Patient Participation in Treatment in the Context of Acute Care

by
Lauren McTier
RN, BN (Hons), Grad Dip Adv Nur (Crit Care), Grad Dip Ed, Grad Cert App Sci (Stats).

Submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy

Deakin University
August, 2013
I am the author of the thesis entitled patient participation in treatment in the context of acute care

submitted for the degree of Doctor of Philosophy

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Full Name: Lauren McTier

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Date: 5th August 2013
Abstract

The notion of patient participation has been integrated into health care policy as a significant component of the processes of achieving patient safety and quality outcomes. To date, the majority of studies of patient participation have focused on patients participating within the contexts of treatment decisions and chronic illness management. There is little understanding of how patients participate in acute care environments when they are experiencing episodic illness or events such as surgery, in order to optimise their recovery. Acute care environments offer unique challenges for the facilitation of patient participation because they are typically characterised by high patient acuity requiring frequent interactions of short duration by multiple clinicians. A better understanding of the multi-faceted aspects of care in these environments will inform strategies to improve patient outcomes.

The research reported in this thesis aimed to explore the current status of participation by patients during an episodic admission to an acute care facility. More specifically, the objectives were to understand the processes of care related to incorporating patient participation in acute care, how patient participation was understood and enacted by patients and nurses, and the barriers and facilitators of patient participation within this setting.
The work explored further, patients’ preferences for participation in their care.

For this exploratory, repeated measures study, a mixed-methods approach was used in a single institution, case study design. The setting was the cardiac surgery ward of a major metropolitan, tertiary referral hospital in Melbourne, Australia. Participation was sought from patients undergoing elective cardiac surgery and permanent nursing staff working in the case study ward. Potential patient participants were identified in the cardiac surgery preadmission clinic and nurse participants were approached on the cardiothoracic ward and invited to participate.

Data collection methods included semi-structured interviews with patients pre- surgery and prior to discharge, naturalistic observation of care processes between patients and nurses, audit of patients’ medical records and focus group interviews with nurses. Four *a priori* treatment goals of recovery: medication management, pain management, pulmonary management and discharge planning, were identified as the orienting framework for the exploration of patient participation in the post-operative context. Semi-structured interviews with patients before surgery (n=130) and prior to discharge (n=98) from hospital provided data regarding patients’ knowledge of their recovery goals and their preference for, and reported role in, achieving these goals. The Control Preference
Scale (CPS) was used to elicit patients’ preference for participation in the recovery goals of care. A modified version of this tool was used to elicit patients’ perceived participation in their recovery goals. Naturalistic observations (n=48) based on the tenets of qualitative exploratory, descriptive research were used to elicit deeper understandings of the clinical practices and interactions between patients and nurses relating to the goals of care that occur during the recovery period after surgery.

Medical record audit (n=130) served to identify current practice in terms of nurses’ documentation of patient participation. Focus group interviews (n=2) with nurses (n=16) explored their perceptions of the way patients participate in key recovery goals, and how patient participation in these goals of care can be facilitated.

The amount of time nurses spend with patients represents one of the opportunities patients have to interact and participate in care. On average, nurses spent 17.4 (SD=12.9) minutes in patients’ rooms during two-hour observation periods. Of that time, an average of 3.8 (SD=3.5) minutes were spent in direct verbal nurse and patient interactions.

All patients had had changes to their cardiovascular medications as a function of their surgical admission. This involved commencing new and ceasing old medications. As a result, their ability to provide a complete list, and state the purpose and side effects of their current cardiac medications
prior to discharge was lower than their preadmission knowledge. Although 25% of patients preferred participation in medication management, no patients reported involvement in medication management while hospitalised. There was no evidence that nurses viewed medication administration tasks as opportunities to facilitate patient participation in medication management either as a safety process during hospitalisation or once patients were discharged from hospital.

Generally, patients knew more about their pain management after their surgical admission when compared to preadmission suggesting that they had participated in their management to some extent. More than half of patients preferred to share responsibility with clinicians to make decisions about pain management. There were many instances where opportunities for patients to participate in pain management were missed either because nurses failed to facilitate participation or patients did not actively seek involvement. The limited time nurses spent with patients was identified as a barrier to patient participation in pain management by both patients and nurses.

In relation to pulmonary management, patients again displayed a greater understanding of their role in deep breathing and coughing exercises after their surgical admission than they did at preadmission. While over half of patients (55%) preferred to make decisions about deep breathing and
coughing exercises, three-quarters of patients (75%) reported they made decisions about deep breathing and coughing during their surgical admission.

Overall, patients were more likely to know their discharge destination, the importance of cardiac rehabilitation, and were intending to attend cardiac rehabilitation as a function of their surgical admission. In relation to patient preference, most patients preferred involvement in decisions about their discharge date and destination however most patients reported clinicians made all decisions relating to these aspects of discharge planning. Nurses’ facilitation of discharge planning focused on the logistics of discharge and arranging cardiac rehabilitation. There was no evidence of nurses preparing patients to self-manage their cardiovascular disease and treatments following discharge during observations of practice.

Audits of medical records failed to reveal any documentation related to patient participation in their care following surgery.

The integrated analyses of the findings revealed two discernible patterns in care delivery that affected the way patient participation was observed and reported to be enacted in acute care practice. These patterns in patient and nurse interactions were identified in relation to the four recovery goals of care after cardiac surgery. Care delivery was either nurse-centred or co-constructed between nurses and patients. The findings suggested that
whether or not care delivery was nurse-centred or co-constructed with patients depended on the nature of the care needs and the culture of practice.

Nurse-centric care delivery was most evident in medication management. Both patients and nurses held very narrow interpretations of the scope of the routine task of medication administration and missed opportunities for ongoing patient education and involvement in safety processes. When patients and nurses understood the role patients could play in achieving goals of care, this reduced ambivalence related to prioritisation of care needs and co-construction of key recovery goals of care was evident. This was observed in pulmonary and pain management (pain assessment) and supported by patient perceptions of greater involvement in these aspects of care.

Substantial redesign of acute health care systems is required in order to achieve patient participation in this context. This redesign would require changes at the macro policy level and meso level of care delivery systems, commitment from all stakeholders including patients, and sufficient resource and financial investment to ensure sustainable change. Health care professional education would also require redesign to incorporate learnings that facilitate patient participation in care and changes in work systems.
Future directions in research need to focus on the interplay of systems of care delivery, health professionals’ skills in facilitating participation and working within interdisciplinary work systems, and patient factors that act as key determinants for the success of patient participation in complex, acute care environments.
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This thesis is dedicated to the memories of Bob (Pa) (1920-2013) and Nan (Nana) Pearson (1924-2009).
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List of publications, conference proceedings and awards arising from the thesis


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Recipient of the Deakin University, School of Nursing and Midwifery Scholarship Award (2011). This is an award for outstanding research scholarship to a student enrolled in the PhD Doctoral program at the School of Nursing and Midwifery, Deakin University, Melbourne, Australia.

Recipient of the Janet A Secatore Nursing Research Award (2009). This is an award for the best nursing poster displayed during Alfred Week, Alfred Health, Melbourne, Australia.

Recipient of the Cabrini Nursing Scholarship Prize (2009). This is an award for the best oral presentation given at the Deakin University School of Nursing, Research School, Melbourne, Australia.

Recipient of the ‘Centaur Nurses Memorial Education Trust’ (2008). This is a $5000 scholarship for post-registration studies in nursing at an Australian University for Division 1 Registered Nurses practicing in Victoria from the National Research and Scholarship Fund Grant, Royal College of Nursing, Australia.

Recipient of an Australian Postgraduate Award (2007-2010). This is a stipend scholarship (over three years) for doctoral studies from the Australian Government.
Abbreviations

**ACHS:** Australian Council on Healthcare Standards

**ACSQHC:** Australian Commission on Safety and Quality in Health Care

**AVR:** Aortic Valve Replacement

**CABG:** Coronary artery bypass graft

**CCI:** Charlson Co-morbidity Index

**CPS:** Control Preference Scale

**CQC:** Care Quality Commission

**DVT:** Deep Vein Thrombosis

**EFT:** Equivalent Full Time

**EPHA:** European Public Health Alliance

**EQUIP:** Evaluation and Quality Improvement Program

**EU:** European Union

**ICU:** Intensive Care Unit

**IOM:** Institute of Medicine

**MMSE:** Mini Mental State Examination
MVR: Mitral Valve Replacement

NHS: National Health Service

NPP: National Priorities Partnership

NPSA: National Patient Safety Agency

SPSS: Statistical Package for the Social Sciences

UK: United Kingdom

UR: Unit Record

USA: United States of America

VCE: Victorian Certificate of Education

WHO: World Health Organization
Chapter One

The research problem

Worldwide, the concept of patients as active participants in their care has been incorporated explicitly into health care policy as an important element in achieving quality patient outcomes. This espoused concept has emerged in conjunction with, and grown in parallel to, the quality and safety movement in health care. Despite the integration of patient participation into organisational mission statements and core values, what is meant by patients participating in their own care is unclear and holds many diverse connotations depending on the context in which it is used. There is discrepancy about the meaning of participation within health care where the term ‘patient participation’ is often used interchangeably with ‘patient involvement’, ‘patient collaboration’, ‘patient partnership’ and ‘patient engagement’ (Brearley, 1990; Cahill, 1998; Greenfield, Kaplan, & Ware, 1985; Gruman et al., 2010; Jewell, 1994; Tutton, 2005).

In health care, the focus of patient participation has predominately been to facilitate patients to participate in decisions about specific medical treatments or to foster self-management in people with chronic life-long illness. There is little understanding of how patients
participate in acute care environments associated with episodic illness in order to optimise their recovery. Acute care environments offer unique challenges for the facilitation of patient participation because they are typically characterised by high patient acuity requiring frequent interactions of short duration by multiple clinicians.

There are several patient and system factors that can reasonably be expected to impact on patients’ ability to participate actively in their own care. Patients need to know their health history and understand treatment goals associated with their illness. This knowledge is usually imparted by clinicians through formal and informal interactions. In addition, the health care system and processes of care must be designed to support patient participation.

The notion of active participation in the context of acute episodic illness presupposes that patients know the goals of their treatment in order to optimise their recovery; know their own health history and are willing to collaborate with health care clinicians to meet their treatment goals. More specifically, if hospitalised patients are to be active participants in their care, it could be argued that they should be aware of the clinical pathway that relates to their particular treatment, be cognisant of changes to their pharmacological management as well as participants in discharge planning. Limited
understanding of their plan of care during hospitalisation may adversely affect patients’ ability to provide informed consent for treatments and to assume their own care after discharge. Consequently, patients’ understanding of their plan of care has the potential to impact the quality and safety of their care while in the acute care setting (O’Leary et al., 2010).

There is emerging recognition that patients and families can play an important role in patient safety in hospital settings by acting as a safety mechanism to monitor care delivery and reduce the incidence and impact of preventable adverse events (Davis, Jacklin, Sevdalis, & Vincent, 2007; Longtin et al., 2010). Despite this, the role patients can play in improving quality of care and their own safety is seriously under-researched. There is needed, research that is focused on patient participation as a method for improving the quality and safety of health care.

Important considerations in pursuing a research agenda in this area is that participation in the context of acute episodes of health care has not been well defined or operationalised. Moreover it is not clear to what extent patients’ desire participation in this context or the extent to which patients can actually participate in achieving their treatment goals. As a platform for designing systems of care that facilitate patient participation, planning curricula for health care
professional education and providing patient information, a clearer understanding of how patient participation is both understood and enacted by patients and clinicians is needed. These insights will provide evidence for interventions to facilitate patient participation in achieving treatment goals in acute care environments and enable measurement of the effect of patient participation on health and safety outcomes.

1.1 Patient participation in the Australian health care context

Within Australian health care, the notion of patient participation is inextricably linked to patients’ rights and responsibilities (Johnson, 2001) and more recently to safety and quality agendas. In 2012, ‘Partnering with consumers’ was selected as one of the three inaugural National safety and quality goals for health care (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2012a). The Australian Council on Healthcare Standards (ACHS), an organisation whose aim is to improve the quality of health care in Australia through continual review of performance, assessment and accreditation, requires evidence of patient participation as a mandatory condition of their Evaluation and Quality Improvement Program (EQUIP) (Australian Council on Healthcare Standards, 2010).
However, there remain ambiguities in guidelines for selecting appropriate evidence and determining the method of data collection.

Within the context of health care overall, individuals can participate at two levels: 1) as ‘patients’ in their own medical care, or 2) as ‘consumers’ in health service planning and health system policy development (Johnson, 2001). The notion of participation has been a component of the quality and safety dialogue at both these levels (ACSQHC, 2012b), although traditionally the service planning and policy development level is where people as consumers were more likely to have an explicit role (Johnson, 2001). In Australia, the focus on activity related to patient participation has been in seeking feedback through patient satisfaction surveys, provision of information to patients and consultation with consumers as key informants of health care outcomes (ACSQHC, 2012b). Less emphasis is placed on actively working with patients as active participants in their day-to-day care (McCaffery et al., 2011). Little is known about how people as patients, participate in their own medical care and safety whilst undergoing treatment in acute care.

