively were dominated by persistent symptoms, particularly nausea, with profound loss of appetite and weight, as well as a hoarse voice he attributed to having had a breathing tube placed during his surgery. A particular experience that flowed through Brad’s story was the problems he had in getting his prescriptions filled and the expense involved. As a veteran of the Korean War, Brad noted the problems he had in negotiating the Veterans Administration (VA) system. In Brad’s words “the whole set up is ridiculous” when he referred to the complexities of negotiating coverage for medications from the VA. Brad used active strategies such as checking in with different health care providers, for example; “getting on the horn” (i.e. making phone calls) to negotiate the complexities involved in getting his prescribed medications through affordable means.

Tim’s story theme was “Being supported and struggling to survive while staying committed and keeping hope”. Tim had reoperations for bleeding immediately after surgery and struggled with overwhelming physical challenges after surgery such as profound fatigue, lack of appetite and weight loss. Nonetheless, Tim shared that he was “committed” to taking care of himself and getting better and this commitment to his recovery showed in his persevering through disabling symptoms. Family support from his sister in law and her daughter was essential in helping Tim at home, especially since his wife had fallen ill when he returned home from the rehabilitation facility.

The theme of Harriet's story was "Learning limitations, looking ahead, and persevering despite the physical challenges of recovery". Harriet's story was based on two interviews; contact with her was lost to phone follow up at the time of her third interview. Harriet shared that she was widowed "many years ago" and lived by herself. After retiring from her career in education, Harriet decided to run for a civic position and won the election. Harriet was clear that the major obstacle to her recovery was her loss of appetite. One month after cardiac surgery, Harriet remarked that she was "just starting to feel like a human being again". In reflecting on her hospital experience and rehabilitation stay, Harriet shared her perceptions of inadequate staffing in both the hospital and in the acute rehabilitation facility during her postoperative stays. In speaking with Harriet, both before and after surgery, the importance of her work to her and her desire to return to work was evident:

I'm feeling better every day. I am so anxious to return to my job. So much is going on up there. And I am on the [] Committee, which is a great honor. And I want to be there. I'm praying the doctor will see it my way

The theme of Ralph's story was "The long journey home: Accepting adversity and loss through caring and engagement in life". Ralph related that he had faced many physical challenges in his life because of ongoing hemodialysis for kidney failure and worsening aortic valve disease. Ralph's story communicates a sense of involvement and social engagement, as well as enjoyment of nature. Ralph's enjoyment of life is portrayed in how he took pleasure in the society of his senior housing community and his enjoyment of cooking and fly fishing with his nephew. Ralph communicated an equanimity about the challenges in his life, both preoperatively, while awaiting surgery and afterwards when faced with the loss of his son. With the burden of preoperative symptoms lifted after his TAVR procedure, and following a lengthy

stay at a skilled nursing facility, Ralph expressed a readiness to resume his independent life at his home two months after his cardiac surgery.

The theme of Jane's story was "Remembering the past in a busy present: keeping track, keeping faith and staying active in new freedom". Like Ralph, Jane was admitted to the hospital for evaluation prior to having aortic valve replacement (TAVR). During our first interview, Jane shared that she was a widow and that her husband had died nine years ago. In the preoperative interview, Jane remarked upon the supportive role of her faith in approaching the events that brought her to have cardiac surgery as well as her trust in her cardiac surgeon. Throughout her recovery from cardiac surgery, Jane struggled with chronic hip pain which initially precluded her from enrolling in cardiac rehabilitation following discharge from the hospital. With the assistance of her daughter, Jane was able to navigate the complex constellation of care that encompassed her follow up care.

The theme of Jill's story was "Enduring loss during a time of physical challenge while longing for independence". Jill shared that when she was younger, "I worked like a man on the farm. I shouldn't tell you what I did do" and then as a bus driver as an older adult until she had had to retire in 2009 because she had broken her knee. Jill remarked that being in poor health had been difficult because "*I miss being independent.----- I took care of my own self*". With the support of her daughter and her family, Jill endured postoperative physical symptoms, including severe constipation, which she found difficult in her recovery. Jill also suffered an acute loss while she was recovering from her surgery in a skilled nursing facility; her brother, her only living sibling, died unexpectedly. Jill valued the independence she had had in the past, prior to her disabling heart condition and as she regained strength, she took pleasure in being able to

perform household tasks and short walks. Jill remarked that she had been told it would take time to recover from surgery:

Yes, it'd be up to a year, anyway, And maybe before, and maybe not. Age is against you too –... "I want to do all I can. I really, really, do".

The theme of Stephen's narrative was "Experiencing caring and support and staying active through adversity during the journey of healing". When I first met Stephen he was awaiting cardiac surgery and a mitral valve surgery on a cardiology unit. He had been admitted to the study hospital after spending two days in a community hospital. Stephen identified that throughout his hospitalization and stay in rehabilitation the caring attitude of staff and supportive environments helped him to heal after surgery. In addition, he recognized his role in actively participating in his recovery was essential:

I'm doing exactly what they tell me to do. When I get up, I don't stay in my pajamas or bathrobe all day. I get dressed. Because if you keep your pajamas on, and bathrobe, you don't want to do a thing all day.

The theme of Allen's story was Facing role changes while recognizing the need for support. Allen was lost to phone follow up after his initial interview; the preoperative interview took place while he was awaiting cardiac surgery. Instead of attending college, as a young man, Allen helped his family and ran a family business in Maine. Allen shared the importance of his work to his identity, "I ran that business [heavy emphasis]. I am that business [heavier emphasis]". Throughout his life, Allen was "the giver" in his family; he was the person that would be sought to succor or give help to others. With the abrupt change from being healthy to having a heart condition, Allen recognized his role had changed; now he needed help and support from others. Allen found the greatest challenge he faced while in hospital was the sense of

separation he experienced from friends and family in the hospital environment and related that he had experienced episodes of confusion while in the hospital awaiting surgery.

Doug's theme was keeping "Coping with loss and healing through reliance on faith and community". Doug was awaiting cardiac surgery on a medical floor when I met him and his daughter was present during our interview; she was actively involved in helping him in his care and she had a background in health as she had been trained as a paramedic. Doug's narrative at this time point focused on the events that had brought him to the hospital, but he also alluded to the loss of his wife, who had died four years prior, almost to the day of his hospital admission. Doug verbalized in his narrative his sense of his wife as still present in his life and this awareness help him on a day to day basis. In addition to facing cardiac surgery, Doug had had a serendipitous finding on his preoperative CT scan that showed a finding on his adrenal gland. After surgery, Doug related the "good news" that the test on his adrenal gland had come back normal; he related that the concern had been that it could have been a malignancy. In terms of his recovery from surgery, Doug related he felt "I think I am still a work in progress, because my endurance is not what it should be...". Despite continued challenges with fatigue Doug verbalized a sense of resolve in participation of his care and participation in rehabilitation, "Right now my attitude is I want to get the most out of it I can...". Despite continuing to miss his wife, Doug related how his religious faith, family and community helped him to cope with the loss.

Cynthia's story theme was "Working to accept changes and face health challenges while longing for her spouse" I met Cynthia when she was awaiting cardiac surgery on a cardiac medical floor in hospital. Cynthia shared the initial events that had brought her to an outside

hospital, and that she suffered periods of confusion and being “out of it” initially in her hospitalization. Cynthia related she still smoked cigarettes; remarking it was her “one vice”.

Cynthia related her outlook and feelings about waiting for surgery:

...of course I’m a little bit nervous. So, I didn’t sleep good last night. I don’t expect I’ll sleep good tonight. So I figured, well, I’ll try to take a little nap this afternoon. I did take a little nap but it wasn’t very long. [Cynthia laughing]. Yeah. Well, it’s like I told the doctor, I said, “ You know if things don’t go right, it’s okay, but I’m not planning on going anywhere.” Cynthia laughing]. So, of course the kids don’t want to hear that, so.... [Cynthia laughing].

In asking Cynthia what had been challenges during this time, she mentioned how she missed home, and also her husband, who had died eleven years ago. This was the only interview with Cynthia, I discovered when recontacting her one month later that she died after her operation, on postoperative day two.

Reflection: This was a very difficult interview for me to code, as the participant passed away two days after surgery. So, to me it was emotional to listen to her words, and feel sad that she did not survive. I found out that she had passed when I called for her second interview and her daughter in law told me she had died in the hospital. I was shocked and felt sorry that I had called and may have upset the family, but she (the daughter in law) seemed grateful for the call and did not seem distressed.

Thematic Findings of Narrative Analysis

As evidenced by the exemplars presented, and by the synopses of other participant narratives, because of the unique subjective nature of human experience, each individual participant’s narrative had distinctive characteristics. In addition, because participant narratives encompassed a similar chronology of experiences, there were also mutual characteristics shared between stories. Through narrative analysis of interview content there emerged shared themes, as

the voices of participants brought forward what was meaningful to them in unfolding stories about their experience of cardiac surgery. Narrative themes that emerged in this study represented participant experiences as processes that unfolded over time. Following content coding of each participant story, a comparison of stories across participants was conducted to identify shared thematic content.

The overarching story of older adult experience of cardiac surgery can be described thematically as: *Moving toward healing: engaged in and appreciating life while conscious of time passing amidst the primacy and struggle of the symptom experience.* The dimensions of this story included three major themes: Each of these three themes will be discussed in this section on thematic findings.

Theme one: Engaged in and appreciating life while conscious of time passing.

Engaged in and appreciating life while conscious of time passing was a shared theme of the story of the older adult experience of cardiac surgery. This theme of engagement emerged from in vivo coding of participant narrative and it encompassed dimensions of participant involvement in activities and work, partaking in, appreciating social relationships and accessing these supports, as well as participant's recognizing their own mortality and experiencing grief and loss during their recovery from surgery.

Participant narrative recounting life as an older adult prior to surgery conveyed a sense of being busy and involved with activities of daily living, being engaged in communities, participating in enriching social and intellectual pursuits and in some cases, continuing to work in paid employment. Of the 13 participants, four were working part time prior to their hospitalization and two noted they were volunteering in the community. Some participants

related that they had wanted to continue working, but had stopped due to their health concerns. There was richness to the detail of the activities that each participant pursued with, at times, a realization that continuing to work was a vital part of who he or she was. Work is what they wanted to do and retirement per se was not desirable.

Allen who had retired from running his own business when he was in his seventies epitomized this sentiment. Allen's work ethic dominated his business career and he proudly described how throughout his career not only how he managed and led his business enterprises but also how he cared for his employees and family as well. As he awaited cardiac surgery in the hospital, Allen related how he had sought another job, speaking in a staccato style of speech that punctuated and emphasized his words:

I couldn't stand not working cuz it would drive me crazy if I didn't work. I wouldn't know what to do. Yup. Get up and lay in bed all day. Take a shower at nine o'clock. Eat breakfast at 1030, well at two o'clock you don't know what the hell to do. So a friend of mine said, 'Do you have any work? What's the matter with you?' I said, 'I'm going nuts!' He said 'What's the matter?' I said 'I don't have an effin thing to do'. 'Right', he said, 'Why don't you get a job?' I said 'Where?' He said at [----]. 'I said can you get me a job there?' He said 'Yeah!' 'Take care of it for me'. Sure enough, he got me my job six years ago so I work at [X]. I'm what they call an on call person.

Another participant, Will, also expressed a desire to remain working as an older adult. Will ran a family owned and operated retail stores throughout his career; then, with retirement, he realized he wanted to continue to work in retail:

Yeah, I retired at sixty-five but I couldn't stay at home. After we sold the business down the Cape we came back ...to Maine. We started building the house ...and in between the house being finished and getting there, I started to get antsy again. I didn't want to go back into business again. So I went to Walmart and made out an application to Walmart. So I've been working at Walmart for ten years.

In other participants the theme of engagement pertained not just to activities such as jobs and leisure interests, but also to relational engagement with family and community. Throughout

their stories, participants related how family and friends assisted them during the process of recognizing a health concern, seeking care, decision making prior to surgery, advocating for them while receiving care and supporting them in their recovery. In addition to family support, participants noted the importance of social networks of friends and church communities. These supports sustained study participants through the process from hospitalization through recovery at home.

The importance of the role of family in supporting and advocating for the participant was illustrated in narrative shared by Will, as he awaited cardiac surgery. Will emphasized the important role of his daughter, a registered nurse, who had helped him navigate his healthcare and interpret health information:

Yeah, well I don't make a move without my RN telling me what to do. In fact, when we came down to talk to [the doctor]... my daughter came with us and she's the one who asks all the questions.

Another participant, Allan, by self definition a gregarious individual, described his need for support during hospitalization and how he experienced of isolation while awaiting cardiac surgery:

...so the hardest thing for me, right now, you know, is I'm separated from everybody...I have a lot of friends, and I am separated from them and so fortunately my daughter will be here, and she spends the whole afternoon...one young fellow who I have been friendly with for twenty five years, I was really friendly with his father, (chuckles) [] is his name is, he was here yesterday, all day...and other than that its...I am not used to being alone.

Multiple participants spoke of an overarching sense of community, that is, the experience of their social networks of friends and family coming together to help them both prior to and after surgery. Doug, who had a large family and a large community network through his church, related the positive aspects of this support as well as the sense that, at times, it could be overwhelming:

Well, I've got a lot of support. I think that's one of the things that's helped me. My family here and my extended family in the church that I go to. I have, it was amazing how much support, I was at the point where I couldn't handle it for a few days. People from church, and friends that are in contact and that type of thing. That was a huge support to me, especially when I first got home.

A particular aspect of the theme of engagement that emerged from participant narrative involved the loss of relationships because of a past death of a loved one or because some participants experienced an acute loss during their hospitalization and recovery. Ralph was in the ICU after his surgery and he learned from his daughter that his son had died. Jill was in a skilled nursing facility when she learned from her daughter that her brother had died. Other participants had experienced in the past the loss of a spouse, divorce, the loss of independence through illness, or the loss of a parent and they shared these experiences and responses in their narrative. Some participants explicitly recognized that the experience of being hospitalized had reignited their experience of loss because of their need for more support during a difficult time. Christine's husband had died eleven years ago. She related this sentiment, while awaiting surgery in the hospital, saying, "It is difficult. I miss my husband, a lot. I mean, more so at this point".

Other participants experienced the timing of an anniversary of a loss coupled with the changes they were experiencing in their health and well being. Doug described how the anniversary of his wife's death this impacted him and how helpful a church member's support and his spirituality was in helping him during hospitalization:

I'll give you an indication of what people will do for you. I was in the hospital on the day of the anniversary of ... [my wife's] death. And I always would go to her grave and put flowers on it [Doug sobbing]. Excuse me. Losing my emotions. Anyway, a church member came in and when he heard that I couldn't go, he did. Excuse me. So those kinds of things help. There are a lot of good people in the world.... [In my religion] we

believe we can be together after this life, so that has helped me...not together physically but still together spiritually.

During the preoperative and postoperative experience, some participants had to integrate the process of recovery and healing in the face of experiencing an acute loss. During a postoperative interview, Ralph broached the news of the loss of his son during his hospitalization and ICU stay.

[Since]... [t]he last time I talked to you, I lost my little son (pause) I expected it. He uh, he was, from 14 to his early 20's, (pause) he was quite a drug addict. It was no surprise. Yeah. Anyway, uh, my youngest daughter is the one that took it real hard. Her and him when they were kids they were always, one supported the other.

In addition to the experience of loss during hospitalization and recovery, there was also a general awareness among participants that time was passing, that they were aging and that their time to live a full life was limited. In sharing their story, participants often tacitly or explicitly reflected on their age when telling their story and talking about their work. This was illustrated by Brad's observations as he approached surgery:

And I'm going to be [octogenarian]. I realize all these things are catching up. And it's never gonna be like it was when I was in my twenties but I want to be able to enjoy these things, what years I've got.

Some participants, such as Brad, reflected a conscious awareness that things will continue to change and this change brought the potential for a loss of health and independence associated with aging. Other participants recognized that their older age impacted the risk level associated with their surgery. In her preoperative interview, Patty noted:

I mean, there are a lot of doctors that wouldn't even do [surgery]... on an [octogenarian] woman. In fact, I teased the surgeon. I said the reason is you just want to add this to your resume. [Patty laughing] Not that he needs anything to add to his resume because he's got quite a good one.

Theme two: Moving forward toward healing. *Moving forward toward healing* was a shared theme of the story of the older adult experience of cardiac surgery. Like the theme of engagement, *moving forward toward healing* encompassed dynamic processes that participants partook of as a part of their recovery and this response can be described as a fluid shift of participant experience to actively pursue the goal of healing and recovery following surgery. The term healing is used to characterize this theme because it is representative of a holistic description of the integrated psychological, physical, spiritual and social processes that encompassed the experiences of participants over time. The theme of moving forward toward healing emerged from in vivo coding of participant narrative and encompassed dimensions of participants' striving for acceptance of changes and looking ahead to the future, as well as self recognition of the importance of being active participants in the process of recovery.

Striving for acceptance of changes and looking ahead to the future. In relating their stories, participants reflected on the present changes in their lives associate with surgery including such as lifestyle adjustments due to their health, as well as past changes they had faced in life, such as circumstances related to the loss of a spouse, and lifestyle changes due to retirement. In discussing the changes that they faced, participants described a diversity of approaches as they strived to accept change in their experience of cardiac surgery. Participants acknowledged that the changes they faced could be unwelcome, that the changes were difficult to accept, often acknowledging that they faced a lack of other options and so that they had to become reconciled to accepting these changes. Cynthia's description of the changes in her life prior to hospitalization is reflective of the how many participants viewed change and acceptance:

I've never been happy with the idea that I had to leave, sell my home and move in town into senior housing. But I couldn't maintain the house, so that was the choice. And I'm

one; I'm the kind of person that it's like, okay, that's the way it is. I mean, whether you like it or not. So you have to live with it the best you can.

Multiple participants related how they strove for acceptances of changes; Patty attributed her ability to accept the need for surgery to childhood experiences in which she did not have choices regarding frequently changing residences in her childhood. Other participants attributed their acceptance to a conscious cultivation of acceptance; John remarked on "the Zen" of accepting what he could not change. Harriet noted explicitly that a sense of trust in her caregivers was essential to being able to accept the process of hospitalization, surgery and recovery. Without that sense of trust the experience would have been very difficult. Other participants remarked that it was part of their personal approach to accept changes brought on by being unwell because of their "easy going" personality, some participants found their spirituality and faith supported them in the process of facing change and uncertainty. In the period awaiting surgery, John was not alone in noting that his faith in God was essential to coping with uncertainty of that time period; he related "I believe in Jehovah God, and I just I pray to him all the time about the operation. I'm a little concerned about it. I'm not afraid about it. I trust my Jehovah God that I love".

An aspect of the theme "striving for acceptance" included participants accepting rehabilitation after surgery, despite their wishes to return home. Nine of the participants in this study spent time following hospital discharge either in an acute rehabilitation setting or in a skilled nursing facility. Participant narrative described a formal network of supports that promoted recovery in these health facilities, but also recognized limitation in the care delivery, as noted by Harriet's recollections:

Well, let me tell you, I am so impressed with nurses and doctors and what they do for people. I mean, I was in the hospital a long while and in the rehab. I mean, relatively long, you know of course it was not forever, but it was quite a while to be in the hospital. And I saw a lot going on that I don't think the public realizes what you do for people. I mean, you humble yourselves for everyone, anything they need. But a huge observation I made, I think you're terribly, terribly short-handed. Am I wrong?...Well, for instance, mostly at the rehab center when you know, if a patient needs attention and pushes the little button. Sometimes it's almost half an hour before somebody comes to help them. And I'm not saying they're being negligent, I mean, I don't think they would intentionally ignore anybody. But it would be wonderful if they had more people to help

For some participants, "striving for acceptance" encompassed a sense of disappointment and discouragement when the benefits of surgery did not meet their expectations. One participant, Will, had a complicated course, but progressed well after surgery. He needed to return to the hospital following discharge for emergency surgery to remove his gall bladder. The operation on his gall bladder involved a clip that came off and needed to be replaced and this further complicated his recovery from cardiac surgery, necessitating blood transfusions, another stay at the hospital and prolonged weakness and debilitation after surgery. Will described his feelings after these events:

The only thing is, is very discouraging is that I had the operation. I had a quad bypass. Now my blood pressure is still high and when I came out of rehab I was taking 5 pills, both for my heart and my diabetes. So my diabetes is somewhat under control. And, like yesterday, when I went to rehab the nurse gave me a receipt to get another med for my high blood pressure. And now I'm up to, when I came out of the hospital I was only taking 5. Now I'm up to 6 or 7. And you know, they don't take one away and give you another one. They just keep on adding on, adding on, adding on. And this is a downer too.

Despite these feelings of discouragement, and in the midst of accepting changes, participant dialogue also evoked a sense of hopefulness as they looked ahead to the future and anticipating a full life after surgery. Participant's narrative showed a commitment to being involved in relationships and wanting to partake in the "rhythms of life" (e.g. the activities they

engaged in prior to surgery) which served to motivate participants to look ahead hopefully and to mark their progress in recovery. John, reflected on his fears of failing to fully recover; even as he nurtured the belief that he would be able to recover his health:

I feel real deep down in my heart, I feel that in time that will be the way it is. I'll get up and move like the way I used to move. But I'm not going to rush it. I'm holding back a little bit. I'll go walk and get things out of my mind and then just walk and think about things or something and- I just don't want to fall back, you know. Fall back one more time and I'm in trouble, you know. It's like being crippled for life. I don't think I could live like that.

Participants related wanting to resume their jobs, their hobbies and outdoor activities. Brad spoke about his the annual journey to northern Maine he had planned for after surgery:

We go [fly fishing], two of my sons and I go for a week every... June. That was the other thing I told the doctor. I want to get in and get out [of the hospital] because I've got to be ready for fly fishing....

Self awareness of the importance of being active participants in the process of recovery. Participant narrative reflected active strategies they used to negotiate the challenge of recovery from cardiac surgery. Once home, participant narrative described networks of support services of nursing services and physical therapy, as well as follow up appointments made with cardiothoracic physicians, primary care physicians, and cardiologists. Of the ten participants interviewed at one month after surgery, five were enrolled in a cardiac rehabilitation program. Of the five participants not enrolled, three had had physical limitations that precluded enrollment in a rehabilitation program, and two others were contemplating enrolling in a cardiac rehabilitation program. Multiple participants described pursuing an active role in their recovery and explicitly noted the importance of increasing activity while observing prescribed activity limitations, monitoring blood values (e.g. warfarin, glucose), weight, diet and

blood pressure, and following exercise programs. For example, after discharge from a skilled nursing facility and with the help of her visiting nurse, Patty kept track of her anticoagulation therapy and monitored her blood sugar levels. Patty came to recognize the need to “take charge” of her care:

The home health nurse is coming several times a week and that’s been good. She’s very good at helping me learn how to use the darn glucometer. I’m just starting for the first time to take charge of my blood count, which I had not done before. ... I had been classified as a diabetic, but I was sort of ignoring it. I was not paying that much attention to my diet. And I was counting on my regular A1 C test to pass (pause) and so I was getting away with not bothering to count. But I’ve got one of those little gadgets now.

At one month after surgery, Tim remarked on his understanding of the importance of being active as he considered enrolling in cardiac rehabilitation:

I don’t know how successful that will be, but I went down and talked to the [physical]therapist there and they assured me that they’d, I guess they monitor extremely well there and they wouldn’t let me do too much. They’d keep track of me. I don’t know how much I’ll be able to accomplish, but, uh, they agreed that I’d only do what I could do..... I’ve learned that much in this thing. What was it somebody was telling me? For every day I sit and do nothing it’s going to take me three days to recover. So, I’m really making a concerted effort to get exercising.

Theme three: Struggling with the primacy and burden of symptom experience.

In addition to the themes of engagement and moving toward healing, an additional emergent theme after cardiac surgery was the participant experience of struggling with burden of symptoms that dominated day to day existence. The theme of struggling with the primacy and burden of symptom experience emerged from in vivo coding of participant narrative. The term “primacy” refers to the dominance of physical and psychological symptoms for participants during their recovery. Participant dialogue, particularly at one month after surgery, detailed struggles to overcome a constellation of postoperative symptoms that at times felt overwhelming.

The theme of struggling with the primacy and burden of symptom experience is evoked by Tim's description of fatigue in the ICU after his surgery and the weakness that prevented him from being able to eat without assistance after surgery:

My energy level's [inaudible] hard....I couldn't believe ..., how far down I would go, I wouldn't have believed them. I couldn't even pick up my arm. My hand, I lost the use of it. Then when I started to get better, they'd bring me lunch ... [voice trails off]. It was an ordeal.

This theme encompassed not just postoperative discourse, but preoperative narrative. The dimensions of this theme encompassed the chronology of participant experiences and included participants noticing changes and alterations in physical symptoms prior to surgery as well as participants struggling with the burden of symptoms after surgery.

Noticing a change: reflecting on alterations in physical symptoms before surgery.

Most participants shared a detailed accounting of the acute events that had brought them to the hospital during the preoperative interview. In recounting these events, they also noted that they had had prodromal changes in their well being, ranging from days to years in advance of the acute event that led them to cardiac evaluation and /or hospitalization. While acute physical symptoms such as chest pain and shortness of breath may have been the precipitating factors that brought a participant to the hospital, multiple participants noted nuanced changes in physical symptoms prior hospitalization. Participants did not appear to recognize the significance of these changes in physical symptoms so consequently they did not seek medical advice. Often in recounting the episode that had brought them to seek care, participants noted that they had been aware of changes in physical symptoms prior to the acute episode and that they made adjustments in their lifestyle, but they did not appear to recognize that the changes were warning signs of cardiac disease. Upon reflection, during the interview process, participants became

aware of prodromal changes in their health and recognized that the symptoms of fatigue and other “occurrences” were significant indicators of changes in their health. In relating their experiences, participants usually framed the change in terms of their functional ability; noting that they were not able to perform their usual activities and in some cases, curtailing usual activities to adjust to the change. One participant, Brad, notes his symptom of fatigue progressing to more frequent episodes which he found frightening and which eventually spurred him to seek medical advice:

In late summer, early fall, I just noticed that I was running out of steam. Just didn't have any energy to do the things that I want to do and normally have done. And so through most of the summer, late summer and early fall I ended up hiring kids to roto-till my garden and do the things that I normally do. I didn't feel really bad, but I had periods where I had light-headedness and almost dizziness. And a couple of them that were [pause] I didn't pass out but a little bit scary, you know?

Tim elucidated his dilemma of trying to ascertain whether or not his symptoms were significant or not:

I wouldn't have gone down to [the hospital] at all if I hadn't got to the top of the stairs one day and felt like somebody was standing on my chest [Tim laughing]. And then I said, 'Well, maybe I better go'. But I'd had chest pains two weeks before that. When you get older, I find that lots of times when there's an occurrence you mentally wonder whether this is something happening or whether you're just getting old. To tell the difference between old age and occurrences sometimes, it's difficult.

Participants recognized, often in reflection, that the changes in physical symptoms they had noticed were indeed significant and in some cases ended up evolving into life threatening events. For some participants, this process of recognizing changes in health had occurred also resulted in them being more reflective about their lives and questioning decisions they had made in the past. For Harriet, this brought awareness that working too hard may have played a role in her

hospitalization. Harriet worked as an elected public official and she remarked on the demands of her job:

... we have this business of having to run every 2 years and so you have to campaign. And that is hard work if you do your job and try to meet all your constituents.....Many, many miles, so I was working extremely hard.... I've knocked on over five thousand doors this summer, and probably contributed to my illness without even knowing it.

Struggling with the primacy and burden of symptoms. Multiple participants reported a spectrum of postoperative symptoms including pain and discomfort, severe loss of appetite after surgery, unintentional weight loss, problems with constipation, as well as extreme fatigue and difficulty sleeping. In general, participants related that the preoperative symptoms that had brought them to the hospital were stabilized. However, postoperatively, a constellation of physical and psychological symptoms made day to day existence a challenge. Thematic content of participant narrative at one month after cardiac surgery suggested that symptoms were overwhelming during the acute phase of their hospitalization and recovery and that participants experienced a sense of loss of control in that time frame. The experience of dealing with the burden of symptoms, struggling to function and feeling overwhelmed by the experience can be seen in participant dialogue in both preoperative and postoperative narrative.

At the time of the first postoperative interview many participants suffered from fatigue, and Patty, Jane, Tim, and Will had upper respiratory tract infections, thus interview times were shortened to mitigate burden to the participant. In recalling their experiences, multiple participants related that periods during their hospitalization were difficult to recollect, or that their recollections were blurred. Patty's description of her ICU experience is characteristic of this sentiment:

I don't know how long I was in ICU, maybe two days or something, two to three. It's a blur because you feel so rotten when you're in there that you really aren't paying much attention, if you can help it [Patty laughing]. Do you know what I mean?Well, it is kind of a blur because you're so (pause) your body's so traumatized for goodness sake. And you're just doing what you have to do.

The participant discourse on the experience of their symptoms focused on the all encompassing nature of the symptoms and the lack of control that participants felt in the moment as well as the struggle to make sense of what was happening, which on some levels, seemed to be beyond comprehension. This struggle to exist with symptom burden is articulated by Will:

I'm in and out of sleep. All day in and out, in and out. And I've gotten to a point now I can't sleep at night. I don't know why. I don't know if it's done something to my (pause) but I don't know I don't sleep nights. I don't know why. I've never had that problem before. It seems like as soon as I lay down for a night's sleep, I get short of breath and I wake up, like if I stay asleep I'm not going to wake up, so I have to wake up....I'm at a point where, instead of being thankful for all the help that I'm getting from my family, I tend to get nasty now, because I don't want to be in pain and I'm still in pain. ... I haven't thought about a thing. I just want to get rid of the pain and get well. That's all I want to do.

Unlike Will, some participants reported a profound loss of appetite after surgery that resulted in weight loss (greater than 30 pounds) and subsequent weakness as the most significant problems after surgery. Harriett described her experience:

Well the hardest thing for me was eating. I could not eat. Everything just tasted metallic. I knew if I tried to swallow it that it wouldn't stay down long. But I'm eating again and now I'm getting my strength back. It makes a tremendous difference. Once you get your taste buds working correctly again... And of course because I didn't eat, I didn't have strength. And I was prone to fainting. I didn't, I only really passed out once, but I had several faint spells.

Other participants reported that fatigue and loss of strength was the most significant problem for them after surgery, as related by Doug at one month after his operation:

Yeah. I tire quickly, there's no doubt about it. I was amazed at how much, you know, you're on the table for what, two or three hours? And it seems to suck two or three years-worth of exercise and life out of you. When you come off there you've totally lost all of

your strength and muscle tone and everything else. By the time you lay around a few more days, you get up, it's amazing how weak I was, but it was a major thing.

At two months after cardiac surgery, all but one patient had returned home. Participants related continuing challenges concerning symptoms they experienced postoperatively as well as the return of chronic symptoms such as back pain and leg pain that had affected them preoperatively. Jane described a problem with chronic leg pain which had bothered her prior to surgery and which persisted after surgery

I also had had a problem with my leg, I mean, it was swollen and it was black and blue and [the doctor]... didn't know what it was. And even as time went on nobody could really diagnose it. But they decided it was because I was taking Coumadin. And that somehow or other just a few days before this, my Coumadin level was 4.9, which is quite high. So they sort of said, "Well that's why you're- this blood is getting down in your leg and so forth." So I guess I accepted that. But to this day, I do not know because, you can't see it, but I can hardly bend my leg from side to side. But in the meantime this leg was bothering me and I was a little more concerned about that, personally, than my heart [Jane laughing]. But nobody else was as I said to my family.... I said, "They don't pay much attention to anything below my waist because they're just interested in the heart." Although that's not totally true, but that was my reaction.

The challenges of the physical and psychological experiences of symptoms after surgery dominated participant discourse especially at one month after surgery. Participants struggled to manage in their recovery with the weight of the symptoms they experienced, and reflectively wondered if the challenges they faced were usual or expected as a part of recovery. Despite the physical and psychological difficulties that each participant faced in their recovery, participant dialogue reflected a resolute approach to navigating their recovery as they strived for acceptance of changes over time, looked ahead to the future and became self aware of the importance of their active participation in the process of their recovery.

Summary of Results

Individual participant stories were analyzed and two of these stories were presented to

serve as exemplars of the older adult experience of cardiac surgery. These exemplars serve to highlight the distinctive and particular nature of the older adult experience of cardiac surgery. Brief narrative summaries of the eleven other participants in the study were presented to contextualize the diversity of participants' experiences after cardiac surgery.

In addition, shared themes across participant stories were analyzed and explored. Participant narratives encompassed a similar chronology of experiences, thus sharing a mutuality of experiences over time between stories. The shared themes that emerged from participant narrative brought forward what was meaningful to participants as their experiences of cardiac surgery unfolded over time. Participants were interviewed prior to surgery while hospitalized in face to face interviews and then by phone at one month and two months postoperatively. Narrative themes that emerged thus represented participant experiences as processes that unfolded over time; these were described by the overarching older adult story of *Moving toward healing: engaged in and appreciating life while conscious of time passing amidst the primacy and struggle of the symptom experience.* The dimensions of this story included three major themes: the theme of moving forward toward healing representative of the integrated psychological, physical, spiritual and social processes that encompassed the experiences of participants across the perioperative period and two months afterwards. This theme encompassed dimensions of *participants' striving for acceptance of changes and looking ahead to the future,* as well as *self awareness of the importance of being active participants in the process of recovery.* Acceptance of changes, as well as active participation in decision making and health maintenance were described as participant's shared their story of cardiac surgery. Participant discourse focused on keeping track of their health, with supportive care services.

This included navigating a stay in rehabilitation facilities, recovery at home as well as enrolling in a cardiac rehabilitation program.

The theme engaged in and appreciating life while conscious of time passing encompassed dimensions of participant involvement in activities and work, partaking in and appreciating social relationships and accessing these supports, as well as participant's recognizing their own mortality and coping with grief and loss experienced during the healing process. The discourse of older adults included a search for meaning within narrative of engagement and involvement. This was manifested by being busy, working and recognizing concurrent roles and responsibilities, participants also were increasingly aware that time was passing, while some were coping with the loss of a family member that occurred during their hospitalization. Others were actively grieving the loss of a spouse during their recovery. Social supports, including family members and community members, were crucial in providing help to these older adults throughout their continuum of care.

The theme of struggling with the primacy of symptom experience encompassed the dimensions of participants noticing changes and alterations in physical symptoms prior to surgery as well as participants struggling with the primacy and burden of symptoms after surgery. In recounting their stories, participants reviewed the events which precipitated the need for acute hospitalization and reflected on experiences, which in retrospect, may have indicated that their condition was worsening. After surgery, participants were struggling with symptoms which dominated their discourse and, at one month after surgery interview length was limited in order to mitigate participant burden. Across the spectrum of patient narrative, symptom experience dominated participant discourse. Preoperatively, while in hospital, participants

related nuanced accounts of the symptom experience that brought them to the hospital. Many participants noticed a prodromal change in their ability to perform usual tasks at home prior to experiencing an acute change which brought them to the hospital. After cardiac surgery, participant discourse reflected struggles with such symptoms as pain, difficulty sleeping, fatigue, depression and loss of appetite and weight loss.

Chapter 5

Discussion

Introduction

This study generated narrative accounts from thirteen older adults who experienced cardiac surgery beginning with the preoperative period to two months after surgery. The overarching narrative theme of older adult experience of cardiac surgery can be described as: *Moving toward healing: engaged in and appreciating life while conscious of time passing amidst the primacy and struggle of the symptom experience.* The unique particular story of each participant unfolded and shared thematic content of participant discourse emerged which can be instrumental in informing knowledge of the older adult experience of cardiac surgery.

Overview of Findings

Participants described looking forward to healing, striving to accept changes and participating in their recovery while expressly recognizing the importance of committing to an active role in regaining health. For some participants, life story e.g. biographical narrative on childhood, young adulthood, or life as an older adult was a starting point for narrative, while other participants focused on the acute health issue which necessitated admission to the hospital. Older adults' stories reflected an appreciation of social relationships, work and activities as well as conscious awareness of time passing, implicitly or explicitly discussing their age within their narrative. Participants discussed how social supports including family, friends and church communities were essential in facilitating their recovery.

Several participants, while navigating the experience of cardiac surgery, were also negotiating a personal loss. Multiple participants communicated that they noticed a change in

physical symptoms prior to the acute episode that brought them to the hospital. Participants experienced a constellation of physical and psychological responses after surgery and the acute recovery period was characterized as a struggle to heal amidst the primacy and burden of symptoms. The discussion that follows in this chapter will present these thematic findings that emerged from narrative analysis in light of present knowledge of older adult experience of cardiac surgery and serve to expand a contextualized understanding of the older adult experience that can inform nursing theory, research, practice, education and policy.