1.2 Patient participation and the quality and safety of care

Advances in technological and medical knowledge have significantly improved outcomes of illness and interventions, yet adverse events
related to treatment continue to pose a major threat to patient safety (Amalberti, Benhamou, Auroy, & Degos, 2011; Cobb, 2004; Kalisch et al., 2012). Adverse events are defined as injury resulting from a medical intervention rather than the underlying condition of the patient (Brennan et al., 1991; Leape, 1994). In Australia, between 7% and 18% of hospitalised patients suffer an adverse event; of which 50% are considered preventable (Ehsani, Jackson, & Duckett, 2006; Hauck, Zhao, & Jackson, 2012; Wilson et al., 1995). The risk of in-hospital death increases 7-fold in patients who experience an adverse event compared to patients without this complication (Ehsani et al., 2006). Adverse events are not limited to Australia. Similar adverse event outcomes have been identified worldwide in findings from studies in the United Kingdom (Vincent, Neale, & Woloshynowycz, 2001), United States of America (Kohn, Corrigan, & Donaldson, 2000), Canada (Baker et al., 2004), Spain (Aranaz-Andrés et al., 2008), Sweden (Soop, Frykmark, Köster, & Haglund, 2009) and France (Michel, Quenon, Sarasqueta, & Scemama, 2004).

Adverse events are associated with higher costs and prolonged patient length of stay. In Australia, the financial cost of adverse events in hospitals was estimated at approximately $2 billion per year (Ehsani et al., 2006). The Institute of Medicine (IOM) report, To Err is Human (Kohn et al., 2000) was a landmark publication that
seized public attention by bringing medical errors and quality of care to the forefront. This report, that generated the stunning headline indicating that 44,000 to 98,000 Americans die each year because of medical errors, galvanized concern and prompted a groundswell for a quality and safety movement in health care (Longo, Hewett, Ge, & Schubert, 2005; Woolf, 2004). The current quality and safety movement was cemented and greatly advanced in 2002 at the 55th World Health Assembly when the resolution on patient safety was immediately adopted urging close attention to patient safety and establishing evidence-based systems for improving safety and the quality of care (World Health Organization [WHO], 2002).

The most commonly cited definition for quality in health care was released by the Institute of Medicine (IOM) in the United States and is defined as “...the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (Lohr, 1992). Six essential characteristics of health care delivery have been described by the IOM to achieve optimal health care quality for all patients. These characteristics are that care should be safe, effective, patient-centred, timely, efficient and equitable (Kohn, Corrigan, & Donaldson, 2001). The IOM asserts that patient involvement in health care may improve the quality and safety of care patients receive (p.
Consequently, a key underlying motivation for facilitating patient participation is the proposition that participation is associated with improved patient safety and quality outcomes. In order to evaluate the evidence supporting this proposition a much clearer understanding of the underpinning multi-faceted components of patient participation and the way patient participation is enacted within health care is essential. These understandings need to be gained within the specific contexts and environments in which participation is expected to occur because the context is likely to be a fundamental factor both in terms of patients’ capacity to participate and the opportunity they have to participate.

1.3 Aims of the study

The purpose of this research program was to explore the current status of patient participation during an episodic admission to the acute care environment, that integrated:

1) How patient participation was understood and enacted by patients and nurses, and

2) The barriers and facilitators of patient participation within this setting.

To meet these aims, a mixed method approach was used in a single case study design (one institution) in the cardiac surgical ward of a
major tertiary referral centre. Patients undergoing cardiac surgery were the participants of choice as surgery for coronary artery and valve disease are excellent examples of acute-on-chronic care needs where patient participation can have short and long term consequences for patient outcomes (Kaplan, Greenfield, Gandek, Rogers, & Ware, 1996). Patients’ and nurses’ ability and willingness to either be involved, or involve patients, in care was investigated. This investigation occurred within the context of care to identify process and system barriers and facilitators of patient participation.

The findings of this study provide important insights into the role patients can play in improving both therapeutic outcomes and the quality of the care they receive. These insights provide a framework for further investigation of ways to facilitate patient involvement in the acute care treatment environment in order to measure the impact of that involvement on health and safety outcomes.

1.4 Overview of thesis

This research program exploring the current status of patient participation during an episodic admission to the acute care environment is presented in nine chapters. The purpose of the literature review, presented in Chapter 2, is to examine the current status of patient participation within acute care contexts. The
existing understanding and enactment of patient participation in acute care is reviewed in order to highlight the need and importance of exploring patient participation during acute episodic admissions to hospital. Patient participation in the contexts of treatment decision making and chronic illness management is examined in order to gain understandings that may be relevant to patient participation in the acute care environment. A framework developed by integrating contemporary literature, is proposed as a guide to the exploration of patient participation in the post-operative context. Four key recovery goals of care: medication management, pain management, pulmonary management and discharge planning are identified as key care factors where patient participation may improve the quality and safety of care.

In Chapter 3, the research program and methods are described. The discussion includes a detailed description of case study design and techniques used to ensure validity and reliability of data. The methods of data collection described in this chapter are patient interviews, naturalistic observation, medical records audit and focus group interviews.

The findings of the study are presented in Chapters 4 to 8 inclusive. In Chapter 4, patient and environmental characteristics are described in order to set the scene for the case study. The findings regarding
patient participation in medication management are presented in
Chapter 5. Findings relating to patient participation in pain
management, pulmonary management and discharge planning are
reported in Chapters 6, 7 and 8 respectively. Integration of the
findings, implications for practice and future research agenda are
presented in Chapter 9.
Chapter Two

The current status of patient participation in acute care

Patient participation in chronic illness conditions has been reported to improve patient outcomes (Deakin, McShane, Cade, & Williams, 2005; Gibson et al., 2002; Guevara, Wolf, Grum, & Clark, 2003; Loh, Leonhart, Wills, Simon, & Harter, 2007) and is proposed to play a role in improving the quality and safety of the health care overall (Longtin et al., 2010). To date, the majority of studies of patient participation have focused on patients participating within the contexts of treatment decisions and chronic illness management. In acute care environments, investigations of patient participation have explored treatment decisions in nursing care. One aspect of acute care where patient participation is likely to impact on many patient and organisational outcomes is in the context of post-surgical recovery.

The purpose of the discussion in this chapter is to examine the current status of patient participation within acute health care. The first section contains a review of the extant literature to provide an outline of the way patient participation has been understood and enacted within the acute care context. While the concept of patient participation is espoused within health care policy documents, the
process of enacting patient participation as a component of high
quality and safe care is unclear and requires further exploration.

In the second section of this chapter, patient participation is
examined in the contexts of treatment decision making and chronic
illness management, where the investigation of patient participation
is well established. Within these contexts, the barriers and facilitators
of, and patients’ and clinicians’ roles in, patient participation are
reviewed to identify factors that may be relevant to patient
participation in the post-operative setting.

Finally, in the third section, a framework for investigating patient
participation in the post-operative context is presented. This
framework has been developed to provide operational definitions
and characteristics of patient participation in the context of surgical
recovery to inform the work presented in this document.

2.1 Understandings and enactment of patient
participation in acute care

Throughout the developed world, the importance of patient
participation has emerged as an essential element in the redesign of
health care processes (Longtin et al., 2010; WHO, 2008). In this
section, consideration is given to the emergence of the concept of
patient participation and how participation has been articulated in
policies, mission statements and core values of health care institutions. The acute care environment is described in order to highlight the distinct characteristics of this care context and the potential implications for patient participation. Examination of various research approaches to the investigation of the enactment of patient participation in acute care identifies variability in the way the concept is operationalised supporting the need for further exploration of patient participation in this environment.

2.1.1 The concept of patient participation

The notion of patient participation has been integrated into health care policy as a significant component of patient safety and quality outcomes. In this section, the concept of patient participation as an aspirational goal of health care generally is explored in terms of the historical drivers, and as a core component within strategic documents of health care organisations.

2.1.1.1 Historical drivers of patient participation in health care

While there has been a gradual shift in health care generally towards making explicit the role of patients as participants in their own care, patients traditionally have been viewed as passive recipients of medical interventions (Ashworth, Longmate, & Morrison, 1992; Biley, 1992; Glenister, 1994; Kennedy, 2003). As such, the expectation of doctors for example, was to define illness, evaluate health status and
control health problems with minimal patient input (Brody, 1980; Parsons, 1951). In 1951, a leading American sociologist, Talcott Parsons, described ‘ideal patient behaviour’ as having motivation to get well, seeking technically competent help, trusting the doctor and complying with medical care (Parsons, 1951). Parsons’ thesis also exempted patients from any responsibility for their own state of health. Historically, this perceived role was the dominant approach in health care limiting patients’ involvement to whether or not to seek medical attention and follow subsequent advice (Brody, 1980; Chewing & Sleath, 1996; Woolf et al., 2005).

In recent years, the perceived role of the patient has changed to one where patients are formally encouraged to participate in care (Ashworth, et al., 1992; Beaver et al., 2007; Beaver et al., 1996; Biley, 1992; Chewing & Sleath, 1996). This change in the espoused role of the patient can be attributed to a number of factors. These include increased patient access to medical information and desire to participate, the development of policy bodies to protect patients’ rights, and the requirements of consent for treatment (Biley, 1992; Kennedy, 2003; Kravitz & Melnikow, 2001).

2.1.1.1 Patients’ desire to participate

In current developed societies, individuals are less likely to accept conventional authority without question and seek greater levels of
control and empowerment over their lives (Coulter & Willis, 2004). This is echoed in health care, where increasingly individuals desire involvement and in some instances, take control of their own health (Coulter & Willis, 2004). This trend, described broadly as the consumer movement in health care (Moloney & Paul, 1991; Topol, 2010), has stemmed from consumers demanding greater access to individualised, immediate and convenient high quality care (Forkner-Dunn, 2003; Jadad, 1999). The consumer movement in health care has been further fuelled by the internet (Biley, 1992; Coulter & Willis, 2004; Kennedy, 2003; Lober & Flowers, 2011) that has fostered a new level of health knowledge among individuals.

This heightened knowledge and increased desire to participate in health care may facilitate active partnerships between consumers and decision makers such as clinicians, policy makers and researchers (Jadad, 1999). Many health care services have responded to the broader community’s desire for involvement in care by mandating consumer involvement in their policies. Alongside this, there is growing acknowledgement that care must be responsive to preferences and values of the consumers of health care services. In response, individual patients and their opinions about care are considered important indicators of its quality (Blumenthal, 1996). This responsiveness is in part underpinned by the belief that patients
have the potential to improve outcomes of care if they are actively involved in their care and treatment (Longtin, et al., 2010).

2.1.1.2 Patients’ rights to participate

Supporting this consumer drive for involvement and partnership in their own care is the notion of upholding patients’ rights. Since the late 1970s, bodies that protect patients’ rights have called for patients to be included in health care decisions through the release of international health care directives (Eldh, Ekman, & Ehnfors, 2006; Oulton, 2000; WHO, 2007). The introduction of these directives made explicit the importance of patient dignity and autonomy and emphasised the right of each individual to participate in care on his or her own terms (Wetzels, Harmsen, Van Weel, Grol, & Wensing, 2007).

2.1.1.3 Patients’ legal requirement to participate

Prior to any medical treatment, a competent patient must give consent for a proposed treatment. In health care, consent is an ethical obligation as well as a legal requirement. In order for consent to be legally valid it must be given voluntarily by a person who has capacity and, in order to be considered informed, must be based on adequate information (Hassan, 2008). The criterion deemed to be adequate information has recently changed through court proceedings.
In Australia, the law has adopted a more patient-focused benchmark in deciding what risks clinicians must disclose to patients. Skene, an Australian Professor of Law at The University of Melbourne and Smallwood, an Emeritus Professor of Medicine and previous Commonwealth Chief Medical Officer (Skene & Smallwood, 2002), highlight the shift from accepting what reasonable doctors might do to supporting what reasonable patients might expect. From a legal perspective, in order for clinicians to fulfil ethical and legal obligations they should find out what patients want to know (Hassan, 2008). This requires clinicians to appreciate patients’ rights to participate, encourage participation and provide adequate time for information processing and discussion. Implicit, is that clinicians must also assess patients’ understanding of their illness and treatment, elicit patients’ preferences for participation, and involve the patient in all aspects of care (Charles, Gafni, & Whelan, 1997; Elwyn et al., 2001; Fraenkel & McGraw, 2007; Loh et al., 2007; Towle & Godolphin, 1999).

In summary, patients’ desire to participate, their rights and legal requirements have been important factors driving policy relating to patient participation in health care. More recently, the potential to improve the quality and safety of health care through patient
involvement underlies the current endorsement of patient participation across the spectrum of health care.

2.1.1.2 Patient participation as a core component of policies, mission statements and core values of health care organisations

The concept of patient participation has been adopted in the policies, mission statements and core values of health care organisations at a global, national and local level. Patient participation in health care has been an aspirational goal in international health care policy for many years. In 1978, the World Health Organization (WHO) identified patient participation as one of the core commitments for primary health care in the Declaration of Alma Ata (WHO, 1978).

Recently, patient participation has been identified as a potentially important quality and safety factor in health care (Longtin et al., 2010). Patient participation as an effective method for improving the quality and safety of health care has not been investigated systematically. Current global policies support the idea of patient participation as a quality and safety factor (WHO, 2006; WHO, 2008) and this is apparent in the way countries incorporate patient participation into their strategic documents.
2.1.1.2.1 The United Kingdom

In the United Kingdom (UK), the National Health Service (NHS) is the publicly funded health care system. Patient participation features in the NHS Constitution (National Health Service, 2009) that includes the purpose, principles and values of the NHS and outlines a number of rights, pledges and responsibilities for staff and patients. By law, the NHS is required to consider the Constitution when making decisions and taking action. A key principle is that “...NHS services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted, on all decisions about their care and treatment” (National Health Service, 2009, p.7). This documentation encourages participation at the level of individual persons’ participating in their own medical care and focuses on decision making.

Major quality and safety organisations within the UK also advocate patient participation in care. In England, the Care Quality Commission (CQC) independently regulates health and social care. In the CQC’s essential standards for quality and safety, individuals can expect to be involved and informed at every stage of their care (Care Quality Commission, 2010), however a clear link between participation and improved patient outcomes is not explicit. The vision for high quality
health care includes support of people to live healthy and independent lives, allowing people to make informed choices about their care and to expect care that is responsive to individual needs (Care Quality Commission, 2010).

Within the National Patient Safety Agency (NPSA), a body of the Department of Health in the UK, patients have been included in round table discussions to elicit patients’ experiences and ensure consumer perspectives are included in processes, products and problem solving. The NPSA includes patient participation in its activities in order to understand patient experience, build trust and comply with legislation (National Patient Safety Agency, 2006). In one initiative patient participation has been used to specifically address staff compliance with hand hygiene. Patients have been invited to ask staff if they have washed their hands (NPSA, 2008). This is an example of where patient participation has the potential to directly affect the quality and safety of care patients receive.

Patient participation is also located within the service strategy of Guy’s and St Thomas’ Hospitals NHS Trust, leaders of health care within the United Kingdom. One of their five strategic values is ‘put patients first’ (King’s Health Partners, 2010). In this organisation patient-centred care is considered to be demonstrated by listening to and acting on views of patients and their carers.
2.1.1.2.2 Europe

In Europe, the significance of patient participation in strategic documents is stated more clearly. The European Union has developed common values and principles that underpin all their health systems (European Union, 2006). A major value is that health systems aim to be patient-centred, meaning “...they aim to involve patients in treatment, to be transparent with them, and to offer choices where this is possible” (European Union, 2006, p.3) The values and principles for their health systems also state, “...Each system aims to offer individuals information about their health status, and the right to be fully informed about the treatment being offered to them, and to consent to such treatment” (European Union, 2006, p.3). Through these values and principles patient participation is encouraged at all levels of health care including at the level where individuals participate in their own care.

The European Public Health Alliance (EPHA) is a not-for-profit association whose mission is to promote and protect the health of all people living in Europe and to advocate for greater participation of citizens in health-related policy making. In 2009, the EPHA produced a draft position paper on patient participation (European Public Health Alliance, 2009). In this paper, patient participation is in
relation to involvement in health decision making at a health system level, not at the level of individuals participating in their own care.

2.1.2.3 The United States of America

In 1998, a ‘Consumer Bill of Rights’ was created in the USA by the Advisory Commission on Consumer Protection and Quality in the Health Care Industry (Health Care Quality Commission, 1998). Patient participation featured as one of the eight areas of consumer rights and responsibilities. Participation in this context relates to patient participation in all treatment decisions related to health care. The Bill states, “…Health care professionals should provide patients with easily understood information and opportunity to decide among treatment options consistent with the informed consent process and give patients the opportunity to refuse treatment and to express preferences about future treatment decisions” (Health Care Quality Commission, 1998, p.4). Participation in the Bill of Rights is at the individual level and relates to participation in treatment decision making.

In 2008, the leading organisations and government bodies in the USA concerned with health care quality including the Institute of Medicine, Joint Commission, National Quality Forum, Agency for Health Care and Quality Research and Institute for Health Care Improvement, met and partnered to develop national priorities and
goals to transform the nation’s health care system (National Patient Priorities, 2008). One of the six priorities targeted by the partnership was patient and family engagement specifically, “…engage patients and families in managing their health and making decisions about their care” (National Patient Priorities, 2008, p.21). Their vision is “…health care that honours each individual patient and family, offering voice, control, choice, skills in self-care, and total transparency, and that can and does adapt readily to individual and family circumstances, and differing cultures, languages, and social backgrounds” (National Patient Priorities, 2008, p.21).

The rationale given for positioning patient and family engagement as a national priority was that patients who play an active role in their health care are key to stronger patient outcomes at a reduced cost (National Patient Priorities, 2008). Patient safety is explicitly linked to patient participation by the National Priorities Partnership (NPP) through the idea that making patient and family engagement a priority will result in reduced patient harm. The notion of participation within the NPP documents is comprehensive and includes patient participation not only in treatment decision making but also in self-care management.

In the USA, patient participation is also reflected in strategic documents within individual health care organisations. An example is
The John Hopkins Hospital, a leading medical facility where patients are encouraged to “partner in their own care and openly communicate with the health care team, participate in treatment choices, and promote patient safety by being well informed and actively involved” (The John Hopkins Hospital, 2011, p.6).

2.1.1.2.4 Australia

In Australia, the Federal Government has introduced reforms to health care with the aim of ensuring quality and safe care for all Australians. In 2006, the Australian Commission on Safety and Quality in Health Care (ACSQH) was established by the Federal, State and Territory governments to develop a national strategic framework and associated work program that would provide guidance to governments in improving safety and quality across the health care system in Australia.

The ACSQH has since developed the Australian Charter of Health Care Rights (ACSQHC, 2008) to include patient participation as an expectation of care delivered within the national health care system. In detail, individuals have the right “…to be included in decisions and choices about their care” (ACSQHC, 2008, p.1). This description relates to patients participating in decision making. In 2012, ACSQH included partnering with consumers as one of the three National safety and quality goals for health care (ACSQHC, 2012a). The goal is
“...that there are effective partnerships between consumers and health care providers and organisations at all levels of health care provision, planning and evaluation” (ACSQHC, 2012b, p.1). This goal recommends patients obtain and understand health information so they can make informed decisions and manage their care and participate in ensuring their own safety.

In order to understand how these national recommendations and guidelines have been translated at a local level, particularly within the acute care context, the incorporation of patient participation into strategic plans of three major metropolitan health services within Victoria, Australia is provided below (Table 2.1). While the notion of patient participation is evident, through patient-centred care in all three plans, there is very little explicit guidance for how the process of patient participation could be implemented or measured.

2.1.1.2.5 Summary

The way health care organisations within various countries depict patient participation in strategic documents is similar. Patients are encouraged to participate in their care by having relevant information in order to make informed decisions. While most documents link patient participation to the quality and safety of care, there is little direction or clarity about what participation actually means ‘in action’; specifically, how patients can participate in their
care to increase the quality and safety of the care they receive and how clinicians can partner with patients to improve care within the acute care environment.
Table 2.1 The inclusion of patient participation in strategic documents of three major metropolitan health services in Victoria, Australia

<table>
<thead>
<tr>
<th>Health Service</th>
<th>Goal</th>
<th>Objective</th>
<th>Action</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Royal Melbourne Hospital Strategic Plan 2010-2015 (Royal Melbourne Hospital, 2010)</td>
<td>Improve the quality and safety of our services</td>
<td>Develop a culture of person-centred care</td>
<td>None provided</td>
<td>None provided</td>
</tr>
<tr>
<td>Alfred Health Strategic Plan 2011-2013 (Alfred Health, 2011)</td>
<td>Patients come first: We will ensure our services focus on patients and their needs throughout the care delivery process. We will strive to provide safe, appropriate and accessible care and services to optimise clinical outcomes</td>
<td>Consumers and where appropriate, carers, are involved in informed decision making about their treatment, care and wellbeing at all stages with appropriate support</td>
<td>None provided</td>
<td>Consumers are involved in decision making and care planning process for their care and staff listen and act on these decisions</td>
</tr>
<tr>
<td>Southern Health Strategic Plan 2010-2013 (Southern Health Strategic Plan, 2010)</td>
<td>Safe and effective person-centred care</td>
<td>Foster an organizational culture of safety and excellence with a focus on person centred care</td>
<td>None provided</td>
<td>None provided</td>
</tr>
</tbody>
</table>

- Ensure effective communication processes between Southern Health and the people for whom we care
- Implement changes to organizational structures and processes to enable the delivery of person-centred care
- Implement processes with the aspiration of achieving zero harm
2.1.2 The acute care environment

Patients are admitted to hospital because they require 24-hour medical and nursing management as a consequence of an episodic illness, trauma, or exacerbation of an existing illness. Medical and nursing management includes diagnostic procedures, surgical, and/or pharmacological intervention. Patients are managed as inpatients because their recovery is dependent on: vigilant monitoring by skilled professionals; ongoing treatment requiring specialised skills or technology; assistance with activities of daily living until they can assume independence; and education to manage their recovery or ongoing health issues once discharged from hospital (Berman et al., 2012). In this section, the acute care environment is discussed in terms of its characteristics that potentially impact on patient participation in this context. The characteristics to be discussed include the generally short duration of engagement of patients with the acute care environment because of shortening patient length of stay and the hospital staffing and care delivery models that may impede patients’ ability, opportunity or willingness to participate in care.

2.1.2.1 Length of stay

Since 1980, the average length of hospital stay in most countries has decreased by two to three days (Ross, Nixon, Snasdell-Taylor, &
Delaney, 1999). Trends in post-operative length of stay after cardiac surgery also revealed a 30% downward shift between 1992 and 1998 for over 100,000 Coronary Artery Bypass Graft (CABG) patients (Cowper et al., 2006). Over the past decade, the average length of stay in hospital following cardiac surgery has ranged from 5.0 to 9.4 days (Aggarwal et al., 2006; Australasian Society of Cardiac and Thoracic Surgeons, 2009; Leegard, Naden, & Fagermoen, 2008; Tran, Chand, Newcomb, Billah, & Shardey, 2011). This time is exceptionally short when considering the health trajectory of a person experiencing ongoing chronic illness.

The limited time clinicians spend with patients during clinical encounters in acute care is recognised to negatively affect patient participation (Gravel, Légaré, & Graham, 2006; Timonen & Sihvonen, 2000). Less time spent with patients limits the extent to which clinicians can build rapport, provide education and assist patients to process information (Fraenkel & McGraw, 2007; Sainio, Lauri, & Eriksson, 2001; Wellard, Lillibridge, Beanland, & Lewis, 2003).

### 2.1.2.2 Hospital staffing

The involvement of multiple clinicians in care delivery and lack of continuity of care provider has implications for patient involvement in care. Patients have reported that lack of continuity in care provider
results in difficulty communicating with clinicians (Bruster et al., 1994; Preston, Cheater, Baker, & Hearnshaw, 1999).

High staff turnover in acute care contributes to lack of continuity between clinicians and patients (Sellgren, Kajermo, Ekvall, & Tomson, 2009). High staff turnover can affect patient participation in two ways. First, clinicians who work in unfamiliar environments may be less likely to involve patients in their care (Gravel et al., 2006; Sainio et al., 2001). Second, lack of continuity of care disrupts rapport building, sequential information provision and education (Sainio et al., 2001).

2.1.2.3 Models of care delivery

The time clinicians spend with patients is tempered by the model of care in which they practice. This is most likely to impact on nursing care delivery. In acute care there are three main models of care that potentially impact on nursing care delivery and hence patient participation. These are total patient care, team nursing, and primary nursing models of care.

In total patient care, a nurse is assigned to a patient and is responsible for the organisation and co-ordination of all the aspects of patients’ care for a designated shift of duty, generally over eight hours (McGillis Hall et al., 2003). A positive aspect of total patient
care reported by nurses is that they can focus on a patient’s needs without the burden of supervising other clinicians (Tiedman & Lookinland, 2004). Nurses reported satisfaction in being fully responsible for the care a patient receives and the ability to focus their complete attention on their patient (Tiedman & Lookinland, 2004), however, within this model, time constraints and lack of continuity of care because of the shift-by-shift allocation of patients may affect nurses’ propensity towards encouraging patients to actively participate in their care.

In team nursing, a group of nurses is assigned to a group of patients on a ward for a designated shift of duty (McGillis Hall et al., 2003). The nurses within the team share responsibility for supervising and delivering care. This model originated in the USA in the 1950s and was seen as a way to decentralise authority from the nurse in charge and increase the professional role of registered nurses (Lio, 1973). Team nursing has the potential to increase communication and co-ordination between nurses and may improve nurses’ personal satisfaction (McGillis Hall et al., 2003). Patient participation within the team nursing model may be difficult because care is delivered by multiple nurses and valuable time is spent coordinating and delegating care rather than communicating with patients (Tiedman & Lookinland, 2004).
Primary nursing is the model of care delivery that affords nurses the opportunity for 24-hour accountability for a specific patient throughout that patient’s stay in hospital (McGillis Hall et al., 2003). Primary nursing supports the professional growth of nurses through its twelve elements: accountability, advocacy, assertiveness, authority, autonomy, continuity, commitment, collaboration, contracting, co-ordination, communication and decentralisation (Zander, 1980). The extended period in which the nurse is the direct caregiver purports to allow for increased opportunities for rapport building, information provision and assessment of patients’ knowledge and understanding of their illness, collaboration and education (Tiedman & Lookinland, 2004). While these models of care exhibit strengths and weaknesses that may affect patient participation, the impact of nursing care delivery models on patients’ ability and willingness to participate in care does not appear to have been investigated.