Findings in Relation to Theory and Nursing Knowledge

This study's findings show the importance of the processes of engagement, social relationships, physical and psychosocial challenges, and the role of acceptance, faith and spirituality in the older adult experience of recovery and the journey toward healing from cardiac surgery. The theme of *engaged in and appreciating life while conscious of time passing* emerged from narrative imparted by participants in this study. This thematic finding is congruent with Erikson's (1959) aging theory and core adult developmental concepts of generativity versus stagnation and integrity versus despair. Initial theoretical work by Erikson suggested that generativity, (i.e. an individual's self appraisal of contributions made to future generations), was a developmental task of middle adulthood (from 40 – 65 years) (Krause, 2009). Later research suggested that the stage of generativity persists throughout the older adult period (greater than 65 years of age) and this continued generativity is an important part of successful aging (Erikson et al., 1986). This evolution of the conceptualization of human development conceived of old age as culminating in "vital involvement", in which the successful negotiation of each developmental

stage, beginning with childhood, culminates in a rich fruition of older adult involvement in the rhythms of life (Erikson et al., 1986).

Discourse in this study reflected Erikson et al. (1986) concept of generativity as participants described leisure, continued work and volunteer contributions, and family relationships that they were engaged in prior to surgery, and that they looked forward to participating in after surgery. Participant dialogue of engagement reflected the present oriented stance of older adults in current activities, work and social relationships while concurrently implicitly or explicitly recognizing the temporality of life. Participant's consciousness of time passing, of being older and aging in the midst of needing cardiac surgery, mirror Erikson's (1959) crisis of 'integrity versus despair'. This stage of older adult development was characterized by Erikson (1959) as the process by which an individual, through introspection, develops a meaningful and coherent understanding of their life. The results of this study suggest that for older adults there is an intriguing interconnection between engagement and life review.

The theme of engagement that emerged from participant narrative in this study also resonates with the nursing theoretical work of Reed (1991a) on self transcendence. Reed (1991a) defines self transcendence in aging as "the expansion of one's conceptual boundaries inwardly through introspective activities, outwardly through concerns about others' welfare and temporally by integrating perceptions of one's past and future to enhance the present" (p.5). Reed (1991a) studied self transcendence in the oldest old and found themes of generativity, introspection, temporal integration and body transcendence. The middle range theory of self transcendence, and its measure, has been studied across the developmental lifespan (Reed, 1991b). Correlates of the self transcendence measure to mental health have been reported in

older adults, including enhanced quality of life, decreased depression and increased interest in self-care (Reed, 2008). The findings of this study suggest there is the need for further theoretical work to be done to explicate how self transcendence is connected to healing in recovery and how nursing practice can support, promote and sustain self transcendence in older adults.

Study findings and relationship based care. Nursing grand theory that focuses on the ontological basis of care for individuals across the lifespan necessarily addresses aging and the older adult in a global manner as a part of the disciplinary knowledge base of human processes. The Roy Adaptation Model (Roy, 1988), a nursing grand theory, provided the theoretical basis for the construction of two middle range nursing theories that focus specifically on nursing practice and the health care of older adults. One middle range theory, proposed by Flood (2005), was developed as a blended theory based on successful aging theory and the Roy Adaptation Model (Roy, 1988) and suggests a basis for nursing interventions that address human adaptive processes to support the mental, physical and spiritual needs of older adults to promote successful aging.

Flood (2005) suggests foundational coping processes of older adults are comprised of functional performance mechanisms (focusing on physiologic inputs), intrapsychic factors (focusing on human adaptive responses to the environment), spirituality (relation to a greater power or being) and gerotranscendence (a shift in worldview and relationships based on wisdom). Flood's (2005) theory is a useful starting point to consider holistic nursing care of older adults facing cardiac surgery because it suggests the domains to which to direct nursing interventions that support the coping processes of older adults i.e. supporting and promoting individual adaptive responses to environmental inputs.

While informing nursing practice, Flood's (2005) theory does not address explicitly the experiences of engagement and social support that were evoked by older adults in this study. This limits the explanatory power of Flood's (2005) theory and suggests a direction for expanding the conceptual elements of this middle range theory to include the importance of a social construct within this framework.

In this study, participants related their satisfaction with the care they received, the importance of trusting in their caregivers, and how that trust was important to their recovery. The importance of trust and relational caring experienced by participants resonates with the foundational theoretical work of Peplau (1952, 1991, 1992) which explored communication and trust in care giving. Peplau's (1992) seminal work on the therapeutic nature of the nurse-patient relationship included core concepts of presence, empathy, empowerment, patient centered objectives and unconditional positive regard and the development of the nurse patient relationship encompassed the processes of orientation, working and resolution. The caring dimensions of the personal relationship between nurse and patient are also the underpinnings of the theoretical work of Leininger (1984), Watson (1979, 1985, 2002) and Newman (1986). Watson and Smith (2002), building on these caring traditions and the conceptual understanding of relational care in nursing, proposed drawing upon multiple theoretical traditions of caring science and the science of unitary human beings to further the basis of relational care as an imperative of the discipline of nursing. This discourse (Watson and Smith, 2002) proposed exploring the commonalities in dominant discourses of nursing theory and has recommended a Unitary Caring Science to unite and inform the foundation of nursing practice, recognizing that "...caring, as a relation way of Being Human,...engages our humanity" (p.454). This proposed

metaparadigm in nursing, referred to as Caring Science, is proposed as unique to the disciplinary focus of nursing and deserving of recognition and exploration using pluralistic approaches (Watson and Smith, 2002). Core concepts central to the focus of the discipline of nursing have evolved and been recognized as inclusive of the relational aspects of the nurse-patient relationship and include caring consciousness, mutual process, patterning, presence and meaning (Newman et al., 2008). Work by Willis et al. (2008) has explored this conceptual understanding and described these relational processes as “facilitating humanization, meaning, choice, quality life and healing in living and dying” as a central unifying focus of the discipline. Continued recognition and exploration of the essential nature of trust and caring in health care and its relationship to healing are pivotal in understanding and acknowledging the complexity, multidimensionality and subjective nature of the older adult experience of recovery and healing.

Strengths in older adults. In the literature reviewed in this study, anxiety and uncertainty were cited as central manifestations linked to the themes of adult experience awaiting surgery (Fitzsimons et al., 2000; Lindsay et al., 2000; McCormick et al., 2006). However, older adults in this study did not predominantly focus on uncertainty and anxiety in their narrative. Participant stories reflected themes of accepting changes, faith and spirituality as part of their approaches to facing uncertainty before and after surgery. An explanation of this disparate finding could be explained by the strength and vulnerability integration (SAVI) model which postulates that emotional regulation changes with aging; it recognizes that older adults have strengths in regulating their emotional health via strategies involving attention, appraisal and behaviors (Charles, 2010). With aging, more attention is given to positive stimuli as opposed to negative stimuli, negative experiences are quickly disengaged from, and self appraisal is present-

oriented with emotional goals of primary importance (Charles, 2010). The SAVI model explains the finding that older adults, in general, experience higher levels of affective well being and posits this is due to “ an awareness of diminished temporal horizons and the self-knowledge and social expertise gained from time lived” (Charles, 2010). This model’s tenets are congruent with the narrative themes of older adults in this study which focused on looking forward, focusing on the present with a conscious awareness that they had limited time ahead of them. According to the SAVI (Charles, 2010) model, in addition to the enhanced ability to self regulate, and essentially ‘be happier’, older adults also face increased physiological vulnerabilities when stressors persist over time which can disrupt homeostasis. Understanding the tension between and among the strengths and vulnerabilities that affect emotional well being in older adults can inform nursing care that supports emotional health during the stress of hospitalization through the recognition of these strategies in older adults and also through the development of psychosocial interventions that recognize and support older adult strategies for emotional well being. The congruence between this study’s findings and the SAVI model suggests the possibility of a blended model of nursing care utilizing the framework of the SAVI model and nursing theory for older adults with particular application to the acute recovery period.

The theme of “moving forward toward healing” emerged from participant stories of recovering from cardiac surgery. Despite the physical and psychological challenges of surgery, participants were resolute in choosing to have surgery, accepting the need to have surgery and working to actively participate in the process of recovery. This theme resonates with the Theory of Power as Knowing Participation in Change (TPKPC) (Barrett, 2010). Barrett’s (2010) theory derived from the Rogerian Science of Unitary Human Beings and the key postulates of openness,

energy fields, pan dimensionality, and pattern. Barrett (2010) describes her theory as “power as knowing participation in change is being aware of what one is choosing to do, feeling free to do it and doing it intentionally”(p.49). The interlinked dimensions of power are awareness of choices, freedom to act intentionally and involvement in making change (Barrett, 2010). In the course of the unfolding of their stories, participants in this study related their decision making with regard to cardiac surgery, noted their awareness of the choices they had made, and the intentional processes they utilized engaging with physicians and family in the process. A dissonant aspect of their process was the feeling of lack of choice due to the severity of their illness, however, once the decision to have surgery was made, participants, like Tim, were “committed” and worked to actively participate in their recovery and take charge of their health care needs. Despite the challenges of physical and psychological symptoms that could be debilitating, participants persevered as evidenced by the majority of participants participating in a formal cardiac rehabilitation program by two months after surgery.

Findings in Relation to the Review of Literature

Engaged in and appreciating life while conscious of time passing. The theme of *engaged in and appreciating life while conscious of time passing* contributes new knowledge to understanding older adult experience. It is notable in that it has not been reported before in the literature which has explored the preoperative experience of adults awaiting cardiac surgery. One explanation for this new finding is that contextual elements of previous studies differ greatly. As noted in the literature review, international studies of surgery (Fitzsimons et al., 2000; Lindsay et al., 2000; McCormick et al., 2006) on adult preoperative experience in Ireland, Scotland and Canada have focused on a younger group of adults (with mean ages of 59, 58.2 and 64

respectively), without a focus on older adult experience. Participants in the reviewed studies were awaiting cardiac surgery in their home settings for extended periods, sometimes over a year surgery (Fitzsimons et al., 2000; Lindsay et al., 2000; McCormick et al., 2006). In contrast, in this study, participants were older (mean age 80.8 years) and had an average wait time of four days prior to surgery. For these reasons, the experience of waiting for surgery and what was shared in participant narrative could reflect the vastly different experiences and composition of the groups who were interviewed.

Another explanation for the finding of the theme of *engaged in and appreciating life while conscious of time passing* is that narrative methodology, as a qualitative methodology, had the potential to elicit new findings, because participants were able to choose where they wished to begin their story and how they wish to recount it. Participants share what is meaningful to them, within the context of their identity. Understanding how an older adult is engaged in his or her life can inform nursing care and provide insight and nursing knowledge as the basis of relational care for that person.

An example of utilizing narrative that builds a foundation to relational health care is illustrated by the narrative of John regarding his passion for gardening. At his preoperative interview, John shared how he grew up on a farm;

I love working in nature. I was a little farm boy. I was always hoping it would probably be mine one day. That was something I really loved.

He communicated how his farm and gardening experience helped him understand how to manage awaiting surgery while in the hospital:

I try not to let it bother me, because I feel like, you know, like planting a garden. If you overdo something with a garden you're going to lose it. But if you sort of nourish it and take your time to make it to good health, I try to live according to that Zen, you know what I mean?

Over time, John recognized that he had had a change in his usual functional status when he realized he could no longer perform his routine gardening activities. John shaped his experience of symptoms within the context of his identity and what he enjoyed and had meaning to him:

I've been pretty good, pretty healthy. The last couple of years I've been noticing a change in myself. I was getting tired a little more. And I kept telling my wife, "I think something wrong here because I don't have that momentum." I'm always moving. I do things fast. That's how my body is, I gotta keep going. But anyway I noticed last year I had to stop several times. I used to hoe two rows at one time back and forth down the row and come up, no problem at all. But last year I had to stop.

John also referenced his recovery to his love of gardening and his ability to perform this garden work; he revisited his wonder at all he wanted to accomplish and how he had not planned to have surgery:

That's my life out there. I do try to work in my garden, the flower beds and all that sort of stuff. I have a lot of work to do here. People can't believe I do this all by myself. I've got ----, I've got two big gardens, I've got beautiful shrubs, small patch of ----, a row of trees, and oh my goodness. I never thought about getting sick. I never planned to do that.

Eliciting this narrative from John informs nursing care of John; his passion for nature informs how he expresses his health care needs across the spectrum of his recovery and it allows his caregivers to connect with John and his health care concerns in a context that is meaningful and significant for John as an individual. This study finding of engagement points to the importance of listening to patient discourse and building knowledge of the person over time to inform a nuanced relational understanding of the person's responses in health and in illness. Throughout participant narrative, engagement in social relationships was reflected in common themes of participant reliance on social support both before surgery, during hospitalization and after discharge. Participants noted that family members helped during acute health changes, visited them while hospitalized, and were involved in decision making about surgery. Multiple

participants remarked upon the importance of having a family member who could advocate for them in the health care system. Another aspect of this social engagement was the experience of changing relationships to family or friends due to loss. Multiple participants shared stories of enduring personal loss and grieving during their recovery. This thematic finding has been alluded to in the work of Raholm & Eriksson (2001) in which a woman recovering from cardiac surgery described the struggle of caring for her husband who later died of cancer. While some participants suffered an acute personal loss during the perioperative period, others were actively grieving the recent loss of a spouse, or a life event (e.g. divorce, moving out of home into assisted living facility). It is not clear from participant narrative if health care providers were aware of this challenge to participants and what measures were taken to assess and support the needs of participants and their families' in bereavement. More research is needed to characterize the experience of loss and to assess that care delivery has supports for loss and grieving in older adults and promote understanding of how individuals integrate these experiences as they heal from surgery.

Additionally, because older adults have a disproportionate burden of chronic illnesses prior to surgery, there is a need for exploration of how an older adult's self concept and identity changes and how the experience of "loss of self" may impact older adult experience in recovery after cardiac surgery (Charmaz, 1983). Recognizing that older adults have faced and may face personal loss during the perioperative period is essential to understanding individual responses to stressors, uncertainty and symptoms such as depression and anxiety. Acknowledging that older adults may experience personal loss during their recovery, or that the feeling of loss is reignited by the circumstances of surgery, speaks to the need for assessment that is individualized to

address the particular needs of the older adult as well as supporting the process of reconstructing relationships as part of the grieving process. Across systems of care, nurses need to be well positioned to assess for patient and family bereavement and for grief during the perioperative period, to learn what is important to patients in the process, access supportive services, such as spiritual care, and plan for patient and family needs following discharge. This echoes the importance of the nursing discipline's call for unitary caring science to serve as a foundation for the nurse patient relationship and inform individualized care based on the meanings of health and illness to the patient and family (Watson & Smith, 2002; Newman et al., 2008; Willis et al., 2008).

Struggling with the primacy and burden of symptom experience. The theme of *Struggling with the primacy and burden of symptom experience* resonates with a previously published study (Lindsay et al., 2000) which reported that adult lived experience prior to surgery can be characterized by themes of changing functional status, symptom distress and reflections on the benefits from surgery. A particular theme that emerged from participant interviews in this study was that participants noted prodromal changes in their well being, ranging from days to years in advance of the acute event that led them to evaluation and/or hospitalization. Interestingly, multiple participants described their prodromal symptom experience in terms of noting new limitations in usual activities they performed, echoing Lindsay et al. (2000) findings of participant concern about preoperative functional ability. This thematic content suggests that participant knowledge of functional limitations is nuanced and can broaden understanding of how individuals sense their health and respond to changes they experience. These participants only seem to recognize in retrospect that the loss of functional ability could have indicated

progression in their heart disease; possibly due to denial of their symptoms or a lack of knowledge of warning signs of cardiac compromise. While functional limitations have been validated in instruments, such as the Minnesota Living with Heart Failure (MLHF) questionnaire, which screen for heart failure in patients, these study results imply that it could be that contextualizing cardiac symptoms for patients, within their scope of daily living, could serve as a complementary means of initiating patient education on primary and secondary cardiac prevention. This type of individualized assessment of symptoms along with measures such as the MLHF questionnaire could serve as an adjunct to nursing care; helping patients process the meaning of symptoms within the context of their experience could be an effective approach to helping patients understand the significance of symptoms and when to seek care.

Fitzsimons et al. (2000), based on Mishel's Uncertainty in Illness theory, have proposed a preliminary conceptual model of waiting for cardiac surgery suggesting that there is an interaction of physical and psychological symptoms with anxiety and uncertainty playing pivotal roles during this period. Fitzsimons et al. (2000) model was developed from interviews with participants in a home setting with long waits e.g. over one year for cardiac surgery which is characteristic of the wait times in countries outside the United States. Most participants in this study showed an acceptance of waiting for surgery and acceptance of the uncertainty in the hospital prior to surgery and their narrative did not focus upon the anxiety and uncertainties in awaiting surgery. Unlike the sample of patients in Fitzsimons et al (2000) study, participants in this study were in an environment where there was close monitoring and treatment of their angina, thus potentially mitigating the symptom of anxiety due to symptom burden. Some

participants in this study found their faith and spirituality supported their acceptance of the situation and comforted them in waiting

Beyond the challenges of symptom burden at discrete points in time, this study and others point to the broad spectrum of physical and psychosocial responses of older adults across their experience of health when navigating the experience of cardiac surgery. It is clear that recovery from cardiac surgery is a process which poses exceptional physical and emotional challenges to older adults. The prevalence of depression and anxiety in cardiac surgery patients is high, depression and dysthymia has been estimated to affect 30-40% of patients who have CABG; and preoperative depression has been linked to increased morbidity and mortality postoperatively (Tully, Baker, & Knight, 2012). Reviewed quality of life (QOL) studies conducted at one month after cardiac surgery have indicated that QOL is at a nadir at 4-6 weeks after surgery with symptoms such as fatigue, anxiety, and depressive symptoms being strong predictors of QOL (Myles, 2001; Rantanen, 2009; Barnason et al., 2008).

Qualitative studies that were reviewed examined postoperative ICU experience in this period noted participant experiences with symptoms such as pain, along with emotional fears related to vulnerability, loneliness and disorientation. A narrative analysis of patient post operative experience found themes of patient surrender of agency, due in part to the technological influence on health care (Lapum et al., 2009). Echoing findings of literature reviewing participant experience during this time period (Doering et al., 2002; Gardner et al., 2005; Theobald & McMurray, 2004), in this study participant discourse was dominated by a feeling of struggle through symptom experience. Symptoms reported included loss of functional ability, fatigue, incisional pain, “being down”, confusion, feeling depressed, constipation,

shortness of breath, and difficulty sleeping. Profound appetite loss and subsequent weight loss was particularly problematic for participants in this study; this finding has been previously reported and could indicate older adults are particularly vulnerable to disruptions in appetite. Chronic pain or health concerns prior to surgery also impacted experience.