### 2.1.2.4 Summary

Length of stay, hospital staffing and the model of care delivery are all likely to play a role in the achievement of patient participation within the acute care environment because they impact on the opportunity patients have to build rapport and engage with clinicians.
2.1.3 The enactment of patient participation in acute care

Within the nursing discipline literature, the commitment to patient participation during acute episodic illness has been evident over several decades (Brody, 1980; King, 1981; Orem & Taylor, 1986). The majority of research has concentrated on understanding patient participation either as a concept (Ashworth et al., 1992; Cahill, 1996; Cahill 1998; Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007; Sahlsten, Larsson, Sjöström, & Plos, 2008) or in terms of patients’ preference for participation in treatment decisions related to nursing care (Degner et al., 1997; Florin, Ehrenberg, & Ehnfors, 2006; Florin, Ehrenberg, & Ehnfors, 2008).

Less attention has been given to the enactment of patient participation at the patient-clinician interface however, there are four notable exceptions. In a Scandinavian study, Timonen and Sihvonen (2000) explored how surgical patients participate in bedside handover using patient (n=74) and nurse (n=118) questionnaires and clinical observation of handovers (n=76). Patients reported tiredness, difficulties in formulating questions, lack of encouragement, difficulties with language used and the short time frame of the handover as barriers to involvement. Patients also felt nurses concentrated on their paper work more than on their interactions with them. Nurses reported higher patient involvement in the
handover compared to patients’ perceived involvement. Clinical observation revealed the average time spent on each handover was three minutes.

Patient participation in discharge planning meetings has been explored using eight purposive and consecutive transcribed video recordings of elderly female medical/surgical patients in Sweden (Efraimsson, Sandman, Hyden, & Rasmussen, 2004). The findings revealed patients’ involvement, in most cases, was limited with little scope for negotiation. It appeared that the majority of decisions had been made by clinicians before the meetings and the purpose of the meetings was to inform patients of their discharge destination.

O’Leary et al. (2010), investigated 241 medical/surgical patients’ understanding of their plan of care in hospitals within the USA. In this study, patient participation was defined as patients’ understanding of their plan of care and was measured by patient-physician agreement on each aspect of the plan of care. Their findings revealed a substantial proportion of patients did not understand their plan of care, therefore by definition had not participated in their care.

In 2001, Baker and colleagues, examined whether physiotherapists sought to involve elderly patients in goal setting within a rehabilitation unit in the USA. Seventy-three initial examinations of
elderly patients by physiotherapists were audio recorded. Physiotherapists and patients were also given opinion surveys to complete, allowing the identification of similarities and differences between practice and perception. The findings revealed that while physiotherapists sought to involve their patients in goal setting the level to which it was achieved was less than the potential for involvement that existed. There were also discrepancies between the opinion surveys and the audio recordings of practice. The opinion surveys by patients rated physiotherapists positively in all aspects of collaboration in meeting treatment goals. Therapists also rated themselves highly in seeking to involve patients in goal setting. However, in the audio taped data few therapists engaged patients in collaborative goal setting. The findings that patients rated therapists highly in collaboration despite the low actual engagement observed, raised questions about the social desirability of patients’ responses and the possibility of a mismatch in patients’ and therapists’ understanding of what it means to participate in goal setting.

The studies reviewed all investigated aspects of care where patients have an opportunity to participate, i.e. through bedside handover, discharge planning, plans of care and goal setting. The findings indicate that these opportunities are not well understood by patients
or clinicians and therefore these opportunities for facilitating patient participation are not optimised.

2.2 Patient participation in treatment decisions and chronic illness management

Patient participation in treatment decisions and chronic illness management is well established both as a fundamental aspect of care and in methods of evaluating its presence. Within the context of treatment, individuals can participate in decisions relating to: 1) surgical intervention, 2) medical management, and 3) nursing care. In chronic illness management, individuals participate in managing their ongoing health requirements.

The known barriers and facilitators of patient participation, and the role patients and clinicians play in achieving participation in these contexts are explored in this section in order to identify learnings that could be applied in the study of patient participation in the post-operative setting.

2.2.1 Patient and clinician-related barriers and facilitators of patient participation

The patient and clinician-related barriers and facilitators of patient participation identified in the professional literature have been
relatively consistent both in patients’ preferred and actual involvement.

2.2.1.1 Patient-related factors

Several patient-related factors have been identified to affect patients’ preferred and actual participation in their own care. These patient factors affecting participation are discussed in relation to patients’ characteristics and their knowledge and understanding of their care.

2.2.1.1.1 Patient characteristics

The investigation of the patient characteristics associated with participation in health care has focused on both preference for participation and actual involvement. The characteristics include age, sex, education level, cultural background, living arrangement, exposure to previous illness and illness severity.

Patient age has been identified as a factor affecting patient preference for participation in treatment decisions across various health care settings. Younger patients have been more likely to prefer active participation (Arora & McHorney, 2000; Deber, Kraetschmer, Urowitz, & Sharpe, 2007; Florin et al., 2006; Mira, Guilabert, Pérez-Jover, & Lorenzo, 2012; O'Donnell, Monz, & Hunskaar, 2007). Actual involvement in care may also be affected by
gender characteristics, where females are more likely to actively participate in care (Street, Gordon, Ward, Krupat, & Kravitz, 2005) than males.

Level of education is associated with preference for participation (Adams, Smith, & Ruffin, 2001; Arora & McHorney, 2000; Deber, et al., 2007; Florin, et al., 2008; O'Donnell & Hunskaar, 2007; O'Donnell, et al., 2007) where patients’ preference for a more active participatory role has been reported in patients with a higher level of education. Education level has also been linked to patients’ actual participation. Street and colleagues (2005) found higher educated patients were generally more active in interactions with doctors than less educated patients.

Cultural background has been reported to affect patients’ actual participation. Patients from ethnic minorities in the region where the research was undertaken were deemed to display less participatory behaviour during clinical observation than people in the ethnic majority for that region (Schouten, Meeuwesen, Tromp, & Harmsen, 2007; Street, et al., 2005). This was also the case in relation to preference for participation, where patients from the cultural minority preferred a passive role in treatment decisions compared with the ethnic majority (O'Donnell, et al., 2007).
A person’s living arrangement also affects their preference for participation. Two separate studies by the same authors (Florin, et al., 2006; Florin, et al., 2008) found patients living alone preferred an active participatory role in their care. In 2000, Mansell et al. determined whether previous experience of an illness predicts patients’ preference for involvement in making decisions. They found prior experience of an illness increased patients’ desire for participation in decision making. This finding is echoed in a later study (Deber, et al., 2007) where familiarity with a clinical condition increased desire for a shared role in decisions compared to a passive role.

Patients have previously reported physical incapability to be a major barrier to participating in their own care. Fatigue (Biley, 1992; Jerant, von Friederichs-Fitzwater, & Moore, 2005; Timonen & Sihvonen, 2000) and pain (Jerant et al., 2005) have been identified as barriers to patient participation. Also, patients with greater illness severity have consistently reported preferring a more passive role in treatment decision making (Arora & McHorney, 2000; Beaver et al., 1996; Mira et al., 2012; O'Donnell & Hunskaar, 2007; O'Donnell et al., 2007).

The characteristics that have been identified as increasing either preference or actual participation are those that would be expected to be associated with higher engagement in care such as education,
socio-cultural and illness experience. These characteristics equip patients with the capability to participate in a complex and demanding role because they very likely affect patients’ knowledge and understanding of their care.

2.2.1.1.2 Knowledge and understanding

The provision of patient information and education are considered the foundation of preparing patients for treatment within health care (Johansson, Nuutila, Virtanen, Katajisto, & Salanterä, 2005). The most significant goal of patient education is to increase knowledge and understanding of their health status so they can participate in their own care (Coulter & Ellins, 2007; Johansson et al., 2005). Knowledge is considered an act of learning gained through experience or education, and understanding is the confidence and ability to apply this knowledge for a specific purpose (The Australian Oxford Dictionary, 2004).

Insufficient knowledge and understanding of care has been shown to be a barrier to patients’ involvement in care (Belcher, Fried, Agostini, & Tinetti, 2006; Biley, 1992; Jerant et al., 2005; O'Leary et al., 2010). Understanding and knowledge of care is affected by patients’ ability to obtain information and interpret the information provided to them (Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009). This ability is known as health literacy. The Institute of Medicine (IOM)
adopted the definition of health literacy defined by Parker et al., (2003, p.147) as, “The ability to obtain, process and understand basic health information and services needed to make appropriate health decisions and follow instructions.” Nutbeam, (2008) a world-renowned expert in public health, goes further and believes health literacy extends to the ability to interact with a health care professional and exert greater control over everyday situations.

People with low health literacy are less able to participate in their own health care (Ishikawa & Yano, 2008; Marks, 2009; McKinstry, 2000; Smith, et al., 2009; Williams, Baker, Honig, Lee, & Nowlan, 1998; Williams, Baker, Parker, & Nurss, 1998). Patients’ characteristics considered to affect their health literacy include age, education level and language proficiency (Ayotte, Allaire, & Bosworth, 2009; Beers et al., 2003; Gazmararian et al., 1999; Marks, 2009; Smith et al., 2009; Williams et al., 1995). The impact of characteristics such as age and education on health literacy suggests that health literacy is very likely to be associated with participation.

2.2.1.1.3 Patient preference

Patients’ preference for participation is another known factor affecting patient participation related to treatment decisions and chronic illness management. Theories of health-seeking behaviour have been helpful in understanding why some patients prefer to
participate in their own care and others do not, and are summarised in Table 2.2. These theories are important in understanding patients’ preference for participation in health care from the perspective of psychological predictors of preference and this work is relatively well developed.

However, whether psychological predictors play a major role in preference for participation in acute care contexts is not clear. In the acute care context, contextual factors such as the processes of care delivery may play a more important part in whether or not patients prefer or actually participate. For example, patients may choose a passive role because despite adequate knowledge and understanding they do not want to be involved in their treatment because of poor physical health (Street, Elwyn, & Epstein, 2012). Others may choose a passive role because they do not understand what it means to participate in the context of acute care.
Table 2.2 Major health-seeking behaviour theories

<table>
<thead>
<tr>
<th>Health Theory</th>
<th>Factors affecting behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Belief Model</td>
<td>Persons perceptions of:</td>
</tr>
<tr>
<td>(Rosenstock, 1974)</td>
<td>• Severity of potential illness</td>
</tr>
<tr>
<td>(Becker, 1974)</td>
<td>• Susceptibility to that illness</td>
</tr>
<tr>
<td></td>
<td>• Benefits of taking preventive action</td>
</tr>
<tr>
<td></td>
<td>• Barriers to taking that action</td>
</tr>
<tr>
<td></td>
<td>• Confidence in ability to perform that action</td>
</tr>
<tr>
<td>Trantheoretical Model</td>
<td>Continuum of persons readiness to change:</td>
</tr>
<tr>
<td>(Prochaska &amp; DiClemente, 1983)</td>
<td>• Pre-contemplation</td>
</tr>
<tr>
<td>(Prochaska, DiClemente &amp; Norcross, 1992)</td>
<td>• Contemplation</td>
</tr>
<tr>
<td></td>
<td>• Preparation</td>
</tr>
<tr>
<td></td>
<td>• Action</td>
</tr>
<tr>
<td></td>
<td>• Maintenance</td>
</tr>
<tr>
<td>Social Cognitive Theory</td>
<td>Persons belief in capability to perform the behaviour</td>
</tr>
<tr>
<td>(Rotter, 1982)</td>
<td>• Perceived incentive to perform behavior</td>
</tr>
<tr>
<td>(Bandura, 1986)</td>
<td></td>
</tr>
<tr>
<td>Theory of Reasoned Action</td>
<td>Personal attitude toward the behavior</td>
</tr>
<tr>
<td>(Fishbein &amp; Ajzen, 1980)</td>
<td>• Influence of social environment or subjective norm</td>
</tr>
<tr>
<td>Theory of Planned Behaviour</td>
<td>Perceived behavioural control over opportunities, resources and skills necessary to perform behavior</td>
</tr>
<tr>
<td>(Ajzen &amp; Driver, 1991)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(In addition to dependent behaviours for theory of reasoned action)</td>
</tr>
</tbody>
</table>
Patients’ preference for participation may not reflect the role they actually assume in clinical practice. Several studies have compared patients’ preference for participation with their reported participation in care and found a substantial mismatch between the stated preferences of patients for the role they wanted to have in decision making and what they felt actually took place (Florin et al., 2006; Ford, Schofield, & Hope, 2003; Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010). In these studies, preference for participation was measured using the Control Preference Scale (CPS), a tool that consists of five statements each portraying a different participatory role in treatment decision making. Patients are asked to rank their participation preferences in order from most preferred to the least preferred option. These roles range from the individual making the treatment decisions, through to the individual making the decisions jointly with the clinician, to the clinician making the decisions (Degner, Sloan, & Venkatesh, 1997).