In this study, participant gestalt of the experience echoes Lindsay et al. (2000) findings of the theme of “the enormity of the experience” of patients who have cardiac surgery. These findings reinforce the picture of symptom experience as encompassing a broad scope of responses including, physical to psychological experiences.

The complexity of symptom experience suggests that multidimensional assessment instruments should be used to capture the broad array of symptoms and their impact on participant experience. The persistence of symptoms suggests that management and follow up of symptoms throughout the acute recovery period is not adequate. The magnitude of appetite and weight loss reported by participants in this study suggest the measures to ensure adequate nutrition should begin preoperatively and follow up postoperatively. In addition, the use of a measure of chronic pain prior to surgery could be helpful in elucidating patient symptom experience in order to better understand how to effectively address chronic pain issues while in hospital and after discharge. The use of a holistic measure prior to surgery could incorporate the meanings that patient’s attach to symptoms, and indicate the measure of distress associated with symptoms, in order to better anticipate and treat patient responses after surgery. Given what is known about the patient experience of cardiac symptoms associated with heart failure and angina and symptom burden during the acute recovery period, extending forward, there is a clear need

for an integrative model of holistic care for this population of patients with a particular focus on reducing symptom burden for these individuals.

Moving forward toward healing. Participant narrative conveyed the complex multifaceted nature of recovery, with thematic content that emerged as *Moving forward toward healing*. Study participants described stories of acceptance of unexpected circumstances and the events which led to the need to have cardiac surgery. Older adults reflected their decision to accept changes as they evolved, as well as the lack of alternative choices in the decision process. Remarkably little dialogue focused on the actual decision making process prior to surgery, though some participants revisited the decision in more detail during the postoperative period. When discussing the decision to have surgery in their narrative, older adults showed an awareness of the choices available to them, an intentional choice to have surgery and participate in their care after surgery. An understanding of how older adults approach cardiac surgery is informed the theory of power as knowing participation in change (Barrett, 2010). Acceptance of the need for surgery and symptom burden during the acute hospitalization period was also part of narrative discourse. Once the participant had made the decision to have surgery, participants reflected on their belief that the decision was necessary and that they felt ready for surgery. Participant acceptance of the circumstances did not imply passivity in decision making processes around care. While participants verbalized that they felt a “lack of control” during hospitalization; nonetheless, once home participants shared stories that showed they felt they were active participants in the process of their recovery. Participants recognized the need for physical activity in their recovery, and for monitoring and “keeping track” of their health, with support from a network of services during this period. The role of the visiting nurse as well as

home physical therapy was viewed by participants as crucial supports in helping participants “stay on track” in their recovery. All participants’ verbalized recognition that cardiac rehabilitation was an important part of their recovery, though at two months after surgery, some participants were not yet well enough to enroll in a cardiac rehabilitation program

Multiple participants remarked on their lack of anxiety during this time period, noting that they found that their spiritual and religious beliefs, as well as family and community, supported them in facing the challenges and uncertainty of the preoperative period. Participants in this study did seek to review the events that brought them to the hospital, indicating this appraisal and review may be helpful to that person understanding the change in their condition and the decision to have surgery.

Implications for Clinical Practice

Findings from this study inform nursing care of older adults undergoing cardiac surgery. Evoking narrative promotes nursing understanding of participant engagement in life and this in turn informs relational care of the person. The complexity of the recovery process and the dynamic needs of persons throughout their recovery suggest the need for a nursing model of care that prioritizes working with and communicating with patients prior to surgery, providing anticipatory guidance to older adults on physical, psychological, spiritual and social aspects of their recovery as well as after surgery, providing continuity of care and building knowledge of the patient throughout the caregiving process (Flanagan, 2005). Knowledge on the older adults experience of cardiac surgery can inform innovative models of care which prioritize creating a healing environment for patients and families such as Hospital Elder Life Programs (Inouye, Bogardus, Baker, Leo-Summers, & Cooney, 2000), Acute Care of Elders (ACE) (Panno,

Kolcaba, & Holder, 2000) programs, the geriatric resource nurse (GRN) role (Lopez, Delmore, Ake, Kim, Golden, & Bier (2002) and Nurses Improving the Care of Hospitalized Elders (NICHE) (Mezey et al., 2004). NICHE, as a systems approach to care of older adults, is currently being implemented and evaluated in 180 hospitals in North America (Boltz et al., 2014). NICHE emphasizes bedside nurse education as well as addressing institutional structures that can facilitate clinical transformational change in the care of older adults and programs such as NICHE have the potential to improve patient outcomes as well as improve the workplace environment for nurses (Boltz et al., 2014).

Instrumental to models designed to address older adult care would be a means of bringing the person's concerns to the fore of the process, not in the form of a chief complaint or symptom but to elicit an individual's story and meanings and co construction of the patient's story in the context of that person's health. A dynamic 'build' of the patient story would have value to clinicians caring for the patient, promoting knowledge of the patient and their responses to health and illness. For example, participants in this study related nuanced changes in functional self assessments but did not recognize these changes as indicators of cardiovascular health; this speaks to a need for understanding the meanings that participants attach to the symptoms they experience. Integrating core concepts of therapeutic communication, adapted from Peplau's (1952, 1991, 1992) interpersonal relations theory, could guide the process of integration of unfolding participant narrative into the mutually constructed plan of care.

Nurses working in relation with the patient come to know the person, understand the meaning and the impact of illness on the patient and family and give the patient an opportunity to be an

active participant in the decisions about their care as well as the goals they have during recovery and the knowledge needed to transition to home (Jones, 2013).

A key aspect of this model would be holistic assessment of identified domains of healing (physical, psychological, spiritual and social) with an emphasis on particular knowledge of the patient, as an individual, to inform care on multiple levels throughout healing and recovery. This particular, individualized knowledge should include assessment of symptom burden prior to surgery and identifying strategies for mitigating symptom burden during the postoperative period. The primacy of symptom experience preoperatively, at one month and at two months after surgery suggests the need for improved multidimensional symptom assessment and symptom management; utilizing measures of acute and chronic pain and symptom distress along with contextual individualized knowledge of the patient. A nuanced understanding of the healing process of older adults can inform modifying clinical pathways of care for older adults and developing benchmarks that can serve to help older adults recognize their progress in healing over time as well anticipate resource allocation over the continuum of care.

In addition, recognizing the need for assessment of chronic illness, grief, and social supports prior to surgery has the potential to improve care throughout the recovery continuum. Current theoretical work on older adults regulation of emotional well being suggests that understanding that older adults may use attentional, appraisal, and behavioral emotion regulation strategies to cope during the period awaiting surgery can be helpful in caring for older adults. It is illuminating to view the process by which older adults face challenges, make choices and participate in change from the standpoint of the theory of power as knowing participation in change (Barrett, 2010). Using the lens of this theory can explicate the process by which older

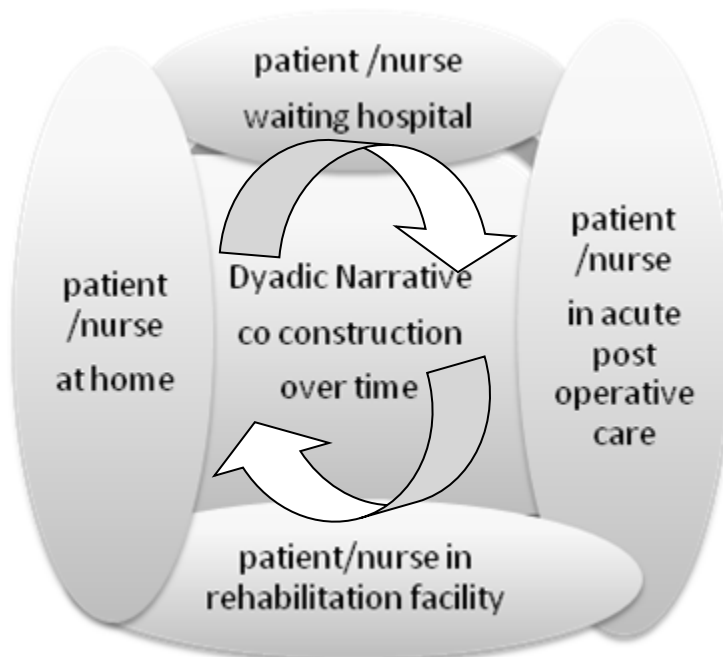
adults approach and engage in the experience of cardiac surgery. Engagement and a network of social supports including family advocacy are informed by the middle range theory of self transcendence and were integral parts of participant narrative; this speaks to the need for continued integration of services for participant care in both the preoperative and postoperative period as well as nursing interventions that support health processes that promote self transcendence.

A model of care which could address this complexity of responses of older adults who have cardiac surgery would integrate a holistic person centered approach across the continuum of care. Bringing these population specific conceptual approaches to the health care transitions of older adults could address the particular vulnerabilities and strengths of older adults with chronic illness in hospitalization and discharge. The essential elements of the TCM model resonate with the needs of the older adults in this study who have had cardiac surgery (Naylor, Feldman et al., 2009, Naylor, Hirschman , O'Connor , Barg , & Pauly; 2013). The TCM provides a patient centric approach to nursing practice informing interventions over time, in a continuum of a care not regulated to one particular setting; e.g. hospital or outpatient setting (Naylor, Feldman et al., 2009; Naylor, Hirschman et al, 2013).

Through the intersection of nursing care over time in healing and recovery, the TCM framework (Naylor, Feldman et al., 2009) is well suited to promoting communication, engaging patients and families, providing holistic assessment of health concerns and symptoms and facilitating co construction of the patient's story over time. The intersection of the dyad of nursing care and patient experience is an opportunity for co construction of narrative that can be shared with the patient, family and multidisciplinary health care team. This story then becomes a

means of knowing the patient more fully, what is of concern and of meaning to the patient and how that may change over time and experience. Utilizing personal narrative of patients has been previously proposed as a pragmatic means of understanding the concerns of patients and of enhancing person centered care. Ekman et al. (2011) have suggested that the time is now to turn to narrative as a vehicle to build holistic understanding the meanings and concerns of persons in health and illness. The impact of bringing forward the story of the person across the continuum of care has the potential to improve satisfaction with care, smooth transitions and decrease length of stay while engaging patients and family members in care and promoting health education and outcomes. Figure 3 is a model of how the temporal experience of the patient has multiple transitions in care and how the intersection of nursing care and patient experience present the opportunity for co- construction of the patient story.

Figure 3. The Intersection of Nurse-Patient Dyadic Co-construction of Narrative



Particular research exploration is warranted of the older adult experience of heavy symptom burden despite the networks of supports in place to serve as resources during recovery. The complexity of the human symptom experience is still the predominant struggle posed to older adults who have cardiac surgery. This findings should spur us to ask deeper questions and look more closely at the systems of care that surround the patient as well as the particular aspects of care that we consider to be standard practice in health care.

Research on the transactional nature of pain assessment is particularly informative in this regard. McDonald's (2009) work has explored the assessment of pain in older adults and semiotics of communication and its impact on pain assessment. In short, how a clinician assesses for pain will influence findings (McDonald & Fedo, 2009). Even in older adults that are able to self report, the manner in which the inquiry is made, the measurement tool utilized and the actual construction of the inquiry can impact what information on pain is elicited (McDonald, Shea, Rose & Fedo; 2009). Continued inquiry into the problem of symptom assessment and integration of this research into clinical practice of symptom assessment and clinical education on the nature of the nuanced transaction between care giver and patient is needed to improve the understanding of how this communication can elicit or fail to elicit patient report.

Implications for Research

Narrative analysis deepens understanding of the concerns of older adults by enhancing collective knowledge of the participant's construction of life events. While there has been foundational theoretical work on understanding aging from multiple disciplinary perspectives, nursing theory that addresses the health care needs of older adults is still developing. There is a need for continued development of the theoretical foundation for care of older adults, with

consideration of using blended deductive theoretical approaches, which may inform middle range theories of developmental care of older adults. In addition, as described in this study of older adults who have cardiac surgery, nursing is well positioned as a discipline to recognize the health care needs of older adults and bring forward the voice, concerns and meanings that are important to older adults.

There is an opportunity for further research on the dyad of nurse-patient to bring forward co-constructed patient narrative that may serve to inform the health care of patients and their families. As the population of older adults who have cardiac surgery is a new demographic, continued research on patient experience is needed to inform the development of patient centered outcome measures in this population of patients. In addition, understanding the experience of postoperative older adults in rehabilitative settings is an understudied area and there is a need exploration of this phenomenon.

Across stories, the primacy and struggle of the symptom experience resonated in participant narrative. There is a need to further understanding of why management of post operative symptoms in older adults is problematic. An integrative nursing model that addresses patient symptom burden and directs interventions across systems of care is needed in order to effectively manage patient symptoms and evaluate the effectiveness of interventions. Given the complexity of recovery and the network of providers caring for patients, an integrative solution would require technical measures as well as interdisciplinary consensus on meaningful measures. Measures of effectiveness would include health care cost, readmission rates, quality measures as well as patient centered outcomes such as patient and family satisfaction. Currently, the NICHE program, a promising systems approach to care of hospitalized older adults which examines

effectiveness measures is underway and evaluation of outcome measures are pending (Boltz et al., 2013). Research elucidating the trajectory of recovery and healing of older adults, including measures which screen for frailty and risk of postoperative cognitive dysfunction are crucial to inform care provision and can inform resource allocation in the care continuum. In addition to comparative research across age groups, research is needed to build understanding of the impact of cultural and ethnic influences on recovery.

As a method, narrative analysis is a method that is well suited to the conduct of nursing research. Narrative analysis can serve as a vehicle for knowing and caring for a person across the spectrum of care and eliciting patient narrative allows the caregiver to, in a holistic sense, come to know the patient through narrative knowledge. Of importance in understanding participant narrative is not simply the content of the narrative, but how stories are told by participants (Riley & Hawe, 2005). How a participant begins his story can cue the caregiver as to how to come to “know” the participant and thus best support the person during their hospitalization and recovery.

How caregivers may elicit stories when caring for older adult patients may be informed by the ways in which participants chose to begin their narrative in this study. Participants were invited to share their story and where they began their stories varied. While some participants began with a focus on the precipitating events that brought them to the hospital, others chose to begin with life story accounts, recounting childhood experiences, experiences from young adulthood, or life as an older adult. Storytelling thus becomes a vehicle for research as well as having the potential to be a vehicle for therapeutic understanding in care giving. Reminiscence is recognized to be a therapeutic mental health intervention in older adults (Westerhof, Bohlmeijer, & Webster, 2010). An intriguing avenue for research would be to explore if

storytelling, like reminiscence, could be a therapeutic intervention in working with acutely ill older adults.

Implication for Nursing Education

Perhaps one of the most important contributions this research makes to collective knowledge on health and illness is to raise and to heighten the appreciation and awareness of clinicians and community to the stories of older adults that have cardiac surgery. Despite the recognition that society is rapidly aging and that our collective society will encompass many older adults in the coming years, nonetheless, the predilection to negatively infer, judge and generalize about an individual based on their chronological age, a form of discrimination referred to as “ageism” is still common in our society (Phelan, 2009). The findings from this study can inform educational programs for nursing education programs as well as other member of interdisciplinary care such as physicians, physical and occupational therapists and care management.

Ageism is also a part of healthcare culture and has been shown to have a negative impact on the quality of treatment of older individuals as well as to restrict their access to care and services (Lothian & Philp, 2001; Courtney, Tong, & Walsh, 2000). Bringing this narrative to the fore has the potential to sensitize clinicians and communities to the strengths, challenges and needs of older adults prior to and during their recovery from cardiac surgery. Education of clinicians has been found to be a strong predictor of attitudes and consequent behaviors toward older adults (Holroyd, Dahlke, Fehr, Jung & Hunter, 2009). The findings from this study may serve as a part of a formal program of education, which is used to inform and sensitize clinicians to the particular health care needs of older adults. Findings from this study can inform

educational curricula designed to address undergraduate, graduate nurse education and doctoral nurse programs as well as clinical education across disciplines. In addition, knowledge of participant experience garnered from this study can be integrated into patient and family teaching both prior to and after cardiac surgery.

Implications for Public Policy

Given the aging population, there is a need for clear recognition of the needs of older adults in health care, both in the United States and worldwide. There is a need for exploration of older adult experience, synthesizing extant knowledge and translating that knowledge into actionable clinical interventions across multiple disciplines. Given the exploration and redesign of the multiple systems of care that older adults “travel” through, health care policy is needed that addresses the integration of networks and systems of care for older adults across settings with the goal of improving care and increasing efficiencies and decreasing health care cost.

One such aspect that policy can support are integrative nursing care models that work on holistic individualized support of patients prior to hospitalization and throughout follow up after surgery. Changes in context for this particular study emphasize the need for policy measures which step out of episodic consideration of patient care and refocus systems of care on the continuum of patient health prior to and following hospitalization. During the conduct of this study, the process of adopting an electronic health record across a consortium of hospitals began. This system facilitated communication of health information throughout patient care systems but nursing facilities and rehabilitation settings are not part of the electronic medical record system and this proves problematic when trying to follow a patient’s “story” through the continuum of care. A grant based system of navigation for all cardiac surgery patients that was instituted in

September 2012 continued with the goal of facilitating the medical transition needs of the patient once discharged to home as well as providing as needed social support via a social worker for challenges assessed during the transition to home. However, the pilot project launched to reduce hospital readmissions in the cardiac surgery population, consisting of an APP led clinic appointment at one week after discharge from the hospital, was discontinued due to a lack of personnel to staff the follow up clinic. There remain multifocal institutional efforts to scrutinize and mitigate the causes of readmission rates following cardiac surgery.

During the conduct of this study, the referral hospital in this study began participation in a CMS pilot project to provide bundled payment for patients that have CABG surgery. Bundled payment, pioneered by the Prometheus model (DeBrantes & Camillus, 2007) funded by the Robert Wood Johnson Foundation, restructures payments for discrete conditions that reward collaboration over systems of care (e.g. prior to hospitalization, during hospitalization and after hospitalization including rehabilitation). Instead of a fee for service model, a bundled payment amount, (based on collective evidence of cost and accounting for patient acuity) is derived for particular conditions and paid to providers of care over a particular episode. The impetus for this plan includes improved coordination and quality of care and preventing avoidable complications, such hospital acquired infections, with the goal of cost savings for both CMS and the providers of care (DeBrantes & Camillus, 2007). The advent of bundled payments points to the need for improved cohesion between systems of care and seamless integration of medical and nursing services that can “talk with each other” and relate the patient plan of care and patient progress through care transitions. Thus, public policy which continues to research and support integrated nursing processes of care for older adults is needed and models of care which recognize

coordination of multidisciplinary care are a priority. Public policy that supports broadening clinical and community conceptions of aging is essential. The contributions and involvement of older adults in society bring myriad advantages to society as a whole, including societal health.