2.2.1.1.4 Summary

Patient-related barriers and facilitators of patient participation in treatment decisions and chronic illness management are a complex interplay of their characteristics, knowledge and understanding of care and preference for involvement. Whether these factors play a primary role in determining participation in acute surgical settings is
yet to be determined. The role of the context and clinician facilitation are likely to temper patients’ preference and actual participation.

2.2.1.2 Clinician-related factors

Clinician-related factors affect patients’ ability and willingness to participate in their own care. In this section, clinician factors affecting patient participation in treatment decisions and chronic illness management are discussed in relation to the information and education provided to patients and the encouragement patients receive to participate.

2.2.1.2.1 Patient education

Patient participation can be affected by the information and education clinicians provide to patients about their health, treatment and involvement in care. In the context of chronic illness, best practice dictates that patients should not need to ask for information about their care but rather they ought to be systematically educated in order to be involved in decisions about their care (Entwistle, Williams, Skea, MacLennan, & Bhattacharya, 2006). In the context of preparing patients for treatment decisions, clinicians are seen to be consistently falling short of providing patients with adequate education in order for them to participate (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999; Bugge, Entwistle, & Watt, 2006; Entwistle et al., 2006; Mira et al., 2012; Paterson, 2001; Van
Den Brink-Muinen et al., 2006). For example, in a study involving the use of structured questionnaires, 104 women gave insights into information provision and decision making prior to their scheduled hysterectomy (Entwistle et al., 2006). Their interview accounts suggested that gynaecologists offered women little opportunity to influence the selection of a surgical procedure. While the women did not express a desire for a greater say in this selection, they did indicate that they would have liked to be informed as to why particular procedures were recommended for them.

Recently, Mira and colleagues (2012) described the type of information that patients receive during consultations with physicians about treatment decisions. A cross-sectional case study with 764 patients and 327 physicians found patients were not routinely informed about medication interactions, precautions and foreseeable complications. Only 19.6% of doctors considered that they could intervene to involve patients in decisions. Again, in this study clinicians are falling short in providing adequate information and eliciting patient understanding and preference for participation.

Elwyn and colleagues (1999) identified a lack of clinical training as a barrier to clinicians providing patients with the information required to participate. Clinician training aimed at improving the involvement of patients in care has shown promising results. Tripicchio et al.
(2009), investigated the effectiveness of a training program for physical and occupational therapists and found that the training program resulted in clinicians providing for a higher level of participation of patients in their treatment planning and goal-setting.

### 2.2.1.2.2 Encouragement

Clinicians’ use of supportive behaviours to facilitate patients to participate is an important factor affecting participation in treatment decisions (Biley, 1992; Gravel, Legare, & Graham, 2006; Larsson et al., 2007).

Clinicians tend to overestimate the extent to which they involve patients in care (Baker et al., 2001; Makoul, Arntson, & Schofield, 1995) and the extent of their encouragement for patients to participate after patients express interest in involvement (Ramfelt & Lutzen, 2005; Street et al., 2005; Towle, Godolphin, Grams, & Lamarre, 2006).

Towle and others (2006), investigated the practice, experiences and views of motivated, trained family physicians as they attempted to implement informed and shared decision making in routine practice and to identify and understand the barriers they encountered. Transcripts of 10 randomly selected consultations and focus group interviews of key informants were analysed. Evidence from
transcripts indicated physicians were able to elicit patient concerns, ideas and expectations (although not about management) and agree on an action plan. Physicians did not elicit preferences for role or information and only sometimes offered choices. Physicians had difficulty achieving full expression of any of the competencies and struggled to integrate informed and shared decision making into their script for the medical interview. The analysis of these transcriptions reveals clinicians have difficulty actively encouraging patients to participate or providing patients with adequate information in order to participate, and do not routinely elicit patients preference for their role in decision making or the amount of information they would like to receive.

Street and colleagues (2005) used more objective measures to examine the extent to which patient participation in medical interactions is influenced by 1) the patient’s personal characteristics; 2) the physician’s communication style; and 3) the clinical setting.

*Post hoc*, cross sectional analysis of 279 physician-patient interactions from three clinical sites was performed. The majority of active participation behaviours were patient initiated rather than prompted by the actions of physicians or through supportive talk. Patients who were more active participants received greater facilitative communication from physicians. These findings are
supported in other research (Ramfelt & Lutzen, 2005) where patients believed clinicians provided information about their illness once they chose to actively participate. Waiting for patients to actively participate before clinicians use facilitative communication and provide education is of great concern, especially when it is known that the characteristics of patients is likely to affect the extent to which they will request a more active role. Moreover, in some contexts exhibiting those behaviours may be more difficult for patients.

2.2.2 The role of patients and clinicians in patient participation

An examination of the role patients and clinicians assume in treatment decisions and chronic illness management provides useful insights into the processes of patient participation and help to establish a framework for investigating the role patients and clinicians could play in meeting treatment goals of care in the post-operative setting.

2.2.2.1 Patient and clinician role in treatment decisions

Ideally, treatment decisions should involve shared decision making processes and two way information transfer between a clinician and patient (Charles et al., 1997). The demand placed on the patient in this setting is to participate in making the treatment decision.
Regardless of the context, for patient participation to be achieved in treatment decisions, patients’ and clinicians’ roles in treatment decision making are clear (Table 2.3). Patients are expected to prepare for participation by having sufficient knowledge (Charles et al., 1997; Entwistle & Watt, 2006; Gruman et al., 2010; Légaré, Moher, Elwyn, LeBlanc, & Gravel, 2007), discussing preferences, being involved in the treatment decision process (Charles et al., 1997; Entwistle & Watt, 2006; Gruman et al., 2010; Légaré et al., 2007) and jointly deciding on the best treatment option with the clinician (Charles et al., 1997; Entwistle & Watt, 2006; Légaré et al., 2007).

The clinician’s role is to encourage and facilitate patients to participate (Fraenkel & McGraw, 2007; Towle & Godolphin, 1999) by, providing appropriate information and enough time for discussion (Charles et al., 1997; Elwyn et al., 2001; Fraenkel & McGraw, 2007; Loh et al., 2007; Towle & Godolphin, 1999), eliciting patients’ preference and understanding (Charles et al., 1997; Elwyn et al., 2001; Fraenkel & McGraw, 2007; Loh et al., 2007; Towle & Godolphin, 1999), involving patients in the treatment decision process (Charles, et al., 1997; Elwyn et al., 2001; Fraenkel & McGraw, 2007; Loh et al., 2007; Towle & Godolphin, 1999) and deciding the treatment with the patient (Charles et al., 1997; Elwyn et al., 2001;
Fraenkel & McGraw, 2007; Loh et al., 2007; Towle & Godolphin, 1999).

2.2.2.2 Patient and clinician role in chronic illness management

In chronic illness management, the demands placed on the patient extends beyond the demand of treatment decisions and interacting with clinicians to include responsibility for ongoing care including medication management, behaviour change to improve symptoms or slow disease progression and interpreting and reporting signs and symptoms (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Hudon et al., 2012; Swendeman, Ingram, & Rotheram-Borus, 2009; Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

The role of the patient and clinician in patient participation within chronic illness management are clear and correspond to the roles outlined in treatment decisions (Table 2.3). In this context, patients are required to prepare to participate by having adequate knowledge and understanding (Gifford & Sengupta, 1999; Glasgow et al., 2002; Gruman et al., 2010; Jerant et al., 2005; Von Korff et al., 1997), discuss priorities (Gifford & Sengupta, 1999; Glasgow et al., 2002; Gruman et al., 2010; Schreurs, Colland, Kuijer, de Ridder, & van Elderen, 2003; Von Korff et al., 1997), and be involved in the goal setting process (Gifford & Sengupta, 1999; Glasgow et al., 2002; Gruman et al., 2010; Jerant et al., 2005; Schreurs et al., 2003; Von
Korff et al., 1997). Patients must also assume responsibility to act according to the agreed goals (Gifford & Sengupta, 1999; Gruman et al., 2010; Jerant et al., 2005; Schreurs et al., 2003) and monitor the effectiveness of treatment (Gifford & Sengupta, 1999; Glasgow et al., 2002; Gruman et al., 2010; Jerant et al., 2005; Schreurs et al., 2003; Von Korff et al., 1997).

The clinician’s role is to partner with patients to ensure they have sufficient knowledge by providing appropriate information (Gifford & Sengupta, 1999; Glasgow et al., 2002; Jerant et al., 2005; Von Korff et al., 1997), eliciting patient priorities (Gifford & Sengupta, 1999; Glasgow et al., 2002; Schreurs et al., 2003; Von Korff et al., 1997), involving patients in the goal setting process (Gifford & Sengupta, 1999; Glasgow et al., 2002; Jerant et al., 2005; Schreurs et al., 2003; Von Korff et al., 1997) and with the patient, monitoring the effectiveness of the treatment (Gifford & Sengupta, 1999; Glasgow et al., 2002; Jerant et al., 2005; Schreurs et al., 2003; Von Korff et al., 1997).

2.2.2.3 Summary

Patient participation in treatment decision making and chronic illness management place quite heavy demands on patients and there are many commonalities in the roles required of patients and clinicians.
The question is whether in the context of acute episodic illness or events patients or clinicians are able to assume these complex roles.

Table 2.3 The role of patient and clinician in patient participation in the contexts of treatment decisions and chronic illness management

<table>
<thead>
<tr>
<th>Patient role</th>
<th>Treatment decisions</th>
<th>Chronic illness management</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• prepare to participate by having adequate knowledge</td>
<td>• prepare to participate by having adequate knowledge and understanding</td>
</tr>
<tr>
<td></td>
<td>• discuss preferences</td>
<td>• discuss priorities</td>
</tr>
<tr>
<td></td>
<td>• be involved in the treatment decision process</td>
<td>• be involved in the goal setting process</td>
</tr>
<tr>
<td></td>
<td>• jointly decide on treatment with the clinian</td>
<td>• assume responsibility to act according to the goals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• monitor the effectiveness of goals</td>
</tr>
<tr>
<td>Clinician role</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment decisions</td>
<td>• encourage patients to participate</td>
<td>• provide appropriate education</td>
</tr>
<tr>
<td></td>
<td>• provide appropriate education and time for discussion</td>
<td>• elicit patients’ preference and understanding</td>
</tr>
<tr>
<td></td>
<td>• elicit patients’ preference and understanding</td>
<td>• involve patients in the treatment decisions process</td>
</tr>
<tr>
<td></td>
<td>• involve patients in the treatment decisions process</td>
<td>• decide the treatment with the patient</td>
</tr>
<tr>
<td>Chronic illness management</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• provide appropriate education</td>
<td>• elicit patient priorities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• involve patients in the goal setting process</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• monitor effectiveness of the goals</td>
</tr>
</tbody>
</table>

2.3 Conceptual framework for investigating patient participation in acute care

The purpose of the discussion in this section is to describe the conceptual framework for investigating patient participation in the
context of acute care, specifically, recovery from cardiac surgery. This framework has been developed to provide the operationalised parameters of patient participation in the surgical context in order to investigate how patient participation is enacted in this setting and to capture the complexities associated with participation in varying goals of care.

### 2.3.1 Clinical pathways

Care processes in acute environments are guided by procedure-specific clinical pathways in order to standardise care and avoid unnecessary variation to increase quality of care delivery and reduce error (Vanhaecht, De Witte, Panella, & Sermeus, 2009). Clinical pathways are considered key strategies in clinical risk management. They are structured, multidisciplinary care plans, incorporating best available evidence, to detail essential steps in the care of patients with a specific clinical problem (Rotter et al., 2010). A clinical pathway is commonly used in patients undergoing cardiac surgery (Alhashemi, Cecconi, della Rocca, Cannesson, & Hofer, 2010; Christensen, Krapf, Kempel, & von Heymann, 2009; Jacavone, Daniels, & Tyner, 1999) and details the expected trajectory of care from hospital preadmission to discharge including predictable milestones, and is visibly proceduralised in order to reduce clinical risk.
Given this procedure-specific routinisation of care, it is a reasonable expectation that the clinical pathway for a particular procedure is communicated to patients in a way that enables them to participate in meeting the goals of care. Distillation of the key goals of care from within the clinical pathway has provided the lens through which patient participation in recovery after cardiac surgery has been investigated.

### 2.3.2 Key treatment goals of care

Within the cardiac surgical context, four *a priori* treatment goals of recovery were identified as goals of care where patient participation may improve the quality and safety of care. These were medication management, pain management, pulmonary management and discharge planning. The rationale for choosing these four aspects of care is two-fold. First, they are fundamental factors in the recovery and rehabilitation from cardiac surgery. Second, participation in these aspects of care places different demands on patients during and following their acute care stay.

#### 2.3.2.1 Medication management

Therapeutic and safe medication management is a key recovery goal of care following cardiac surgery. Medicines are a primary therapy in chronic cardiovascular disease, and are commonly used during acute
episodic illness/events for pain management, haemodynamic and cardiac stability and prophylaxis. Patients often have ongoing treatments related to comorbidities and frequently, commence new medicines during this time (Bryant, Knights, & Salerno, 2003).