Study Limitations

Study participants reflected the demographic profile of the state in which they live, but did not include diversity of race or ethnicity that may have further informed cultural considerations in the study of older adults. This study was of short duration, literature reviewed for this study reported that older adults have a prolonged recovery process following cardiac surgery. Thus, this study captured only a few months of the process of recovery after cardiac surgery, and as such, more remains to be told of the story of older adults who have cardiac surgery.

In addition, because of participant fatigue, interview lengths were of short duration and at times limited extensive exploration of participant experience. Because of the sampling process, selection bias could be present in the sample that consented to participate in this study.

Participants who did not consent may have had different experiences, and hence, different thematic content could have evolved from such a sample. In addition, while participants were informed that the research study would strive to protect their confidentiality, participants may not have felt comfortable sharing narrative that reflected badly on the hospital or on the caregivers involved in their care. All participants in this study required hospitalization prior to surgery, but were clinically stable. These participants may not be representative of older adults that have cardiac surgery that come to the hospital on the same day admission, nor of older adults that are in intensive care prior to surgery.

Summary

As the population of the U.S. ages, the demographic of persons undergoing cardiac surgery is shifting to include a large proportion of older adults (Etzioni & Starnes, 2011). To better understand the experience of older adults who have cardiac surgery, this study elicited the unscripted stories of thirteen older adults at three points in time across the experience. Thematic content from participant interviews reflected their engagement in life while conscious of time passing as well as nuanced accounts of physical changes in the period prior hospitalization.

Following surgery, participants described a broad range of symptom experience and these descriptions dominated participant discourse at one month and at two months after surgery. Participants also shared stories of the challenge of enduring loss and facing bereavement and grief during their experience.

Findings from this study may inform nursing practice, research and policy. Evoking narrative promotes nursing understanding of participant engagement in life and this in turn informs relational care of the person. Nursing care has the potential to develop, implement and support psychosocial interventions that support older adult strategies for emotional regulation. Care for older adults who have cardiac surgery requires recognition of the need for assessment and support for bereavement and grief during hospitalization and recovery.

There is a need for continued development of the theoretical foundation for care of older adults, with consideration of using blended deductive theoretical approaches that may inform developmental care of older adults. Given the network of services and multiple systems of care that older adults “travel” through, health care policy is needed that addresses implementation of

novel nursing care models that support the integration of networks and systems of care for older adults across settings with the goal of improving individualized holistic care of older adults.

References

- Afilalo, J., Eisenberg, M. J., Morin, J. F., Bergman, H., Monette, J., Noiseux, N., . . . Boivin, J. F. (2010). Gait speed as an incremental predictor of mortality and major morbidity in elderly patients undergoing cardiac surgery. *Journal of the American College of Cardiology*, 56, 1668-1676. doi:10.1016/j.jacc.2010.06.039
- Alexander, K. P., Roe, M. T., Chen, A. Y., Lytle, B. L., Pollack, C. V., Jr., Foody, J. M., . . . Peterson, E. D. (2005). Evolution in cardiovascular care for elderly patients with non-ST-segment elevation acute coronary syndromes: results from the CRUSADE National Quality Improvement Initiative. *Journal of the American College of Cardiology*, 46, 1479-1487. doi:10.1016/j.jacc.2005.05.084
- Allen, K. E., & Wellard, S. J. (2001). Older women's experiences with sternotomy. *International Journal of Nursing Practice*, 7, 274-279. doi:10.1046/j.1440-172x.2001.00282.x
- American Nurses Association. (2010). Nursing's social policy statement : the essence of the profession. Silver Spring, Md: Author.
- Angus, J. (2001). The material and social predicaments of home: Women's experiences after aortocoronary bypass surgery. *Canadian Journal of Nursing Research*, 33, (2) 27-42.
- Bakker, R. C., Osse, R. J., Tulen, J. H. , Kappetein, A. P., & Bogers, A. J. (2012). Preoperative and operative predictors of delirium after cardiac surgery in elderly patients. *European Journal of Cardio-Thoracic Surgery*, 41, 544-549. doi: 10.1093/ejcts/ezr031

- Barnason, S., Zimmerman, L., Anderson, A., Mohr-Burt, S., & Nieveen, J. (2000). Functional status outcomes of patients with a coronary artery bypass graft over time. *Heart Lung, 29*, 33-46. doi: 10.1016/S0147-9563(00)90035-9
- Barnason, S., Zimmerman, L., Nieveen, J., Schulz, P., Miller, C., Hertzog, M., & Rasmussen, D. (2008). Relationships between fatigue and early postoperative recovery outcomes over time in elderly patients undergoing coronary artery bypass graft surgery. *Heart Lung, 37*, 245-256. doi: 10.1016/j.hrtlng.2007.09.003
- Barnason, S., Zimmerman, L., Nieveen, J., Schulz, P., & Young, L. (2012). Patient recovery and transitions after hospitalization for acute cardiac events: An integrative review. *Journal of Cardiovascular Nursing, 27*, 175-191. doi:10.1097/JCN.0b013e318239f5f5
- Barrett, E. A. M. (2010). Power as knowing participation in change: What's new and what's next. *Nursing Science Quarterly, 23*, 47-54. doi: 10.1177/0894318409353797
- Barry, L. C., Kasl, S. V., Lichtman, J., Vaccarino, V., & Krumholz, H. M. (2006). Social support and change in health-related quality of life 6 months after coronary artery bypass grafting. *Journal of Psychosomatic Research, 60*, 185-193. doi:10.1016/j.jpsychores.2005.06.080
- Bengtson, V. L., Gans, D., Putney, N. M., & Silverstein, M. (2009). Theories About Age and Aging. In V. L. Bengtson, M. Silverstein, N. M. Putney & D. Gans (Eds.), *Handbook of theories of aging*. (pp. 3-23). New York: Springer.

- Bergman, H., Ferrucci, L., Guralnik, J., Hogan, D. B., Hummel, S., Karunananthan, S., & Wolfson, C. (2007). Frailty: An emerging research and clinical paradigm-issues and controversies. *The Journals of Gerontology*, 62(7), 731-737.
- Bold, C. (2012). *Using narrative in research*. Los Angeles: Sage.
- Boltz, M., Capezuti, E., Shuluk, J., Brouwer, J., Carolan, D., Conway, S., . . . Galvin, J. E. (2013). Implementation of geriatric acute care best practices: initial results of the NICHE SITE self-evaluation. *Nursing & Health Sciences*, 15, 518-524. doi: 10.1111/nhs.12067
- Booth, J., Clayton, T., Pepper, J., Nugara, F., Flather, M., Sigwart, U., & Stables, R. H. (2008). Randomized, controlled trial of coronary artery bypass surgery versus percutaneous coronary intervention in patients with multivessel coronary artery disease: Six-year follow-up from the Stent or Surgery Trial (SoS). *Circulation*, 118, 381-388. 10.1161/circulationaha.107.739144
- Bui, A. L., Horwich, T. B., & Fonarow, G. C. (2011). Epidemiology and risk profile of heart failure. *Nature Reviews Cardiology*, 8, 30-41. doi:10.1038/nrcardio.2010.165
- Cara, C. (2003). A pragmatic view of Jean Watson's caring theory. *International Journal for Human Caring*, 7(3), 1-7.
- Carstensen, L. L., & Lockenhoff, C. E. (2003). Aging, emotion, and evolution. *Annals of the New York Academy of Sciences*, 1000, 152-179. doi: 10.1196/annals.1280.008
- Charles, S. T. (2010). Strength and vulnerability integration: A model of emotional well-being across adulthood. *Psychological Bulletin*, 136, 1068-1091. doi.org/10.1037/a0021232

- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, 5, 168-195. doi: 10.1111/1467-9566.ep10491512
- Chee, J. H., Filion, K. B., Haider, S., Pilote, L., & Eisenberg, M. J. (2004). Impact of age on hospital course and cost of coronary artery bypass grafting. *The American Journal of Cardiology*, 93, 768-771. doi:10.1016/j.amjcard.2003.11.058
- Christakis, N. A., & Allison, P. D. (2006). Mortality after the hospitalization of a spouse. *The New England Journal of Medicine*, 354, 719-730. doi: 10.1056/NEJMsa050196
- Clark, A. M., Savard, L. A., Spaling, M. A., Heath, S., Duncan, A. S., & Spiers, J. A. (2012). Understanding help-seeking decisions in people with heart failure: a qualitative systematic review. *International Journal of Nursing Studies*, 49, 1582-1597. doi:10.1016/j.ijnurstu.2012.05.010
- Courtney, M., Tong, S., & Walsh, A. (2000). Acute-care nurses' attitudes towards older patients: A literature review. *International Journal of Nursing Practice*, 6, 62-69. doi:10.1046/j.1440-172x.2000.00192.x
- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches (2nd Ed.)*. Thousand Oaks: Sage.
- DeBrantes F. & Camillus J. A. (2007). *Evidence informed case rates: A new health care payment model* (no. 1022). New York: Commonwealth Fund.
- DeFrances, C. J., Cullen, K. A., & Kozak, L. J. (2007). *National Hospital Discharge Survey: 2005 Annual summary with detailed diagnosis and procedure data* (DHHS Publication

- No 2008-1736). National Center for Health Statistics. Retrieved from Centers for Disease Control and Prevention website: http://www.cdc.gov/nchs/data/series/sr_13/sr13_165.pdf
- Doering, L. V., McGuire, A. W., & Rourke, D. (2002). Recovering from cardiac surgery: What patients want you to know. *American Journal of Critical Care*, 11(4), 333-343.
- Dunckley, M., Ellard, D., Quinn, T., & Barlow, J. (2007). Recovery after coronary artery bypass grafting: patients' and health professionals' views of the hospital experience. *European Journal of Cardiovascular Nursing*, 6, 200-207. doi: 10.1016/j.ejcnurse.2006.09.003
- Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., . . . Sunnerhagen, K. S. (2011). Person-Centered Care — Ready for Prime Time. *European Journal of Cardiovascular Nursing*, 10, 248-251. doi: 10.1016/j.ejcnurse.2011.06.008
- Erikson, E. H. (1959). *Identity and the life cycle: Selected papers*. New York: International Universities Press.
- Erikson, E. H., Erikson, J. M., & Kivnick, H. Q. (1986). *Vital involvement in old age*. New York: Norton.
- Etzioni, D. A., & Starnes, V. A. (2011). The epidemiology and economics of cardiothoracic surgery in the elderly. In M. R. Katlic (Ed.), *Cardiothoracic surgery in the elderly*. (pp. 5-24). New York: Springer.
- Falcoz, P. E., Chocron, S., Stoica, L., Kaili, D., Puyraveau, M., Mercier, M., & Etievent, J. P. (2003). Open heart surgery: one-year self-assessment of quality of life and functional

outcome. *Annals of Thoracic Surgery*, 76(5), 1598-1604. doi.org/10.1016/S0003-4975(03)00730-6

Farooq, V., van Klaveren, D., Steyerberg, E. W., Meliga, E., Vergouwe, Y., Chieffo, A., . . . Serruys, P. W. (2013). Anatomical and clinical characteristics to guide decision making between coronary artery bypass surgery and percutaneous coronary intervention for individual patients: development and validation of SYNTAX score II. *Lancet*, 381, 639-650. doi:10.1016/S0140-6736(13)60108-7

Federal Interagency Forum on Aging-Related Statistics. *Older Americans 2010: Key indicators of well-being*. Retrieved from <http://www.agingstats.gov>

Fitzsimons, D., Parahoo, K., & Stringer, M. (2000). Waiting for coronary artery bypass surgery: A qualitative analysis. *Journal of Advanced Nursing*, 32, 1243-1252. doi:10.1046/j.1365-2648.2000.01595.x

Flanagan, J. (2005). Creating a healing environment for staff and patients in a pre-surgery clinic. In C. Picard & D. Jones (Eds.), *Giving voice to what we know* (pp. 53-63). Boston: Jones and Bartlett.

Flood, M. (2005). A mid-range nursing theory of successful aging. *Journal of Theory Construction & Testing*, 9(2), 35-39.

Frank, A. W. (1998). Just listening: Narrative and deep illness. *Families, Systems, & Health*, 16, 197-212. doi: 10.1037/h0089849

- Gardner, G., Elliott, D., Gill, J., Griffin, M., & Crawford, M. (2005). Patient experiences following cardiothoracic surgery: An interview study. *European Journal of Cardiovascular Nursing*, 4, 242-250. doi: 10.1016/j.ejcnurse.2005.04.006
- Gee, J.P. (1991). A linguistic approach to narrative. *Journal of Narrative and Life History/Narrative Inquiry*, 1(1), 15-39.
- Gelsomino, S., Lorusso, R., Livi, U., Masullo, G., Lucà, F., Maessen, J., & Gensini, G. F. (2011). Cost and cost-effectiveness of cardiac surgery in elderly patients. *Journal of Thoracic and Cardiovascular Surgery*, 142, 1062-1073. doi:10.1016/j.jtcvs.2011.02.013
- Graham, M. M., Ghali, W. A., Faris, P. D., Galbraith, P. D., Norris, C. M., & Knudtson, M. L. (2002). Survival after coronary revascularization in the elderly. *Circulation*, 105, 2378-2384. doi: 10.1161/01.CIR.0000016640.99114.3D
- Hall, M. J., DeFrances, C. J., Williams, S. N., Golosinskiy, A., & Schwartzman, A. (2010). *National Hospital Discharge Survey: 2007 Summary*. (DHHS Publication No. 2011-1250). National Center for Health Statistics. Retrieved from Centers for Disease Control and Prevention website: <http://www.cdc.gov/nchs/data/nhsr/nhsr029.pdf>
- Hall, M.J., Levant, S., & DeFrances, C. J. (2012). *Hospitalization for congestive heart failure: United States, 2000–2010* (no. 108). National Center for Health Statistics. Hyattsville, MD.
- Hall, J. M., & Powell, J. (2011). Understanding the person through narrative. *Nursing Research and Practice*, 2011, 1-10. doi: 10.1155/2011/293837

- Hall, J. M., Roman, M. W., Thomas, S. P., Travis, C. B., Powell, J., Tennison, C. R., . . .
- McArthur, P. M. (2009). Thriving as becoming resolute in narratives of women surviving childhood maltreatment. *American Journal of Orthopsychiatry*, 79, 375-386. doi: 10.1037/a0016531
- Hartford, K. (2005). Telenursing and patients' recovery from bypass surgery. *Journal of Advanced Nursing*, 50, 459-468. doi: 10.1111/j.1365-2648.2005.03427.x
- Hastings, S. N., Purser, J. L., Johnson, K. S., Sloane, R. J., & Whitson, H. E. (2008). Frailty predicts some but not all adverse outcomes in older adults discharged from the emergency department. *Journal of the American Geriatrics Society*, 56, 1651-1657. doi: 10.1111/j.1532-5415.2008.01840.x
- Herlitz, J., Brandrup-Wognsen, G., Caidahl, K., Haglid, M., Hartford, M., Karlson, B. W., . . .
- Sjöland, H. (2008). Symptoms of chest pain and dyspnea and factors associated with chest pain and dyspnea 10 years after coronary artery bypass grafting. *Nursing Research and Practice*, 156, 580-587. doi:10.1016/j.ahj.2008.04.017
- Hertzog, C., Kramer, A. F., Wilson, R. S., & Lindenberger, U. (2008). Enrichment effects on adult cognitive development can the functional capacity of older adults be preserved and enhanced? *Psychological Science in the Public Interest*, 9, 1-65. doi: 10.1111/j.1539-6053.2009.01034.x
- Holloway, I., & Freshwater, D. (2007). *Narrative research in nursing*. Malden, MA: Blackwell.

- Holroyd, A., Dahlke, S., Fehr, C., Jung, P., & Hunter, A. (2009). Attitudes toward aging: Implications for a caring profession. *Journal of Nursing Education*, 48(7), 374-380.
- Holstein J. A. & J. F. Gubrium , D. (2012). Introduction: Establishing a balance. In J. A. Holstein & J. F. Gubrium (Eds.), *Varieties of narrative analysis* (pp. 1-10). Thousands Oaks, CA: Sage Publications.
- Hunt, J. O., Hendrata, M. V., & Myles, P. S. (2000). Quality of life 12 months after coronary artery bypass graft surgery. *Heart Lung*, 29, 401-411. doi:10.1067/mhl.2000.110578
- Inouye, S.K., Bogardus, S.T., Baker, D.I., Leo-Summers, L. & Cooney, L.M. (2000). The hospital elder life program: A model of care to prevent cognitive and functional decline in older hospitalized patients. *Journal of the American Geriatrics Society*, 48(12), 1697–1706
- Institute of Medicine. (2010). The Future of Nursing. Retrieved from <http://www.iom.edu/Reports/2010/The-Future-of-Nursing-Leading-Change-Advancing-Health.aspx>
- Iqbal, J., Francis, L., Reid, J., Murray, S., & Denvir, M. (2010). Quality of life in patients with chronic heart failure and their carers: A 3-year follow-up study assessing hospitalization and mortality. *European Journal of Heart Failure*, 12, 1002-1008. doi:10.1093/eurjhf/hfq114
- Jaarsma, T., Beattie, J. M., Ryder, M., Rutten, F. H., McDonagh, T., Mohacsi, P., . . . McMurray, J. (2009). Palliative care in heart failure: A position statement from the palliative care

- workshop of the Heart Failure Association of the European Society of Cardiology.
European Journal of Heart Failure, 11, 433-443.doi:10.1093/eurjhf/hfp041
- Jackson, C. F., & Wenger, N. K. (2011). Cardiovascular disease in the elderly. *Revista Espanola de Cardiologia*, 64(8), 697-712.
- Jin, K. (2010). Modern Biological Theories of Aging. *Aging and Disease*, 1(2), 72–74.
- Jones, D. A. (2007). A synthesis of philosophical perspectives for knowledge development. In C. Roy & D. A. Jones (Eds.), *Nursing knowledge development and clinical practice* (pp.163-176). New York: Springer.
- Jones, D. A.(2013). Nurse- patient relationship: Knowledge transforming practice at the bedside. In J. Ives-Erickson, D. A. Jones, & M. Ditomassi (Eds.) M. *Fostering Nurse-Led Care* (pp.86-121). Indianapolis, In.: Sigma Theta Tau International.
- Keller, C. (1991). Seeking normalcy: the experience of coronary artery bypass surgery. *Research in Nursing and Health*, 14, 173-178.doi: 10.1002/nur.4770140303
- Kim, T. S. (2009). The theory of power as knowing participation in change: A literature review updated. *Visions: The Journal of Rogerian Nursing Science*, 16(1), 19-25.
- Krause, N. (2009). Deriving a sense of meaning in late life: An overlooked forum for the development of interdisciplinary theory. In V. L. Bengtson, M. Silverstein, N. M. Putney & D. Gans (Eds.), *Handbook of theories of aging* (pp. 101-116). New York: Springer.