Safe medication management during hospitalisation can decrease patients’ risk of serious adverse events due to medication error and after discharge, improve health outcomes through therapeutic use of medicines and reduce the risk of readmission to hospital (Chewing & Sleath, 1996). In addition, accurate medication reconciliation on admission to hospital can minimise medication errors that may harm patients as a direct result of hospitalisation (Thompson, 2007).

The role of patients in medication management during hospitalisation is changing. The traditional passive acceptance of medications administered by clinicians is no longer the accepted role for patients when considering medication safety (Grantham, McMillan, Dunn, Gassner, & Woodcock, 2006). Patients must have a clear understanding of their prescribed medications if they are to participate in medication safety in hospital and optimise therapeutic benefits and decrease risks after discharge from hospital. This requires that patients participate in medication administration in hospital and learn about any changes that have been made to their
medications so that they can continue ongoing management of their medications once discharged.

2.3.2.2 Pain management

Effective pain management is a key recovery goal following surgery and, because of the nature of cardiac surgery, ineffective pain control has the potential to affect patients’ short and long term quality of life and safety outcomes. After cardiac surgery, post-operative pain is linked to an increase in the incidence of atelectasis and pneumonia (Huang, Cunningham, Laurito, & Chen, 2001). Poorly controlled pain is manifested as ineffective breathing patterns, reduced patient mobility and prolonged recovery (Wynne & Botti, 2004). In addition, poorly controlled sternotomy pain in the post-operative period has been associated with the development of chronic pain (Lahtinen, Kokki, & Hynynen, 2006).

The experience of pain is subjective (Jensen, Karoly, O’Riordan, Bland, & Burns, 1989), therefore, in order for clinicians to understand patients’ level of pain and provide appropriate interventions patients must participate in their pain management. The concept of the benefit of patient participation in pain management is well established. Patients are key informants, playing an essential role in reporting their pain, acting as advocates for appropriate pain treatment and monitoring the effectiveness of treatment.
2.3.2.3 Pulmonary management

The goal of pulmonary management following cardiac surgery is to prevent the risk of pulmonary dysfunction leading to complications. Management includes deep breathing and coughing exercises to achieve positive airway pressures and alveolar recruitment (Tucker et al., 1996). Deep breathing and coughing makes sense from a physiological perspective (Temporelli & Ambrosetti, 2011) and is a routine aspect of post-surgical recovery however, the evidence to support pulmonary exercises in the post-operative context is equivocal (Slade, 2013; Pasquina, Merlani, Granier, & Walder, 2003).

The performance of voluntary deep breathing and coughing necessitates patient participation in particular, because of the high frequency of exercises that is required, and because the exercises can exacerbate wound pain. Patient participation in pulmonary exercises is an interesting concept to investigate because the benefits of participation in this context remain unclear and this may affect clinicians’ propensity to facilitate patient participation in this aspect of care. In relation to pulmonary management patients need to know how to correctly perform the exercises and commit to undertaking the exercises on a very frequent basis possibly without regular clinician input.
2.3.2.4 Discharge planning

Discharge planning is a key recovery goal of care following cardiac surgery as it has an important health promotion role and poor planning has the potential to affect long term recovery. Effective discharge planning results in reduced patient readmission rates and improves post discharge recovery (Carroll & Dowling, 2007; Naylor et al., 1999; Phillips et al., 2004; Shepperd et al., 2010).

Participation in discharge planning is about the recognition by patients and clinicians that the surgical intervention is in the context of a chronic illness and the goal is to optimise patients’ long term health outcomes. In this context, patient participation in discharge planning is the interface between acute and chronic illness management and is an opportunity to prepare patients for ongoing self-management. Participation in discharge planning places greater demands on patients as they manage the transition from hospital to home and assume responsibility for their ongoing health needs.

The four key goals of care place different demands on patients in terms of what is required to participate. Although these demands differ, the communication and collaboration between patients and clinicians to develop a shared understanding of their required roles to achieve patient participation in each care goal are likely to be similar.
The conceptual framework for investigating the roles patients and clinicians assume is based on the learnings derived from patient participation in the contexts of treatment decisions and chronic illness management described earlier in this chapter. It is proposed therefore that patient participation in acute care requires that patients exhibit the following:

- **prepare to participate by incorporating knowledge and understanding** of their medications, pain management, pulmonary management and discharge planning;

- **be involved in decisions** about their medications, pain management, pulmonary management and discharge planning;

- **assume responsibility** in negotiating participation in medication management, pain management, pulmonary management and discharge planning and,

- **monitor the effectiveness** of their medications, pain management, pulmonary management and discharge planning

Clinicians assist patient participation by assuming the following:

- **encourage and exhibit supportive behaviours to facilitate patients to participate** in medication management, pain management, pulmonary management and discharge planning;

- **provide education/information and sufficient time for discussion** about medications, pain management, pulmonary management and discharge planning;
- elicit patients’ preference for participation and understanding of their medications, pain management, pulmonary management and discharge planning;

- involve patients in decisions about their medications, pain management, pulmonary management and discharge planning; and

- monitor the effectiveness of their medications, pain management, pulmonary management and discharge planning.

The framework for investigating patient participation during acute episodic illness is based on two key propositions:

1. Patients’ preference for participation in the recovery goals of care varies based on the demands each goal places on patients; and

2. Barriers and facilitators to the enactment of patient participation in the recovery goals of care are multi-faceted and include patient, clinician and environmental factors.

Figure 2.1 presents the conceptual framework for the investigation of patient participation in acute care.
Figure 2.1 Conceptual framework for the investigation of patient participation following cardiac surgery

**Acute care environment**
- Length of stay
- Hospital staffing
- Model of care delivery

**Clinicians**
- Provision of education/information
- Allow sufficient time for discussion
- Encouragement and exhibition of supportive behaviours

**Patients**
- Characteristics
- Knowledge and understanding
- Preference

**Patient Participation in recovery goals of care**
- Prepared with knowledge and understanding
- Assumed responsibility
- Involved in decisions
- Monitor effectiveness
2.4 Conclusion

Patient participation in acute care has been clearly identified as a key component of the quality and safety agenda worldwide. The notion of participation has been articulated in policies, mission statements and core values of health care institutions however the operationalisation of participation has largely been limited to consumer participation. Patient participation within the acute care environment at the level of individual patient engagement point-of-care, during hospitalisation is poorly articulated and under investigated.

Patient participation in treatment decisions and chronic illness management has been well researched. The acute care environment presents unique factors that are likely to impact significantly on patients’ ability and opportunity to participate in care irrespective of their preference for participation. However, learnings derived from the contexts of treatment decisions and chronic illness management provide a useful framework for the investigation of patient participation in acute care.

To gain an understanding of how patient participation is understood and enacted by patients and clinicians after cardiac surgery, four key goals of recovery were identified as an organising framework for observing patient and
clinician interactions. The goals of care were selected on the basis that patient participation may influence the quality and safety of care delivered.

In the chapter to follow, the research program, methodology and methods applied in designing a mixed methods case study of patient participation in acute care are described in detail.
Chapter Three

The research program and methods

In this chapter, the research program and methods used to conduct the study are described in detail. While there is emerging interest in patients participating in their own care within the acute care environment, there have been few attempts to explore patient participation in the context of post-operative management during a hospital admission. There is needed, a better understanding of how patient participation is understood and enacted by patients and nurses at a time of high illness acuity. In addition, the process of care factors that act as barriers and facilitators of participation within the acute setting are not well understood.

3.1 Research aims

The purpose of this research program was to explore the current status of patient participation in meeting the goals of care during an episodic admission to the acute care environment, that integrated:

1. How patient participation was understood and enacted by patients and nurses, and
2. The barriers and facilitators of patient participation within this setting.
The study addressed four specific research questions:

1. What was patients’ knowledge and understanding of their post-operative recovery goals of care?
2. What were patients’ preferences for participation in their post-operative recovery goals?
3. Were patients’ experiences of post-operative recovery goals commensurate with their preferred participation in these goals?
4. How did nurses facilitate patient participation in meeting post-operative recovery goals?

For this study, four *a priori* treatment goals of recovery were identified to guide the exploration of patient participation in the post-operative context (Figure 3.1). The rationale for choosing these goals was detailed in Chapter 2, Section 2.3.2.

<table>
<thead>
<tr>
<th>Medication management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain management</td>
</tr>
<tr>
<td>Pulmonary management</td>
</tr>
<tr>
<td>Discharge planning</td>
</tr>
</tbody>
</table>

Figure 3.1 Recovery goals of care
The research program and methodological approach employed in this study are outlined and discussed in the following sections. The discussion includes an overview of the context, research design, data collection procedures, data analysis and ethical considerations.

### 3.2 The research program

In order to explore the current status of patient participation during an episodic admission to the acute care environment, a case study approach was chosen, where the ‘case’ referred to a cardiac surgical ward. Case study is “the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances” (Stake, 1995, p. xi) and is the method of choice when a contemporary phenomenon, such as patient participation, is located within a real-life context (LoBiondo-Wood & Haber, 1994; Yin, 2009).

#### 3.2.1 Context

For this case study, the unit of analysis was the cardiac surgery ward of a major, metropolitan, tertiary referral hospital. Cardiac surgery was chosen as the focus for the case study because cardiac surgery for coronary artery disease is an excellent case of acute-on-chronic care where patient participation can have short term and long term consequences for outcomes
(Kaplan et al., 1996). The unit of analysis was therefore a small group within a large organization (Yin, 2009). In the next section, the methodological issues associated with case study design are discussed together with justification for the approach used in this research program.

### 3.2.2 Methodological rigour

The study reported in this thesis explored the current status of patient participation during an episodic admission to the acute care setting. In order to achieve this it was necessary to have a methodological approach that encompassed the multiple environmental, clinician and patient factors that may impact on the realisation of patients’ preferred and reported participation in this setting. Case study design was considered the ideal method for this exploration as the tenets of such a design are able to accommodate technically distinctive situations where there is a reliance on multiple sources of evidence. Case study design allows data convergence in a triangulating fashion and benefits from the prior development of theoretical propositions to guide data collection and analysis (Yin, 2009).

Four tests have been commonly used to establish the quality of any empirical social research. They are construct validity, internal validity, external validity
and reliability and these apply to case study design (Yin, 2009). This section addresses how these tests were applied to ensure methodological rigour.

### 3.2.2.1 Construct validity

Construct validity is the extent to which the operational methods measure a theoretical construct or trait (LoBiondo-Wood & Haber, 1994; Yin, 2009). To meet the test of construct validity it was necessary to ensure that:

1. Patient participation was defined in terms of specific concepts and that it was related to the original objectives of the study, and
2. Operational measures that match the concepts were identified (Yin, 2009).

To increase construct validity three tactics were used. The first was the use of triangulation. Triangulation is the use of multiple methods for the collection and interpretation of data about a phenomenon, in order to obtain an accurate representation of reality (Polit & Hungler, 1997). In this study triangulation was achieved using two methods: data triangulation and method triangulation. Data triangulation involves multiple techniques to collect and interpret the data (Jick, 1979) and method triangulation involves two or more distinct methods for gathering data (Jick, 1979). Used in this way, triangulation
provides multiple measures of the same phenomenon (triangulation) with the aim of corroborating the same fact or phenomenon (Yin, 2009).

The second tactic was to establish a chain of evidence or audit trail. The purpose of maintaining a chain of evidence is to allow an external observer to follow the derivation of any evidence from initial research questions to ultimate case study conclusions (Yin, 2009). Maintenance of a chain of evidence was achieved by following the steps suggested by Yin (2009) and is summarised at the end of this chapter in the overview of the research program. The last tactic to increase construct validity was to provide a report of findings for review by key informants (Yin, 2009). In this study, nurse participants were the key informants.

3.2.2.2 Internal validity

Maintaining construct validity required a number of important approaches. Internal validity is the degree to which it can be inferred that the experimental treatment, rather than an uncontrolled condition resulted in the observed effects (LoBiondo-Wood & Haber, 1994). An exploratory case study is not concerned with a causal relationship therefore addressing internal validity in this way is not required (Yin, 2009). For case study methodology, research internal validity extends to the broader problem of making inferences. The
specific approaches for dealing with internal validity in case study design may include pattern matching, explanation building, addressing rival explanations and using logic models. Pattern matching was the chosen method, where predicted patterns are compared to empirically based patterns (Yin, 2009). In this study the key propositions (Figure 3.2) were the predicted patterns. Comparison of these propositions to the final research outcomes is the process of pattern matching. If the propositions match the research outcomes then internal validity of the results is strengthened (Yin, 2009).

1. Patients’ preference for participation in the recovery goals of care varies based on the demands each goal places on patients

2. Barriers to the enactment of patient participation in recovery goals of care are multi-faceted and include patient, clinician and environmental factors

![Figure 3.2](image.png)

Figure 3.2 Key propositions underpinning the investigation of patient participation during acute episodic illness

3.2.2.3 External validity

External validity is the degree to which findings of a study can be generalised to other populations or environments (LoBiondo-Wood & Haber, 1994) and is a major barrier when undertaking case study research (Yin, 2009). Yin (2009) believes critics typically state that single case studies offer a poor basis for generalising beyond the study population to other populations. However, such
critics are implicitly contrasting the situation to survey research in which a sample is intended to generalise to a larger universe. Survey research relies on statistical generalisation whereas case studies rely on analytic generalisation. In analytic generalisation the investigator is striving to generalise a particular set of results to some broader theory (Yin, 2009).

### 3.2.2.3 Reliability

Reliability is the consistency or constancy of a measuring instrument (LoBiondo-Wood & Haber, 1994). The goal of ensuring reliability is to minimise errors and biases in the study. Two tactics to address reliability are to use a case study protocol and case study database (Yin, 2009). The case study protocol contains not only the research questionnaire but the procedures and general rules to be followed when using the questionnaire to enable replication of the research (Yin, 2009). This thesis is an extended version of a case study protocol that incorporates the case study questions, propositions, data collection methods, analysis and evaluation.

The raw data collection from the investigation including questionnaires, case study notes, recorded interviews and observations should be stored in a case study database for secondary analysis, independent of reports by the original
investigator (Yin, 2009). All data from this study are stored indefinitely in a secure database at Deakin University.

3.2.3 Research design

The research program comprised of a single institution case study, mixed method, repeated measures design to explore patient participation following cardiac surgery. The combination of qualitative and quantitative elements of this mixed method design complement each other by providing richness to the data that would not be possible using one method alone (Gillham, 2000).

The study was implemented in three main stages using semi-structured interviews, naturalistic observation, medical record audit and focus group interviews. In the first stage, patients were interviewed in the preadmission clinic. The second stage was conducted within the cardiac surgery ward after patients had undergone surgery where naturalistic observations and the first focus group with nurses were conducted. Medical record audit was also undertaken at this time. In the third and final stage another focus group with nurses was performed and patients were interviewed again, prior to discharge. Nurses were chosen as the clinician to be focused on in the study because of: a) their role in 24-hour care delivery; and b) their role in frontline assessment and management of the key goals of care under investigation.
3.2.4 Setting

The case study was conducted in a 390-bed, major, metropolitan, tertiary referral, teaching hospital in Melbourne, Australia. The hospital has a major role in the provision of specialist tertiary and quaternary services on a state-wide and national basis and cardiac surgery is one of these specialist services. Currently, the hospital has a reputation as one of the world’s leading health care providers, largely attributable to its progressive developments in acute care, medical research and health care teaching.

At the hospital, a new cardiac and thoracic centre was opened in 2008. The centre is a 54-bed ward comprising 12 acute beds, 36 step-down beds and a 6-bed cardiac day procedure unit. The centre provides a totally integrated service for medical and surgical cardiac patients. Patient case-mix includes acute myocardial infarction, cardiac and thoracic surgery and acute heart failure including pre and post heart transplantation.

At the organisational level of the hospital patient participation is incorporated within the hospital’s strategic plan through a Community Participation Plan (Alfred Health, 2010). The plan contains five key result areas and a number of measures of success that forms the foundation of the plan. The plan also illustrates how community participation can be addressed across three key
levels of the health service system: individual care level; program or
departmental level and organisational level. At the individual care level
measures of success include:

- Patients are provided with evidence-based information about condition
  and treatment options;
- Inclusive practice in care planning is demonstrated;
- Patients are involved in decision making and the care planning
  processes for their care, and staff act on these decisions;
- Patients receive up to date, appropriate and culturally sensitive
  information;
- Patients receive information about rights and responsibilities.

The notion of patient involvement is also reflected in the nursing department’s
mission statement, core values and objectives, albeit at a more non-specific
level compared with the hospital’s current strategic plan. The mission
statement for the nursing division at the hospital is:

“...To provide outstanding nursing care and service in an environment where
we see our values in action in every interaction with patients, carers and
colleagues.”
Core values for the nursing division are patient-centred care, respect and trust.

The guiding objectives for nursing included:

- Provide patient centred care
- Demonstrate excellent nursing practice
- Encourage and enable a collaborative approach to care
- Demonstrate continuous service improvement and development
- Develop leadership behaviours in all nurses
- Employ people who demonstrate commitment to our vision.

As the hospital was a tertiary referral centre, patients tended to have higher acuity with multiple co-morbidities and poor cardiac function compared to patients admitted to other hospitals in the region. The cardiac surgery ward had an annual throughput of approximately 538 patients at the time of data collection. Of these, 429 patients underwent coronary artery bypass graft (CABGs) and/or valve replacement surgery. Nurses with varying levels of experience ranging from graduate nurses to clinical nurse specialists in cardiac surgery worked in the ward.

### 3.2.5 Procedures

Although the research program was implemented in three main stages, data were collected simultaneously. Initial approval to conduct the study in the
cardiac surgery unit was gained from the clinical co-director, cardiovascular
and respiratory (nursing), and the nurse unit manager.

Potential patient participants were identified in the cardiac surgery
preadmission clinic. Preadmission staff members were consulted regarding the
suitability of approaching each patient at that time. Patients were given a copy
of the Patient Information and Consent Form (Appendix A) and invited to
participate in the study. Patients could elect to consent to either the
preadmission and pre-discharge interviews or the naturalistic observations or
both. Patients were aware they could revoke their consent at any time without
it effecting their treatment or care. Patients were assured they would not be
identifiable in publications or reports arising from this study. Figure 3.3
illustrates the decision tree developed to guide patient recruitment and data
collection.
Nurses were informed of the study during ward meetings and through interactions with the researcher on the ward. Plain language statements (Appendix B) were distributed to all nursing staff members and an invitation to participate was offered. Nurses had the opportunity to ask questions and clarify their role with the researcher. Nurses could consent to either the...
naturalistic observations or focus group interviews or both. Nurses were assured every effort would be made to maintain confidentiality and that they would not be identifiable in publications or reports arising from this study. Figure 3.4 illustrates the decision tree developed to guide nurse recruitment and data collection.

Other clinicians who were observed incidentally, during the two-hour observation periods were made aware of the study by the researcher and the researcher gained verbal consent to stay with the patient. No interactions between these clinicians and patients were made as this was not the focus of the study.

To arrange the naturalistic observations nurses who were assigned to receive a post-operative cardiac patient on the ward were contacted by the researcher. The researcher arranged to be in the ward prior to the time the patient was estimated to return from the intensive care unit to facilitate completion of consent forms.
Figure 3.4 Nurse recruitment and data collection

Sample
Nursing staff
(n=97 EFT)

Eligibility
Permanent workforce
Cardiothoracic ward

Observations (n=40)
Nurses observed based on their provision of direct care for patients who had consented to participate

Focus group interviews (n=2)
1. First focus group (n=4)
2. Second focus group (n=12)
3.2.6 Research participants

3.2.6.1 Patients

One-hundred and thirty patients scheduled to undergo cardiac surgery who presented to the preadmission clinic were recruited to participate in the study between April 2008 and December 2008. Of these, 98 patients went on to have surgery during the subsequent data collection period between April 2008 and April 2009. The inclusion criteria for patients was scheduled cardiac surgery and attendance at the cardiac surgical preadmission clinic. Patients below 18 years of age were excluded.

A subset of 48 patients was recruited sequentially using stratified, purposive sampling according to age (≥ 65 years and < 65 years) and sex for the observation component of the study (Figure 3.5). This number was considered appropriate for the purpose of rich description of patient and clinician interactions (Patton, 2002). Patients were stratified according to age and sex in order to achieve an even distribution of males and females and patient age.

In case study design, the typical criteria regarding sample size are irrelevant. Instead, the decision regarding size should reflect the number of case replications that are considered appropriate in the study (Yin, 2009). The interviewed patients represented approximately 30% of patients who
underwent cardiac surgery at the hospital during the 12-month period of data collection. The majority of patients who were not recruited were emergency admissions for cardiac surgery and did not attend the preadmission clinic. Of the patients invited to participate in the study only one patient declined consent. This was equivalent to a 99 per cent (n=130) consent rate in recruitment of patients in the preadmission clinic.

3.2.6.2 Nurses

All registered nurses who were part of the permanent workforce on the cardiac surgical ward (approximately 97 Equivalent Full Time [EFT]) were invited to participate. Forty nurses consented and participated in the 48 observation periods. Sixteen of the ward nurses were included in the focus group interviews based on availability for participation.

3.2.6.3 Inclusion criteria

Patients

- Elective cardiac surgery including coronary artery bypass grafts and/or valve replacements.
- Attendance at cardiac preadmission clinic

Nurses

- Permanent staff member on cardiac surgical ward.
3.2.6.4 Exclusion criteria

Patients

- Age less than 18 years

Figure 3.5 Stratified purposive sampling for patient observation

3.3 Methods

3.3.1 Patient interviews

To elicit patients’ understanding of the selected post-operative recovery goals and their preferences for, and experiences of, participation in these goals, patients were interviewed twice: during the preadmission period and prior to discharge from hospital following their surgery. Pre-discharge interviews were
conducted on the day of planned discharge. The duration of preadmission patient interviews ranged in length from 35 to 60 minutes while the pre-discharge interviews ranged from 15 to 45 minutes in duration. Patients’ responses were recorded verbatim and at times repeated back to patients for clarity.

One of the most important sources of case study information is via interview (Yin, 2009). The overwhelming strength of the face to face interview is the richness of the communication that is possible (Gillham, 2000). Semi-structured questions were used along with a validated tool to evaluate patients’ knowledge of, preferences for, and experience of participation in their care prior to and following cardiac surgery. Semi-structured questions are typically based on a flexible topic guide that provides a loose structure of open ended questions to enable exploration of experiences and attitudes (Robson, 2002).

The patient participation questionnaires (preadmission [Appendix C] and pre-discharge [Appendix D]) were designed to be used as tools to assist and guide the patient interviews. The semi-structured questions in the tools were themed around the four key recovery goals of care: medication management, pain management, pulmonary management and discharge planning.
3.3.1.1 Patient knowledge

In order to assess patients’ knowledge about the key goals of care, a range of questions were framed using existing professional literature and the current processes of postoperative care (Table 3.1). A rubric was developed to score patients’ knowledge regarding each goal of care. Following analyses, a final binary outcome was determined where patients’ ability to answer questions about recovery goals of care was judged to be ‘known’ or ‘not known’. During the pre-discharge interview, the same topics for each goal of care explored at the preadmission interview were repeated to determine whether there were any differences in knowledge between preadmission and pre-discharge.

Patients’ reported current medications were reconciled with the medications listed in their medical record at the time of each interview.
Table 3.1 Expected patient knowledge of post-operative care

<table>
<thead>
<tr>
<th></th>
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<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Name of medications</td>
<td>1. Importance of reporting pain</td>
<td>1. Technique for performing deep breathing and coughing exercises</td>
<td>1. Discharge destination</td>
<td></td>
</tr>
<tr>
<td>2. Purpose of medications</td>
<td>2. Importance of controlling pain</td>
<td>2. Importance of deep breathing and coughing exercises following surgery</td>
<td>2. Benefits of attending cardiac rehabilitation</td>
<td></td>
</tr>
<tr>
<td>3. Side effects of medications</td>
<td>3. Pharmacological and non-pharmacological treatments available to manage pain</td>
<td>3. Requirement for adequate analgesia prior to deep breathing and coughing</td>
<td>3. Intention to attend cardiac rehabilitation</td>
<td></td>
</tr>
</tbody>
</table>

3.3.1.2 Patients’ preference and reported participation

To elicit patients’ perceptions of their preferences and expectations of participation in their recovery prior to surgery, preadmission interviews were guided by three main topics:
a) Desire to participate in care while recovering from surgery

b) Barriers to participating in recovery

c) Facilitators to participating in recovery

To elicit patients’ perceptions and experiences of participation in their recovery following surgery, pre-discharge interviews were guided by four main topics:

a) Participation in care while recovering from surgery

b) Satisfaction with level of participation

c) Barriers to participating in recovery

d) Facilitators to participating in recovery

Both the preadmission and pre-discharge interview guidelines included a validated data collection tool, the Control Preference Scale (CPS), to elicit patients’ preference for participation and reported participation in achieving recovery goals.

3.3.1.2.1 The Control Preference Scale

The CPS was developed to measure how treatment decisions are made among people with life threatening illnesses. The control preferences are defined by the creators of the scale as “the degree of control an individual wants to assume when decisions are being made about medical treatment” (Degner et
and has been validated in varying contexts (Degner et al., 1997; Elkin, Kim, Casper, Kissane, & Schrag, 2007; Florin et al., 2006; Ford et al., 2003). The CPS consists of five statements that each portray a different role in treatment decision making using a preference statement (Degner et al., 1997). These roles range from active where the patient makes the decisions, through to shared where the patient makes decisions jointly with clinicians, to passive where clinicians make the decisions. For this study the word ‘physician’ was changed to ‘clinician’ to ensure all members of the health care team were considered by the patient when allocating a decision role. Patients’ preference for participation in their care was elicited by providing patients with five preference statement cards in random order separately for each recovery goal of care. When patients were given the cards a separate question was asked about each goal of care as shown below:

**Medication management**
Who decides what medications and when to take them?

**Pain management**
Who decides when and how to report, assess and treat pain?

**Pulmonary management**
Who decides the frequency and amount of deep breathing and coughing exercises to undertake?

**Discharge planning**
Who decides when and where you go following discharge?
Patients were instructed to rank their preference for each goal of care using the cards and then were asked:

Why did you rank your preference in this way?