- Labov, P., & Waletzky, J. (1967). Narrative analysis: Oral versions of personal experiences. In J. Helm (Ed.), *Essays on the verbal and visual art* (pp.12-46). Seattle: University of Washington Press.
- Lapum, J., Angus, J. E., Peter, E., & Watt-Watson, J. (2010). Patients' narrative accounts of open-heart surgery and recovery: Authorial voice of technology. *Social Science & Medicine*, 70, 754-762. doi:10.1016/j.socscimed.2009.11.021
- Lee, D.H., Buth, K. J., Martin, B. J., Yip, A. M., & Hirsch, G. M. (2010). Frail patients are at increased risk for mortality and prolonged institutional care after cardiac surgery. *Circulation*, 121, 973-978. doi: 10.1161/circulationaha.108.841437
- Leegaard, M., & Fagermoen, M. S. (2008). Women's descriptions of postoperative pain and pain management after discharge from cardiac surgery. *Journal of Clinical Nursing*, 17, 2051-2060. doi: 10.1111/j.1365-2702.2007.02217.x
- Leegaard, M., Nåden, D., & Fagermoen, M. S. (2008). Postoperative pain and self-management: women's experiences after cardiac surgery. *Journal of Advanced Nursing*, 63, 476-485. doi: 10.1111/j.1365-2648.2008.04727.x
- Leegaard, M., Rustøen, T., & Fagermoen, M. S. (2010). Interference of postoperative pain on women's daily life after early discharge from cardiac surgery. *Pain Management Nursing*, 11, 99-107. doi:10.1016/j.pmn.2009.04.001
- Leininger M. M. (1984). *Care: The essence of nursing and health*. Thorofare, New Jersey: Charles B. Slack.

- Leslie, D. L., Marcantonio, E. R., Zhang, Y., Leo-Summers, L., & Inouye, S. K. (2008). One-year health care costs associated with delirium in the elderly population. *Archives of Internal Medicine*, 168, 27-32. doi:10.1001/archinternmed.2007.4.
- Likosky, D. S., Dacey, L. J., Baribeau, Y. R., Leavitt, B. J., Clough, R., Cochran, R. P., . . . O'Connor, G. T. (2008). Long-term survival of the very elderly undergoing coronary artery bypass grafting. *Annals of Thoracic Surgery*, 85, 1233-1237.
doi:10.1016/j.athoracsur.2007.12.066
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, California: Sage.
- Lindquist, R., Dupuis, G., Terrin, M. L., Hoogwerf, B., Czajkowski, S., Herd, J. A., . . . Knatterud, G. L. (2003). Comparison of health-related quality-of-life outcomes of men and women after coronary artery bypass surgery through 1 year: findings from the POST CABG Biobehavioral Study. *American Heart Journal*, 146, 1038-1044.
doi:10.1016/S0002-8703(03)00451-4
- Lindsay, G. M., Smith, L. N., Hanlon, P., & Wheatley, D. J. (2000). Coronary artery disease patients' perception of their health and expectations of benefit following coronary artery bypass grafting. *Journal of Advanced Nursing*, 32, 1412-1421. doi:10.1046/j.1365-2648.2000.01621.x
- Lopez, M., Delmore, B., Ake, J.M., Kim, Y.R., Golden, P. & Bier, J. (2002). Implementing a geriatric resource nurse model. *Journal of Nursing Administration*, 32(11), 577-585

- Loponen, P., Luther, M., Wistbacka, J. O., Korpilahti, K., Laurikka, J., Sintonen, H., . . . Tarkka, M. R. (2007). Quality of life during 18 months after coronary artery bypass grafting. *European Journal of Cardio-thoracic Surgery*, 32, 77-82.
doi:10.1016/j.ejcts.2007.03.045
- Lothian, K., & Philp, I. (2001). Maintaining the dignity and autonomy of older people in the healthcare setting. *British Medical Journal*, 322(7287), 668-670.
- Luttik, M. L., Blaauwbroek, A., Dijker, A., & Jaarsma, T. (2007). Living with heart failure: Partner perspectives. *Journal of Cardiovascular Nursing*, 22(2), 131-137.
- Macleod, C. E. (2009). Nurses transforming the spousal caregiving experience: health as expanding consciousness and patient recovery at home after cardiac surgery. (Doctoral Dissertation). Retrieved from Proquest.
- Marshall, C., & Rossman, G. B. (2006). *Designing qualitative research*. Thousands Oaks, CA: Sage .
- McAdams, D., & Bowman, P. (2001). Narrating life's turning points:Redemption and contamination. D. McAdams, & A. Lieblich (Eds.), *Turns in the road: Narrative studies of lives in transition* (pp.3-34). Washington, DC: American Psychological Association.
- McCormick, K. M., Naimark, B. J., & Tate, R. B. (2006). Uncertainty, symptom distress, anxiety, and functional status in patients awaiting coronary artery bypass surgery. *Heart & Lung*, 35, 34-45. doi:10.1016/j.hrtlng.2005.08.002

- McDonald, D. D. (2009). Older adults' pain descriptions. *Pain Management Nursing*, 10, 142-148. doi:10.1016/j.pmn.2008.09.004
- McDonald, D. D., & Fedo, J. (2009). Older adults' pain communication: the effect of interruption. *Pain Management Nursing*, 10, 149-153. doi:10.1016/j.pmn.2009.03.003
- McDonald, D. D., Shea, M., Rose, L., & Fedo, J. (2009). The effect of pain question phrasing on older adult pain information. *Journal of Pain and Symptom Management*, 37, 1050-1060. doi:10.1016/j.jpainsymman.2008.06.008
- McKellar, S. H., Brown, M. L., Frye, R. L., Schaff, H. V., & Sundt, T. M., (2008). Comparison of coronary revascularization procedures in octogenarians: A systematic review and meta-analysis. *National Clinical Practice of Cardiovascular Medicine*, 5, 738-746. doi:10.1038/ncpcardio1348
- Mezey, M., Kobayashi, M., Grossman, S., Firpo, A., Fulmer, T. & Mitty, E. (2004). Nurses improving care to health system elders (NICHE): Implementation of best practice models. *Journal of Nursing Administration*, 34(10), 451–457.
- Mirabel, M., Iung, B., Baron, G., Messika-Zeitoun, D., Detaint, D., Vanoverschelde, J. L., . . . Vahanian, A. (2007). What are the characteristics of patients with severe, symptomatic, mitral regurgitation who are denied surgery? *European Heart Journal*, 28, 1358-1365. doi:10.1093/eurheartj/ehm001
- Mishel, M. (1990). Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship*, 22, 256–262. doi: 10.1111/j.1547-5069.1990.tb00225.x

- Mishler, E.G. (1986). *Research interviewing: Context and narrative*. Harvard University Press.
- Mohr, F. W., Morice, M. C., Kappetein, A. P., Feldman, T. E., Stahle, E., Colombo, A., . . . Serruys, P. W. (2013). Coronary artery bypass graft surgery versus percutaneous coronary intervention in patients with three-vessel disease and left main coronary disease: 5-year follow-up of the randomised, clinical SYNTAX trial. *Lancet*, *381*, 629-638. doi:10.1016/S0140-6736(13)60141-5
- Myles, P. S., Hunt, J. O., Fletcher, H., Solly, R., Woodward, D., & Kelly, S. (2001). Relation between quality of recovery in hospital and quality of life at 3 months after cardiac surgery. *Anesthesiology*, *95*, 862-867. doi: 10.1097/00000542-200110000-00013
- Naylor M.D., Feldman P., Keating S., Koren M.J., Kurtzman E.T., Maccoby M., & Krakauer R. (2009). Translating research into practice: Transitional care for older adults. *Journal of Evaluation in Clinical Practice*, *15*, 1164-1170. doi: 10.1111/j.1365-2753.2009.01308.x
- Naylor M.D., Hirschman K.B., O'Connor M., Barg R., & Pauly M.V. (2013). Engaging older adults in their transitional care: What more needs to be done? *Journal of Comparative Effectiveness Research*, *2*, 1-12. doi:10.2217/cer.13.58
- Neugarten, B. L. (1974). Age groups in American society and the rise of the young-old. *Annals of the American Academy of Political and Social Science*, *415*, 187-198. doi: 10.1177/000271627441500114
- Neugarten, B.L. (1979). Time, age, and the life cycle. *American Journal of Psychiatry*, *136*, 887-894. doi: 10.1176/ajp.136.7.887

- Newman, M.A. (1986). *Health as expanding consciousness*. St Louis: C.V. Mosby.
- Newman, M. A., Sime, A. M., & Corcoran-Perry, S. A. (1991). The focus of the discipline of nursing. *Advances in Nursing Science*, 14, 1-6.
- Newman, M. A., Smith, M.C., Pharris, M.D. & Jones, D. (2008). The focus of the discipline revisited. *Advances in Nursing Science*, 31, E16-E27. doi: 10.1097/01.ANS.0000311533.65941.fl
- Orem, D. E., Renpenning, K. M., & Taylor, S. G. (2003). *Self care theory in nursing : Selected papers of Dorothea Orem*. New York: Springer.
- Panno, J.M., Kolcaba, K. & Holder, C. (2000). Acute care for elders (ACE): A holistic model for geriatric orthopaedic nursing care. *Orthopaedic Nursing*, 19(6), 53–60.
- Pel-Littel, R. E., Schuurmans, M. J., Emmelot-Vonk, M. H., & Verhaar, H. J. (2009). Frailty: defining and measuring of a concept. *The Journal of Nutrition, Health & Aging*, 13(4), 390-394.
- Peplau, H. (1952). *Interpersonal relations in nursing*. New York: G.P. Putnam.
- Peplau, H. (1991, re-issued). *Interpersonal relations in nursing: A conceptual frame of reference for psychodynamic nursing*. New York: Springer.
- Peplau, H. (1992). Interpersonal relations: A theoretical framework for application in nursing practice. *Nursing Science Quarterly*, 5, 13–18. doi: 10.1177/089431849200500106

Phelan, A. (2008). Elder abuse, ageism, human rights and citizenship: Implications for nursing discourse. *Nursing Inquiry*, 15, 320-329. doi: 10.1111/j.1440-1800.2008.00423.x

Pihl, E., Jacobsson, A., Fridlund, B., Strömberg, A., & Måtensson, J. (2005). Depression and health-related quality of life in elderly patients suffering from heart failure and their spouses: a comparative study. *European Journal of Heart Failure*, 7, 583-589.
doi:10.1016/j.ejheart.2004.07.016

Plach, S. K., & Stevens, P. E. (2001). Midlife women's experiences living with heart disease. *Applied Nursing Research*, 14, 201-209. doi:10.1053/apnr.2001.26862

Pokras, R. 1982. *National Health Survey Series: Surgical Operations in Short Stay Hospitals: 1978*. (DHHS Publication No 82-1722). National Center for Health Statistics. Retrieved from Centers for Disease Control and Prevention website:
http://www.cdc.gov/nchs/data/series/sr_13/sr13_061.pdf

Polkinghorne, D. E. (1996). Explorations of narrative identity. *Psychological Inquiry*, 7, 362-367. doi:10.1207/s15327965pli0704_13

Popovic, J. R. (2001). *National Hospital Discharge Survey: 1999: Annual summary with detailed diagnosis and procedure data* (DHHS Publication No. 2001-1722). National Center for Health Statistics. Retrieved from the Centers for Disease Control and Prevention website:
http://www.cdc.gov/nchs/data/series/sr_13/sr13_151.pdf

- Raholm, M. B. (2002). Weaving the fabric of spirituality as experienced by patients who have undergone a coronary bypass surgery. *Journal of Holistic Nursing*, 20, 31-47. doi 10.1177/089801010202000104
- Raholm, M. B., & Eriksson, K. (2001). Call to life: Exploring the spiritual dimension as a dialectic between suffering and desire experienced by coronary bypass patients. *International Journal for Human Caring*, 5, 14-20.
- Reed, P. G. (1991a). Self-transcendence and mental health in oldest-old adults. *Nursing Research*, 40(1), 5-11.
- Reed, P. G. (1991b). Toward a nursing theory of self-transcendence: Deductive reformulation using developmental theories. *Advances in Nursing Science*, 13(4), 64-77.
- Reed, P. G. (2008). Practitioner as theorist: A reprise. *Nursing Science Quarterly*, 21, 315-321. doi:10.1177/0894318408324318
- Richards, L., & Morse, J. M. (2007). *Readme first for a user's guide to qualitative methods* (2nd ed.). Thousand Oaks, California: Sage.
- Ricoeur, P. (1973). The model of the text: Meaningful action considered as a text. *New Literary History*, 5(1). Retrived from <http://www.jstor.org/stable/40970072>
- Riessman, C. K. (1993). *Narrative analysis*. Newbury Park: Sage Publications.
- Riessman, C. K. (2002). Narrative Analysis. In A. M. Huberman & M. B. Miles (Eds.), *The qualitative researcher's companion* (pp. 217-270). Thousand Oaks, California: Sage Publications.

- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Los Angeles: Sage Publications.
- Riley, T., & Hawe, P. (2005). Researching practice: The methodological case for narrative inquiry. *Health Education Research*, 20, 226-236. doi: 10.1093/her/cyg122
- Robinson, A. W. (2002). Older women's experiences of living alone after heart surgery. *Applied Nursing Research*, 15, 118-125. doi: 10.1053/apnr.2002.34139
- Robley, L. R., Ballard, N., Holtzman, D., & Cooper, W. (2010). The experience of stress for open heart surgery patients and their caregivers. *Western Journal of Nursing Research*, 32, 794-813. doi: 10.1177/0193945910361469
- Roger, V. L., Go, A. S., Lloyd-Jones, D. M., Benjamin, E. J., Berry, J. D., Borden, W. B., . . . Turner, M. B. (2012). Executive summary: heart disease and stroke statistics--2012 update: a report from the American Heart Association. *Circulation*, 125, 188-197. doi: 10.1161/CIR.0b013e3182456d46
- Rogers, C., & Keller, C. (2009). Roy's adaptation model to promote physical activity among sedentary older adults. *Geriatric Nursing*, 30, 21-26. doi:10.1016/j.gerinurse.2009.02.002
- Rosenfeld, R., Smith, J. M., Woods, S. E., & Engel, A. M. (2006). Predictors and outcomes of extended intensive care unit length of stay in patients undergoing coronary artery bypass graft surgery. *Journal of Cardiac Surgery*, 21, 146-150. doi: 10.1111/j.1540-8191.2006.00196.x

- Rossman, G. B., & Rallis, S. F. (2003). *Learning in the field :An introduction to qualitative research* (2nd ed.). Thousand Oaks, California: Sage Publications.
- Roy, C. (2008). *The Roy adaptation model* (3rd ed.). Upper Saddle River, NJ: Pearson Prentice Hall.
- Roy, S. C. (1988). An explication of the philosophical assumptions of the Roy Adaptation Model. *Nursing Science Quarterly*, 1, 26-34. doi: 10.1177/089431848800100108
- Rumsfeld, J. S., Magid, D. J., O'Brien, M., McCarthy, M., MaWhinney, S., Shroyer, L.W., . . . Hammermeister, K. E. (2001). Changes in health-related quality of life following coronary artery bypass graft surgery. *Annals of Thoracic Surgery*, 72(6), 2026-2032.
- Sandelowski, M., & Barroso, J. (2003). Toward a metasynthesis of qualitative findings on motherhood in HIV-positive women. *Research in Nursing & Health*, 26, 153-170. doi: 10.1002/nur.10072
- Schou, L., & Egerod, I. (2008). A qualitative study into the lived experience of post-CABG patients during mechanical ventilator weaning. *Intensive and Critical Care Nursing*, 24, 171-179. doi:10.1016/j.iccn.2007.12.004
- Schocken, D. D. (2000). Epidemiology and risk factors for heart failure in the elderly. *Clinics in Geriatric Medicine*, 16(3), 407-417.
- Sheridan, B. C., Stearns, S. C., Rossi, J. S., D'Arcy, L. P., Federspiel, J. J., & Carey, T. S. (2010). Three-year outcomes of multivessel revascularization in very elderly acute coronary

- syndrome patients. *The Annals of Thoracic Surgery*, 89, 1889-1894.
doi:10.1016/j.athoracsur.2010.03.003
- Smith, M. C. (2011). Integrative review of research related to Margaret Newman's theory of health as expanding consciousness. *Nursing Science Quarterly*, 24, 256-272. doi: 10.1177/0894318411409421
- Speziale, H. S., & Carpenter, D. R. (2007). *Qualitative research in nursing : Advancing the humanistic imperative* . Philadelphia: Lippincott Williams & Wilkins.
- Stockmann, C. (2005). A literature review of the progress of the psychiatric nurse-patient relationship as described by Peplau. *Issues in Mental Health Nursing*, 26, 911-919.
doi:10.1080/01612840500248197
- Tabloski, P. A. (2010). Principles of geriatrics. In P. Tabloski (Ed.), *Gerontological nursing* (pp.57- 86). Upper Saddle River, NJ: Pearson.
- Tan, M. C., Felde, A., Kuskowski, M., Ward, H., Kelly, R. F., Adabag, A. S., & Dysken, M. (2008). Incidence and predictors of post-cardiotomy delirium. *American Journal of Geriatric Psychiatry*, 16, 575-583. doi:10.1097/JGP.0b013e318172b418
- Theobald, K., & McMurray, A. (2004). Coronary artery bypass graft surgery: discharge planning for successful recovery. *Journal of Advanced Nursing*, 47, 483-491. doi: 10.1111/j.1365-2648.2004.03127.
- Thomas, S. P., & Hall, J. M. (2008). Life trajectories of female child abuse survivors thriving in adulthood. *Qualitative Health Research*, 18, 149-166. doi: 10.1177/1049732307312201

- Tolmie, E. P., Lindsay, G. M., & Belcher, P. R. (2006). Coronary artery bypass graft operation: Patients' experience of health and well-being over time. *European Journal of Cardiovascular Nursing*, 5, 228-236. doi: 10.1016/j.ejcnurse.2006.01.007
- Tully, P. J., Baker, R. A., & Knight, J. L. (2008). Anxiety and depression as risk factors for mortality after coronary artery bypass surgery. *Journal of Psychosomatic Research*, 64, 285-290. doi:10.1016/j.jpsychores.2007.09.007
- Van Kan, G.A., Rolland, Y., Bergman, H., Morley, J. E., Kritchevsky, S. B., & Vellas, B. (2008). The I.A.N.A Task Force on frailty assessment of older people in clinical practice. *Journal of Nutrition, Health & Aging*, 12, 29-37. doi: 10.1007/BF02982161
- Varadarajan, P., Kapoor, N., Bansal, R. C., & Pai, R. G. (2006). Clinical profile and natural history of 453 nonsurgically managed patients with severe aortic stenosis. *Annals of Thoracic Surgery*, 82, 2111-2115. doi:10.1016/j.athoracsur.2006.07.048
- Velazquez, E. J., Lee, K. L., Deja, M. A., Jain, A., Sopko, G., Marchenko, A., . . . Rouleau, J. L. (2011). Coronary-artery bypass surgery in patients with left ventricular dysfunction. *New England Journal of Medicine*, 364, 1607-1616. doi: 10.1056/NEJMoa1100356
- Watson, J. (1979). *Nursing: The philosophy and science of caring*. Boston: Little, Brown.
- Watson, J. (1985). *Nursing: Human science and human care: A theory of nursing*. Norwalk, Conn.: Appleton Century Crofts.
- Watson, J. (2002). Intentionality and caring-healing consciousness: a practice of transpersonal nursing. *Holistic Nursing Practice* 16(4), 12-19.

- Watson, J. (2008). *Nursing: The philosophy and science of caring*. Boulder: University Press of Colorado.
- Watson, J. & Smith, M.C. (2002). Caring science and the science of unitary human beings: a trans-theoretical discourse for nursing knowledge development. *Journal of Advanced Nursing*, 37(5), 452-461. doi:10.1046/j.1365-2648.2002.02112.x
- Welstand, J., Carson, A., & Rutherford, P. (2009). Living with heart failure: An integrative review. *International Journal of Nursing Studies*, 46, 1374-1385.
doi:10.1016/j.ijnurstu.2009.03.009
- Westerhof, G., Bohlmeijer, E., & Webster, J. (2010). Reminiscence and mental health: A review of recent progress in theory, research and interventions. *Ageing & Society*, 30, 697-721. doi:10.1017/S0144686X09990328
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52, 546-553. doi: 10.1111/j.1365-2648.2005.03621.x
- Wiedemann, D., Bernhard, D., Laufer, G., & Kocher, A. (2010). The elderly patient and cardiac surgery - a mini-review. *Gerontology*, 56, 241-249. doi: 10.1159/000248761
- Willis, D. G., Grace, P. J., & Roy, S. C. (2008). A central unifying focus for the discipline: facilitating humanization, meaning, choice, quality of life, and healing in living and dying. *Advances in Nursing Science*, 31, E28-E40. doi: 10.1097/01.ANS.0000311534.04059.d9

World Health Organization. (2002). Active ageing: A policy framework.

<http://www.who.int/iris/handle/10665/67215>

Zingone, B., Gatti, G., Rauber, E., Tiziani, P., Dreas, L., Pappalardo, A., . . . Spina, A. (2009).

Early and late outcomes of cardiac surgery in octogenarians. *The Annals of Thoracic Surgery*, 87, 71-78. doi:10.1016/j.athoracsur.2008.10.011

Appendix A.

Studies Exploring Quality Of Life after Cardiac Surgery

Citation	Sample Size	Design	Instrument	Key Findings
Barnason et al. 2000	51 3, 6, & 12 months	Prospective Repeated Measures	SF-36 Activity instrument	QOL improved over 12 months, women had lower preoperative QOL than men, lowest QOL scores were at 3 months
Hunt et al. 2000	123 3 & 6 months	Cross sectional Comparative	SF-36 Cleveland Clinic Severity Scale	Significant association between QOL and poor sleep, pain. Short term memory impairment in 41 % of patients
Rumsfield 2001	1744 6 months	Prospective Observational	SF-36	Patients who are relatively healthy preoperatively do not improve QOL postoperatively
Myles et al. 2001	120 POD 3, 1 & 3 months	Prospective Observational	SF-36 QOR Scale	Significant increase in QOL at 3 months, not at 1 month
Lindquist et al. 2003	Men 405 Women 269 6 weeks, 6 months, 1 year	Prospective Comparative	Functional Status Questionnaire CE S-D	Recovery similar in women and men, but women have lower QOL preoperative and at 1 year than men Nadir of QOL at 6 weeks
Falcoz 2003	293 1 year	Prospective	SF-36	Preoperative QOL is predictive of 1 year cardiac functional status. CABG patients do not recover as well when compared to patients who had valve surgery
Barry 2006	1164 6 months	Prospective	SF-36	Perceived instrumental social support was associated improved mental functioning, not with physical function
Loponen 2007	302 6 , 12, 18 months	Prospective	15D Questionnaire	Improved QOL for both men and women postoperatively, QOL for pts> 75 at 18 months same as preoperative QOL

Citation	Sample Size	Design	Instrument	Key Findings
Barnason et al. 2008	119 6weeks, 3 months	Prospective Comparative	SF-36	Fatigue strongly impacts measures of early recovery at 6 weeks esp. anxiety and depressive symptoms at 6 weeks , at three month anxiety persisted
Rantanen 2009	163 1, 6, 12 months	Prospective	15 D Questionnaire	QOL lowest at one month after surgery Social support was not associated with changes in QOL

CABG = Coronary Artery Bypass Surgery QOL = Quality of Life, SF-36 = Medical Outcomes Short Form, 15D Questionnaire

Appendix B

Review of the Literature: Patient Experience of Cardiac Surgery

Author/year/country	Topic of study	Method	Sample	Time of interviews Age range (mean)
<u>Preoperative</u>				
Fitzsimons, Parahoo, & Stringer (2000) Ireland	Waiting for CABS	Qualitative Descriptive	59 men 11 women Random Selection (secondary analysis)	Preoperative 39-72(59)
Lindsay, Smith, Hanlon, & Wheatley (2000) Scotland	Perceptions of health prior to surgery and one year after cardiac surgery	Qualitative Descriptive	170 men 44 women Convenience	Preoperative Postoperative 39.9-79.3 (58.2)
McCormick, Naimar, & Tate (2006) Canada	Waiting for CABS	Mixed methods	38 men 4 women Convenience	Preoperative (64) 10 patients over the age of 71
<u>Intensive Care Unit</u>				
Gardner, Elliott, Gill, Griffin, & Crawford (2005) Australia	Patient experiences after CABS	Exploratory Qualitative	4 men 4 women Purposive	In hospital(ICU) 29-85 Median 75
Schou & Egerod (2008) Denmark	Experience of mechanical ventilation	Descriptive qualitative Purpose	8 men 2 women Purposive	ICU 35-84(65)

Author/year/country	Topic of study	Method	Sample	Time of interviews Age range (mean)
<u>Postoperative</u>				
Keller (1991) United States	Describing experience of coronary artery bypass surgery	Grounded Theory	8 men 1 women Purposive	Postoperative (average of 5 months after surgery) 51-73
Lindsay et al., (2000) *see above				
Raholm & Eriksson (2001) Finland	Exploring the dialectic of suffering and desire in spirituality	Hermeneutic phenomenology	4 men 3 women Purposive	Postoperative (2 to 5 years) 56-72 men 48-67 women
Raholm (2002) Finland	Exploring the concept of spirituality in cardiac surgery patients	Hermeneutic phenomenology	439 men 125 women Convenience	Postoperative men (67.2) women(70.6)
Doering, McGuire & Rourke (2002) United States	What patients want caregivers to know about recovery from CABS	Qualitative descriptive	66 men 23 women Convenience	Postoperative (1 week and 6 weeks) 57.6 44-71(57.6)
Theobald & McMurray (2004) Australia	Psychosocial issues facilitating Recovery	Qualitative Descriptive	22 Men 8 Women Convenience	Postoperative (1 month and 1 year) (65)
Gardner et al., (2005) * see above				
Hartford (2005) Canada	Telehealth intervention with qualitative arm	Qualitative descriptive	7 male 3 female Purposive	Postoperative (up to 7 weeks) 39-67 (59.3)
Tolmie, Lindsay, & Belcher (2006) Scotland	Experience Of Well- Being After CABS	Descriptive Qualitative	119 Men 9 Women Convenience	Postoperative (7 years) 42-81(63.8)

Author/year/country	Topic of study	Method	Sample	Time of interviews Age range (mean)
Dunkley, Ellard, Quinn, & Barlow (2007) United Kingdom	Patients' views of recovery after CABS	Mixed Methods	8 men 3 women Random	Postoperative (8 months) (70)
Lapum, Angus, Peter, & Watt- Watson (2010) Canada	Patient discharges experiences and transitions, the impact of technology	Narrative Analysis (Dialogic)	8 women 8 men Purposive	Postoperative (up to 6 weeks) 59-85
Robley, Ballard, Holtzman, & Cooper (2010) United States	Experience of stress after CABS (both patients and caregivers)	Hermeneutic Phenomenology	9 men 1 women Purposive	Postoperative (2 weeks to one month) 39-76
<u>Postoperative Women's Experience</u>				
Plach & Stevens (2001) United States	Midlife women's experiences recovering from cardiac surgery	Qualitative descriptive	13 women Purpose	Postoperative (2 years) Ages 51-66 (59)
Allen & Wellard (2001) Australia	Older women's experiences with sternotomy	Hermeneutic phenomenology	4 women Convenience	Postoperative (3-12 months) 69-79
Angus 2001 Canada	Experiences of women after OHS at home	Ethnography	3 women Purposive	Postoperative (4 weeks and 4 months) 75, 53, and 50
Robinson (2002) United States	Older women living alone after cardiac surgery	Qualitative Descriptive	12 Women Purposive	Postoperative (6 months-2 Years) 57-77(69)

Author/year/country	Topic of study	Method	Sample	Time of interviews Age range (mean)
Leegaard & Fagermoen (2008)	Women's descriptions of postoperative pain and pain management after discharge from cardiac surgery	Qualitative Descriptive	9 Women Convenience	Postoperative 44–70 (55.7)
Leegaard, Nåden, & Fagermoen (2008)	Postoperative pain and self-management: women's experiences after cardiac surgery	Qualitative Descriptive	10 Women Convenience	Postoperative (8–14 days) 52–82 (61.4)
Leegaard, Rustoen & Fagermoen (2010) Norway	Interference of postoperative pain on women's daily life after early discharge from cardiac surgery	Mixed methods	10 women Convenience	Postoperative (8–14 days) 52–82 (61.4)

Appendix C.

Interview Guide: Preoperative Interview

Time of interview:

Date:

Place:

Patient Initials:

Study Number:

Description of Setting

Interview Guide Outline

- Review: Informed Consent, explain purpose of study and invite prospective participant feedback, Reassert assurances of maintaining participant confidentiality,
- Negotiation and Warm up Greetings, Introductions, thank participant, negotiate interview with the participant, invite participant to shape interview as the expert including time frame,
- Gather Demographic Data (see form)
- Begin: Interview Process, then Wrap Up
- Debriefing and Closure

Script of Patient Interview (In-hospital)

Review: *I appreciate very much your time and the opportunity to hear about your experiences. I want to start by assuring you that I keep all your information and what you share with me is confidential and anonymous. Your health care team does not have any access to this information. As you know, I am a nurse conducting research, collecting older patient's stories of their experience of cardiac surgery. I believe that health care providers can learn from your stories and help nurses and other clinicians learn how to improve your health care.*

Negotiation and Warm up: *If you feel tired or want to stop this interview at any time, please let me know and we can close the interview and reschedule it if you wish. Usually, these interviews last about 30 minutes, but we can talk a shorter amount of time if you start to feel tired. We can also talk longer, up to 60 minutes, if you wish to. I want to let you know that you are the expert and I want to learn from you what is important to you at this point in your life. And, I would like to continue to learn from you, in this interview that is taking place before surgery what is important to you.*

I'd like to start by asking this question: As you prepare for cardiac surgery, I would like to invite you to share what you feel is important to you at this time in your life and to tell me your story. Please feel free to start your story where you think best.....

Possible Probes:

Can you tell me how this came about?

Can you tell me what happened?

Can you tell me about a particular moment that stands out for you?

What do you mean by [term used by participant]?

What was that like for you?

What was particularly hard at that time?

Were there things that helped?

Were there things that made things harder at that time?

How have you found it to talk about your experience?

Begin Wrap Up

- Begin negotiating closure of the interview with the participant
- Example of Script: *We are coming close to the time allotted for this interview, I wonder if there are any other important points you would like to share with me?*
- Debriefing: *I wonder if you could share with me any concerns or difficulties you may have had with this interview process.*

Wrap up

Negotiate time and date of follow up interview, negotiate a “reminder phone call” the day before the next interview in addition to a written reminder note that will be mailed to the patient at their address. Invite the patient to contact the PI if they wish to add any information to

this interview or if they have any questions and give them the PI's phone number. Thank the patient for their time and participation.

Patient Questions around medical care:

Should a patient have specific questions around their current medical care the patient the researcher will refer the patient to their current nurse and attending physician to obtain information about the patient's questions. The PI will assist the patient in compiling a list of any medically related questions that they have and so that the patient can provide this list to their nurse or attending physician.

Patient expressions of emotional distress:

Should a patient express emotional distress, such as crying, agitation, anger or withdrawn behavior and signs of depression, the PI will discuss this concern with the patient and encourage the patient to seek support from their nurse and attending physician for support for their distress. The PI will notify the bedside nurse of the patient's distress and note this in the patient's chart so that the rest of the health care team is aware of the patient's possible need for additional emotional support. The PI will follow up with the bedside nurse within 24 hours to ascertain if the patient received additional support or if any additional follow up on the part of the PI is necessary.

Patient request for support group information post surgery:

Patient's who express an interest in an ongoing support group for those who have had cardiac surgery will be referred to their health care provider for access to this information but

will also be given contact information for the American Heart Association support groups for patients who have had cardiac surgery (Mended Hearts organization which has a support group at Maine Medical Center).

Appendix D

Patient Information Form and Contact Information

Patient Name: _____

Date of Birth: _____ Sex (circle one): Male Female

Language Preference (if not English) _____

Marital Status (circle one):

Single

Married

Widowed

Other _____

Type of surgery planned: _____

Name of cardiac surgeon: _____

Name of primary care provider: _____

Occupation(s): _____

Currently working (circle one): Yes No

If retired, what year did you retire? _____

Type of current occupation _____

Current Activities _____

Patient Contact Information

Street Address: _____

Apt. No.: _____

City: _____

State _____

Zip Code: _____

Home phone: (____) _____

Work phone: (____) _____

Cell/Pager number: (____) _____

Email Address: _____

Secondary contact information:

In case of difficulty contacting you, the researcher, Kathleen Keane, asks if you would share the name of a close friend or relative who would know your current contact information.

Secondary contact Information

Secondary contact Name: _____

Secondary Contact Phone: (____) _____

Secondary Contact Address:

Street Address: _____

Apt. No.: _____

City: _____

State _____

Zip Code: _____

Secondary Contact Email address:

Thank you!

Appendix E

Interview Guide: Postoperative Phone Interview

- Interviewee Pseudonym:
- Study Number:
- Date:
- Time
- Interview Number (Postoperative 1 2 3 4 5)
- Date of patient's surgery
- Procedure(s):
- Setting:

Interview Guide Outline

- **Review with Patient** Introduce self, explain purpose of study , review confidentiality and invite prospective participant feedback
- **Warm up** Thank participant, negotiate interview with the participant, invite participant to shape interview as the expert as well as negotiate the time frame of interview.
- **Begin:** Interview Process, then Wrap up and review of demographic data and contact information (See form Participant Demographic and Contact Information: Form A)
- **Debriefing**

Phone Script

- *Hi Mr./Mrs./Ms _____, my name is Kathleen Keane and I am recontacting you by phone as a part of a research study on the experience of older adults who have had cardiac surgery.*
- *I am a doctoral student at Boston College and I also work at Maine Medical Center as a nurse. As a part of this research study, we talked before you had cardiac surgery about your experiences coming to surgery. I am calling you now to follow up with a phone interview with you to review with you the information you shared with me before you had surgery and to also hear about your experiences since then.*

- *I want to assure you that your responses will remain confidential and that your information will remain anonymous. Any details that identify you such as your name or date of birth will be removed from the interview record.*
- *The information you share with us about your experiences is important because health care providers can improve how they care for other patients by learning from your experiences. I am happy to share the written research summary of this project with you when it is finished.*
- *This interview can take approximately 30 minutes or less to complete. If at any time you are tired or wish to stop the interview for any reason, we can do so. The interview length varies from person to person and if you wish to talk longer than 30 minutes, we can. As a part of the interview process, I will be audio-taping our conversation so I can accurately record your story. This information remains confidential; it will be transcribed by me and by a secretary who is trained in keeping patient information confidential.*
- *Negotiate interview with patient: Is this a good time to have this interview by phone? Do you have any concerns about continuing to participate in this research study? What amount of time would you like to spend on this phone interview?*
- *I'd like to start with reviewing some of the experiences you shared with me in our interview prior to your surgery [Share short synopsis of patient preoperative narrative with the patient] Can you tell me if what I have read to you sounds like it is an accurate summary of your preoperative experiences? Is there anything you would like to add?*
- *Now, I would like to hear more about your experiences since we had that first interview. I want to let you know that you are the expert and I want to learn from you what is important to you at this point in your life. And, I would like to continue to learn from you, in this interview after your surgery. I would like to invite you to share what you feel is important to you at this time in your life and to tell me your story. Please feel free to continue your story where you think best.....*
- Possible Probes:

Can you tell me how this came about?

Can you tell me what happened?

Can you tell me about a particular moment that stands out for you?

What do you mean by [term used by participant]?

What was that like for you?

What was particularly hard at that time?

Were there things that helped?

Were there things that made things harder at that time?

How have you found it to talk about your experience?

Patient Questions around medical care:

Should a patient have specific questions around their current medical care the patient the researcher will refer the patient to their current health provider (MMC Cardiothoracic Surgery Service or their PCP, whichever is providing care). The PI will assist the patient in compiling a list of any medically related questions that they have and also in providing the patient with their health care provider phone number, if they do not have it).

Patient expressions of emotional distress

Should a patient express emotional distress, such as crying, agitation, anger or withdrawn behavior and signs of depression, the PI will refer the patient to their health care provider for further follow-up. The PI will assist the patient, if they are willing, in contacting their health care provider and provide health care provider information contact information for the patient and family if they do not have it available.

Patients who express an interest in an ongoing support group for those who have had cardiac surgery will be referred to their health care provider for access to this information but will also be given contact information for the American Heart Association's support group info for patients who have had cardiac surgery.

Begin Wrap Up

- Begin negotiating closure of the interview with the participant
- Example of Script: We are coming close to the time allotted for this interview, I wonder if there are any other important points you would like to share with me?
- Debriefing: I wonder if you could share with me any concerns or difficulties you may have had with this interview process.

Wrap up

Negotiate time and date of follow up interview, negotiate a “reminder phone call” the day before the next interview in addition to a written reminder note that will be mailed to the patient along with their gift card in the amount of \$25.00. Invite the patient to contact the PI if they wish to add any information to this interview or if they have any questions and give them the PI’s phone number and a self addressed (to PI) envelope to send written information to the PI, if they wish. Thank the patient for their time and participation.

Other notes:

Interviewer's style: friendly, courteous, conversational, and unbiased.

Give the interviewee feedback as appropriate.

- Encourage patient to elaborate. Example: You mentioned two things ... is there anything else you'd like to add?"
- In the case of a response with vague I-don't-know... Examples:

"Let me read the question again; perhaps I didn't make it too clear"

"There's no wrong or right answer, I am just seeking your opinion."

"Taking everything into consideration, what do you think?"

"On the basis of the way things look to you now, what do you think?"

Resource list for patient interview

1. Patient’s Cardiothoracic Surgical Attending

2. Patient’s Primary Care Provider

3. Information on Cardiac Support Groups after Surgery

The Mended Hearts, Inc.

Mended Hearts volunteers offer peer-to-peer support to patients, family members and caregivers

via:

- Hospital Visiting – In person visit from a Mended Hearts volunteer while you are recovering
- Online Visiting – Email check in and provide materials electronically
- Phone Visiting – Calling to provide a word of hope

8150 N. Central Expressway, M2075

Dallas, Texas 75206

Information Line: 1-888-HEART99 (1-888-432-7899)

National Office: 214-296-9252

Fax: 214-295-9552

Email: info@mendedhearts.org

Appendix F

Institutional Review Board Approval



BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0498

IRB Protocol Number: 13.076.01

DATE: November 16, 2012

TO: Kathleen Keane

CC: Dorothy Jones

FROM: Institutional Review Board – Office for Research Protections

RE: Older Adult Narrative of the Experience of Cardiac Surgery

Notice of IRB Review and Approval
Expedited Review as per Title 45 CFR Part 46.110, FR 60366, FR, # 6 & 7

The project identified above has been reviewed by the Boston College Institutional Review Board (IRB) for the Protection of Human Subjects in Research using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following standard conditions:

1. You are approved to conduct this research only during the period of approval cited below;
2. You will conduct the research according to the plans and protocol submitted (approved copy enclosed);
3. You will immediately inform the Office for Research Protections (ORP) of any injuries or adverse research events involving subjects;
4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the informed consent documents that have the IRB approval dates stamped on them (approved copies enclosed).
6. You will give each research subject a copy of the informed consent document;

7. You may enroll up to 15 participants. You may not enroll more than this number of participants without seeking IRB approval. To do so will be a violation of the conditions of IRB approval and, if federal funding is involved in your project, a matter of non-compliance that we must report to the federal government. This could significantly and negatively impact your research.
8. If your research is anticipated to continue beyond the IRB approval dates, you must submit a Continuing Review Request to the IRB approximately 60 days prior to the IRB approval expiration date. Without continuing approval the Protocol will automatically expire on November 15, 2013.

Additional Conditions: Any research personnel that have not completed an acceptable education/training program should be removed from the project until they have completed the training. When they have completed the training, you must submit a Protocol Revision and Amendment Form to add their names to the protocol, along with a copy of their education/training certificate.

Approval Period: November 16, 2012-November 15, 2013.

If you are conducting research using an online survey (e.g. Survey Monkey, Qualtrics), the IRB requires that the approval dates appear on the online consent page of your survey. Please copy and paste the statement below onto your survey:

The Boston College IRB has approved this protocol from November 16, 2012-November 15, 2013 .

Boston College and the Office for Research Protections appreciate your efforts to conduct research in compliance with Boston College Policy and the federal regulations that have been established to ensure the protection of human subjects in research. Thank you for your cooperation and patience with the IRB process.

Sincerely,

Stephen Erickson
Director
Office for Research Protections

Its



Maine Medical Center

MaineHealth

Maine Medical Center
Research Institute

Kathleen Keane, RN, BSN
Maine Medical Center
Cardiac Surgery Recovery Unit 22
Bramhall Street
Portland, ME 04102



Attention:

Re: Notice of Expedited Approval

(IRB #4075) Older Adult Narrative of the Experience of Cardiac Surgery

Date: 08/30/2012

This is to inform you that on 8/30/2012 the Maine Medical Center IRB approved the above research study, including:

- Informed Consent (Version Date: August 29, 2012)
- Research Plan (Version 1 August 28th, 2012)
- Appendix A (Demographic/Contact Info Form)
- Appendix B (Preoperative Interview Guide/Script)
- Appendix C (Post operative Interview Guide/Script)
- Appendix D (Project Funding Information)

The purpose of this research is to explore the narrative accounts of older adults who have had cardiac surgery to inform the understanding and health care of this population of patients. Narrative analysis will be used to explore the trajectory and turning points of recovery for older adults by following participant's stories of the time prior to and following cardiac surgery.

This study has received **Expedited Approval** according to federal regulation 45 CFR 46.110(b)(1).

Please be aware that the IRB will be notified of this action at the meeting on **09/25/2012**.

The approval period is from **08/30/2012 to 08/30/2013**. Your study number is **4075**. Please be sure to reference this number in any correspondence with the IRB.

Please be aware that even though you now have IRB approval, it is Maine Medical Center's policy that a commercially funded protocols, or protocols subject to sub-contract, must have a fully executed contract (signed by all parties) prior to beginning any activity related to this protocol.

Before a subject can be entered into this project, he/she must sign and be given a copy of the informed consent document. The original consent form should be kept in your files, available for review for up to three years from the date of termination of the project. A copy should be kept in the subject's chart (if applicable).

Continued approval is conditional upon your compliance with the following requirements:

- All protocol amendments and changes to approved research must be submitted to the IRB and not be implemented until approved by the IRB except where necessary to eliminate apparent immediate hazards to the study subjects.
- Significant changes to the study site and significant deviations from the research protocol must be reported.
- Serious and unexpected adverse events must be promptly reported to the IRB
- Please complete and submit reports to the IRB as follows:

Renewal of the study - complete and return the Progress Report Request 4-6 weeks prior to the expiration of the approval period. The study cannot continue after **08/30/2013** until re-approved by the IRB.

Completion, termination, or if not renewing the project - send the report upon completion of the study.

We (I) certify that the Maine Medical Center Institutional Review Board is in compliance with good clinical practice.

Please call our office if you have any questions about the terms of this approval (Research Compliance Office, 207-396-8183).


Eric Larsen, M.D., IRB Chairperson

Copy: File

Enclosure: Informed Consent Document

Appendix G
Informed Consent

8-30-2012

 Maine Medical Center	Human Research Protection Program Institutional Review Board Authorization to Participate in a Research Project and Permission to use or Release Protected Health Information (PHI)	
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STUDY TITLE: *Older Adult Narrative of the Experience of Cardiac Surgery*

CONSENT VERSION DATE: *August 29, 2012*

HOSPITAL OR INSTITUTION: *Maine Medical Center*

INVESTIGATOR: *Kathleen M. Keane*

SUBJECT'S NAME (printed): _____

You are being asked to volunteer for a research study. Research studies include only people who choose to take part. In order to decide whether you should agree to be part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent. Please take your time to make your decision.

You are being asked to take part in this study because you are an older adult (greater than or equal to 70 years of age) and you are planning to have cardiac surgery.

WHY IS THIS STUDY BEING DONE?

This research is being done in order to understand the experience of cardiac surgery and learn from you what is important to a patient before you have surgery as well as what the experience of cardiac surgery will be like for you. The goal of this research is to improve the care that is given to older adults who have cardiac surgery.

HOW MANY PEOPLE WILL TAKE PART IN THE RESEARCH STUDY?

Up to 15 people will take part in this study at Maine Medical Center.

WHAT IS INVOLVED IN THE STUDY?

If you take part in this research study, you will have the following procedures:
The study consists of meeting with the researcher, Kathleen Keane for at least two interviews, with the possibility of three more interviews over a total period of 12 months. The information you share in your interviews will remain confidential and will not be shared with your health care providers. Each interview will be digitally audiotaped. A more detailed description of each interview follows:

APPROVED
8-30-2012

1. After you consent to participate, the first interview will be here in the hospital before you have surgery in person with Ms. Keane. Ms. Keane, will meet with you and ask you to share what is important to you and what your experience is coming to cardiac surgery. For example, the following type of questions will be asked: "As you prepare for cardiac surgery, I would like to invite you to share what you feel is important to you at this time in your life and to tell me your story. Please feel free to start your story where you think best....."

If feasible, in order to provide a private place for your interview, a private room will be reserved for you to meet with Ms. Keane, on the unit where you are hospitalized. The interview will be audiotaped and will take 30 minutes or less; if you are tired or want to stop the interview you can do so at any time. Ms. Keane, will work with you to find an interview time and length that is convenient for you. At the end of the first interview, Ms. Keane, will schedule a tentative time and date for the second interview which will take place approximately 4- 6 weeks after surgery. Ms. Keane, will call you at your home or where you are living 2-3 days before the second scheduled phone interview, as a reminder about your second interview.

At the end of the interview, Ms. Keane, will provide you with her phone number and an envelope addressed to her should you wish to reach her.

To thank you for your time and participation in this study, a VISA gift card worth \$25.00 will be given to you at each interview. One 25.00 gift card will be given to you at the completion of the first in person interview with Ms. Keane.

2. The second interview will then take place by phone about 4 to 6 weeks after surgery at your home or where you are living after you have had cardiac surgery. To thank you for your time and participation in this study, at the completion of this phone interview, Ms. Keane, will mail a 25.00 VISA gift card to you.

3. If you wish, you will have the option of being re-contacted by Ms. Keane after these first two interviews for three more interviews. These three follow up interviews will take place at 8-12 weeks after surgery, 6 months after surgery and 12 months after surgery. In each follow up phone interview, Ms. Keane will ask you to share the story of your experiences after cardiac surgery. To thank you for your time and participation in this study, at the completion of each subsequent phone interview, Ms. Keane, will mail a 25.00 VISA gift card to you.

Please check the box below if you are willing to be re-contacted for the three follow up interviews at 8-12 weeks after surgery, 6 months after surgery , and 12 months after surgery.

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HOW LONG WILL I BE IN THE STUDY?

If you are willing to only have the first two interviews you will be in the study for approximately two months. If you are willing to continue in the study after the first two interviews, you will be in the study for approximately one year after your surgery. One of the purposes of recontacting you after the first two interviews is to review the information you have shared in your interviews and check with you to see if you feel the information the researcher has summarized represents your story accurately.

The researcher may decide to take you out of this study if you are not healthy enough to participate in the interview process.

You can stop participating in this research study at any time. There is no obligation to continue to participate in this study after you are enrolled, and you can withdraw at any time. Withdrawing from this research study will not affect the health care you receive as a patient at the hospital or the health care you receive after hospitalization.

WHAT ARE THE RISKS OF THE STUDY?

There is a risk of loss of confidentiality in this study. Ms. Keane, will make every effort to protect your confidential patient information. The tape recordings of interviews will remove identifying names and information when transcribed and a pseudonym (a "made up" name) will be inserted instead. Identifying information from the interviews that you share with the researcher is not shared with the health care team that is taking care of you in the hospital. Patient experiences that may be published in a research journal have all identifying information removed.

There is a possible risk of feeling emotionally distressed in sharing your story before and after surgery. While you are in the hospital, if you would like emotional support for this distress, Ms. Keane will contact your health care team, your bedside nurse and/or doctor to let them know you may need additional emotional support. After surgery, if you would like additional emotional support; Ms. Keane, will assist you in contacting your cardiac surgeon's office or your primary health care provider in order to locate additional support services for you.

ARE THERE BENEFITS TO TAKING PART IN THE RESEARCH STUDY?

There is no direct benefit to you from being in this study. However, your participation may help others in the future as a result of knowledge gained from this research.

WHAT OTHER OPTIONS ARE THERE?

Instead of being in this study, you have the option not to participate in this study. This will in no way affect your health care treatment as a patient.

WHAT ABOUT CONFIDENTIALITY?

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your audiotaped interviews will be kept in a password protected computer which is only accessible to Ms. Keane. All identifying information such as

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your true name and birth date will be removed when the interviews are transferred into writing and a pseudonym (or false name) will be assigned to each tape. A code book which links your true name with the audiotaped interviews will be kept separately from the written out interviews and will be kept in a password protected computer. The writing out of the interview into text form will be performed by a certified transcriptionist. Personal health information such as your name, birth date and type of surgery will also be kept separately from the written out interviews and kept in a password protected computer.

WHAT ARE THE COSTS?

You or your insurance company will not be charged for any tests or services specifically required by this research study unless the tests or services are clinically indicated or part of your standard treatment. You will still be responsible for the cost of your usual ongoing medical care, including procedures, non-study medications, and tests that your study doctor or regular doctor requires during this study as part of your usual medical care.

WHAT IF I AM INJURED DUE TO MY PARTICIPATION IN THIS STUDY?

In the case of injury or illness resulting from this research study, medical treatment will be available at the usual charge.

Maine Medical Center has no policy or plan to pay for any injuries that you might receive as a result of your participation in this study. However, this does not take away your rights to seek or collect compensation for injury related to malpractice, fault, or blame on the part of those involved in the research, including the hospital.

You or your insurance company will be responsible for any costs resulting from underlying disease or treatments provided to you outside of this research study.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Taking part in this study is your choice. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled.

We will tell you about new information that may affect your willingness to stay in this study.

PERMISSION TO USE OR RELEASE IDENTIFIABLE HEALTH INFORMATION FOR RESEARCH PURPOSES

Because information about you and your health is personal and private, it generally cannot be used in this research study without your written permission. If you sign this form, it will provide that permission. This section of the consent document is intended to inform you about how your health information will be used or disclosed in this study.

8-30-2012

Your information will only be used in accordance with this authorization form and the informed consent form and as required or allowed by law.

WHY AM I BEING ASKED TO RELEASE THIS INFORMATION?

As part of this research study, you are being asked to allow investigator to collect health information about yourself. This information will be collected, entered onto a database with the health information from others taking part in this research study, and studied in order to understand your experience of cardiac surgery and help improve the health care delivered to cardiac surgery patients. Investigator may also need to obtain copies of any medical records you have with other health care providers.

WHAT AM I BEING ASKED TO RELEASE?

For this research study, the following information will be collected:

Your name
Your address
Your sex
Your date of birth
Your language preference
Your past medical history
Your occupation
Your activities
Your type of surgery
The name of your surgeon
The name of your primary care provider
Your marital status
The name of a close friend or family member who can serve as a secondary contact

WHO WILL SEE THIS INFORMATION?

Personnel or members of the Maine Medical Center Institutional Review Board, personnel from the Office of Human Research Protections or any regulatory agency may see parts of your medical records related to this research study and, therefore, will see your name and other personally identifiable information about you. The information collected is the property of investigator, and you will not be able to get it back. In the event of any publication regarding this study, your identity will not be disclosed.

WILL THE INFORMATION COLLECTED AS PART OF THIS STUDY BE DESTROYED WHEN IT IS NO LONGER NEEDED?

It is difficult for the researcher, Kathleen Keane to know how long your information will be kept at least until the end of the research study, but most likely it will be kept on a database at the investigator's office for an indefinite length of time. We do not know when your information will no longer be used, and there is no expiration date after which it will be discarded.

WILL THE INFORMATION COLLECTED AS PART OF THIS STUDY BE DESTROYED WHEN IT IS NO LONGER NEEDED?

It is difficult for Kathleen Keane to know how long your information will be kept. Your information will most likely be kept on the database at the home office of Kathleen Keane, the researcher for an indefinite length of time. We do not know when your information will no longer be used, and there is no expiration date after which it will be discarded.

CAN I STOP MY INFORMATION FROM BEING USED?

If you leave the study, and do not wish to have any more of your personal data collected, you must notify *Kathleen Keane* in writing. You may also call *Kathleen Keane* at 207-450-4209 and your request to stop collecting information will be honored, but you must also notify *Kathleen M Keane* in writing. To notify *Kathleen M Keane* in writing, send your request to:

Kathleen M Keane
Cardiothoracic Intensive Care Unit
Maine Medical Center
22 Bramhall Street
Portland, Maine 04102

Any data that has already been collected will continue to be seen and used as described previously.

WHAT IF I DO NOT AUTHORIZE YOU TO COLLECT AND RELEASE MY HEALTH INFORMATION?

If you agree to be in this research study, you are authorizing the release of your health information as part of the research. If you do not want to release your health information, you may not take part in this research study (do not sign this form if you do not want to take part in this research study, or you do not want to release your health information).

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

For questions about the study or a research-related injury contact *Kathleen Keane* at 207-450-4209.

For questions about your rights as a research participant, contact the Maine Medical Center Institutional Review Board (which is a group of people who review the research to protect your rights) at (207) 396-8183.

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I have read, or have had read to me, the above information before signing this consent form. I agree to participate in this research study. I also authorize use or disclosure of my personal health information for the purpose of this research. I have been offered ample opportunity to ask questions and have received answers that fully satisfy those questions.

DO NOT SIGN THIS FORM AFTER THIS DATE →

8.30-2013

Signature of Patient or Authorized Representative

Date/24 hour time

Printed Name of Patient or Authorized Representative

Signature of the Person Obtaining Consent

Date/24 hour time

Signature of Witness

Date/24 hour time

A signed copy of this consent form must be given to each subject entering the study.

Signature of the witness is necessary only when the person signing the consent is other than the subject or if this is an international study being conducted under ICH GCP (E6)