This question was asked in order to understand the reason/s why patients chose a certain role and to identify barriers and facilitators of patient participation related to each recovery goal. While the CPS requires patients to rank their preference for participation, their first ranked preference was analysed as their preferred participation. The CPS was adapted for the pre-discharge interview where it was used to obtain patients’ experiences of participation by eliciting who they perceived made the decisions about the four recovery goals. At this time patients were instructed to choose only one option that best described their actual involvement. Once patients had indicated their perception of who made the decisions they were asked either a, b or c depending on their CPS result:

a) Why did the clinicians make the decisions?

b) Why did you make the decisions together?

c) Why did you make the decisions?
For example if patients reported they made the decisions about medication management they were asked, ‘Why did you make the decisions?’

3.3.1.3 Patient characteristics

The preadmission questionnaire also incorporated questions about patients’ characteristics. These data were collected to describe study participants and investigate specific patient characteristics that may influence patients’ preference for, and reported participation in, care within the post-operative context. Patient characteristics were chosen based on previous research where patients’ preference and involvement in their care has been affected by these characteristics. These included age (Arora & McHorney, 2000; Deber et al., 2007; Florin et al., 2006; Mira et al., 2012; O’Donnell et al., 2007), sex (Arora & McHorney, 2000; Florin et al., 2008; Street et al., 2005), level of education (Adams et al., 2001; Arora & McHorney, 2000; Deber et al., 2007; Florin et al., 2008; O’Donnell & Hunskaar, 2007; O’Donnell et al., 2007), cultural background (Schouten et al., 2007; Street et al., 2005; O’Donnell et al., 2007), living arrangement (Florin et al., 2006; Florin et al., 2008), previous surgery (Deber et al., 2007; Mansell et al., 2000), and illness severity (Arora & McHorney, 2000; Beaver et al., 1996; Mira et al., 2012; O’Donnell & Hunskaar, 2007; O’Donnell et al., 2007).
Patients’ cultural background was measured using language spoken at home, the need for interpreter, country of birth and age of arrival to Australia (if applicable) as criteria.

**3.3.1.3.1 Charlson Co-morbidity Index**

The Charlson Co-morbidity Index (CCI) was used to measure patients’ illness severity. The Charlson co-morbidity index (CCI) reflects the cumulative increased likelihood of one-year mortality (Charlson, Szatrowski, Peterson, & Gold, 1994); the higher the score, the more severe the burden of co-morbidity. Each patient’s co-morbidity is assigned with a weight of 1, 2, 3 or 6 depending on the risk of dying associated with this condition (Table 3.2). The sum of the score is calculated and the person is given a total score that predicts mortality.

**3.3.1.3.2 The Six-Item-Screener**

In the pre-discharge questionnaire, patients’ cognitive status was assessed, using the Six-Item-Screener (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002) to identity patients’ ability to retain information at this time. The Six-Item-Screener is a brief and reliable instrument that identifies cognitive impairment in participants using six items from the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975). Its overall diagnostic properties are comparable to the full MMSE. The six items include
three temporal orientation questions (day of the week, month and year) and three item recall (apple, table, and money) questions. A score of equal to, or less than four is comparable to a score of 23 or less on the MMSE which has been generally accepted to indicate the presence of some cognitive impairment (Folstein et al., 1975; Mitrushina & Satz, 1991).
Table 3.2 Charlson Co-morbidity Index – Weighting of clinical conditions

<table>
<thead>
<tr>
<th>WEIGHT</th>
<th>CLINICAL CONDITION</th>
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<tbody>
<tr>
<td>1</td>
<td>Myocardial infarction</td>
</tr>
<tr>
<td></td>
<td>Congestive heart failure</td>
</tr>
<tr>
<td></td>
<td>Peripheral vascular disease</td>
</tr>
<tr>
<td></td>
<td>Dementia</td>
</tr>
<tr>
<td></td>
<td>Cerebrovascular disease</td>
</tr>
<tr>
<td></td>
<td>Chronic pulmonary disease</td>
</tr>
<tr>
<td></td>
<td>Connective tissue disease</td>
</tr>
<tr>
<td></td>
<td>Diabetes without complications</td>
</tr>
<tr>
<td></td>
<td>Stomach ulcer</td>
</tr>
<tr>
<td></td>
<td>Chronic liver disease or cirrhosis</td>
</tr>
<tr>
<td>2</td>
<td>Hemiplegia</td>
</tr>
<tr>
<td></td>
<td>Moderate to severe kidney disease</td>
</tr>
<tr>
<td></td>
<td>Diabetes with complications</td>
</tr>
<tr>
<td></td>
<td>Tumours</td>
</tr>
<tr>
<td></td>
<td>Leukaemia</td>
</tr>
<tr>
<td></td>
<td>Lymphoma</td>
</tr>
<tr>
<td>3</td>
<td>Moderate to severe liver disease</td>
</tr>
<tr>
<td>6</td>
<td>Malignant tumours &amp; metastasis</td>
</tr>
<tr>
<td></td>
<td>AIDS</td>
</tr>
</tbody>
</table>
3.3.2 Naturalistic observations

Observation is particularly suitable for case study research as observation allows for a complex research notion, such as patient participation, to be viewed as a total entity (LoBiondo-Wood & Haber, 1994). In this study, the method of observation was based on the principles of naturalistic observation where the role of the observer was not concealed but the observer did not intervene. Participants were aware of the observer but the observer did not attempt to change behaviour (Lincoln & Guba, 1985; Patton, 2002). The naturalistic observations were based on the tenets of qualitative exploratory descriptive research (Patton, 2002).

The purpose of observation was to provide a thick and rich description of the interactions that occurred between nurses and patients in order to understand patients’ experiences of participation. In addition, observation was used to explain the context of care delivery and enable the researcher to identify potential barriers and facilitators of patient participation within the environment of the cardiac surgery ward. Observation sessions enhanced the rigour of the study allowing a view of the enactment of patient participation in clinical practice. This approach has been used to investigate the effects of clinicians’ choice of words on patient participation (Drew, Chatwin & Collins,
2001) and to identify barriers and opportunities for shared decision making and understanding (Ariss, 2009).

The naturalistic observations were undertaken over a nine month period from May 2008 to January 2009. Each observation covered a two-hour period and aimed to observe patients within 24-hours of their return to the ward from intensive care following cardiac surgery. This time represented high needs in terms of care processes but not the high acuity associated with the one-to-one care provided in the intensive care unit. The handover period was chosen as the preferred observation time as this was anticipated to be the time when nurses were commencing their work shift and would most often interact with patients in order to fully assess their status and goals of care (Berman et al., 2012).

Nurse and patient participants were told the purpose of the research was to explore how patients participate in their care following cardiac surgery. All observations were performed by one researcher, an experienced surgical intensive care nurse in the role of complete observer. The researcher did not contribute to patient care or discuss patient care with the nurses. The observation data were recorded in detail using a portable digital voice recorder and the duration of the interactions (the time when the interaction
commenced and was judged to have been completed) was also noted using field notes.

Some time was spent by the researcher in the ward prior to the observations to promote familiarity with ward personnel and decrease awareness of staff in an attempt to minimise a potential Hawthorne effect. The Hawthorne effect denotes the propensity for research participants to perform differently because they are being observed (LoBiondo-Wood & Haber, 1994). The researcher was positioned in the corner of the patient’s room. If patients left the room during the observation the researcher followed closely behind in order to capture nurse–patient interactions that occurred outside patients’ rooms.

### 3.3.3 Focus group interviews

Two focus group discussions with nurses were conducted. The purpose of the first focus group was to explore nurses’ perceptions of patient participation and their role in facilitating patients to participate in their care following surgery. The purpose of the second focus group was the same, but was conducted 11 months following the first focus group and nurses were presented with the preliminary research findings immediately prior to the second focus group. The purpose of providing the research findings was to
explore with nurses their perceptions of the data. The two focus groups were conducted with four and twelve ward nurses respectively and lasted approximately one hour. These were audio recorded and transcribed verbatim.

The focus group was chosen to enable interaction of group members to prompt discussion and questions as well as provide an understanding of shared experiences that would not be gained through interview alone (LoBiondo-Wood & Haber, 1994). It is recommended that focus groups be predominantly homogenous (LoBiondo-Wood & Haber, 1994), although the focus group consisted of only nurses, the nurses had a variety of years of experience working in the cardiac surgery area.

A time period of one-hour was allocated for both focus group interviews. Despite attempts by the researcher to draw out discussion in the first focus group, nurses appeared hesitant to expand their descriptions of participation with further probing suggesting that the notion of participation was not an area of practice where they had explicit views. As a result, the first focus group provided less data than anticipated. This was not the case in the second focus group interview, where provision of preliminary findings appeared to facilitate the discussion.
3.3.4 Medical record audit

A medical record audit was conducted to identify current practice in terms of documentation of patient participation. The purpose was to explore processes of care delivery and provide insight into practices related to the communication of goals of care. This audit was selected to provide additional information, specifically, the relationship between what is being done and what is being documented in regards to patient participation in the post-operative context. What was looked for was evidence of a focus on patients’ understanding and participation in their recovery, reports of interactions with patients relating to pain and its treatment or discharge planning. Surprisingly, in the review of 98 medical records, no data were able to be extracted that were indicative of patient participation following cardiac surgery. This may in part be attributed to the use of a clinical pathway for the care of patients undergoing cardiac surgery where documentation pertains to variations in the pathway.

While this pathway provides scope for nurses to provide patient education, eliciting specific understanding from patients regarding medication and pulmonary management is allocated respectively, to the pharmacist and physiotherapist. Nursing staff are required to discuss and confirm patients’ preference for cardiac rehabilitation and at discharge provide patients with
their medications. The expectations are that nurses provide information to
patients about care following discharge and confirm patients’ understanding
of this information. It was assumed therefore that nursing staff performed
these activities as no variations were documented in the clinical pathway to
suggest otherwise. However, there was no additional documentation relating
to patients’ participating in their own care such as, ‘Patient instructed on
benefits of deep breathing and coughing and shown correct technique’ or
‘Patient undertook deep breathing and coughing exercises hourly with
prompting from nursing staff.’ Patient medical records were also accessed in
order to extract information about patients’ demographic details, diagnosis
and medical history. In addition, patients’ medication charts were audited to
identify changes to patients’ preadmission medication program as a
consequence of surgery.

3.4 Data Analysis

As a mixed methods case study design, both qualitative and quantitative data
analysis was required. A major strength of case study data collection is the
opportunity to use many difference sources of evidence and research methods
to triangulate findings for the same research objectives (Patton, 2002; Yin,
2009).
3.4.1 Qualitative analysis

The data that emerged from the patient preadmission and pre-discharge interviews, the observation periods and the focus groups were analysed using broad qualitative description research tenets. The patient interviews and questionnaires were transcribed verbatim. Data relating to patients’ knowledge of recovery goals were analysed for content and transformed and entered into SPSS in order to quantify specific aspects of patients’ knowledge statistically. Taped recordings during the observation periods and focus groups were transcribed in full. Analysis of the transcriptions involved content analysis as outlined by Burnard (1991). Content analysis is a method for the objective, systematic and quantitative description of communications (LoBiondo-Wood & Haber, 1994). Content analysis was undertaken to count, cluster and describe the frequency, duration and initiators of interactions between nurses and patients in relation to recovery goals of care during the observation period. Thematic analysis based on qualitative description was used to identify themes in the data derived from the patient interviews, naturalistic observations and nurse focus group interviews.

3.4.2 Quantitative analysis

Quantitative data obtained through patient interviews and questionnaires and the observation period were analysed using Statistical Package for the Social
Science (SPSS) version 18.0. Statistical significance was accepted at $p<0.05$. A systematic approach was applied to quantitative data analysis. Summary descriptive statistics were used to present the characteristics of the study population, differences between the overall sample and the patients who participated in the naturalistic observations, referred to as the ‘observed sample’, and to describe the environmental characteristics.

Patients’ knowledge, their preference and reported participation in their recovery goals of care were explored using descriptive statistics. Categorical variables were reported as frequencies and percentage data. Continuous variables were reported as means and standard deviations. Repeated measures data from each recovery goal were explored in order to be able to describe and quantify differences in patients’ knowledge between the preadmission and pre-discharge periods. Patients’ preference and reported participation in recovery goals of care were cross-tabulated with patient characteristics to identify significant univariate predictors of patients’ preference and reported participation. Where appropriate, inferential statistics were used with chi-square comparisons.

Attempting multivariate analysis was not feasible in this study due to the inadequate sample size. This was in part related to the number of predictor
variables for model inclusion but mainly because of the small numbers in some categories that continued despite collapsing categories.

3.5 Ethical Considerations

Approval to conduct the study was obtained from the Human Research Ethics Committees at Deakin University (Approval number: EC 47-2008) (Appendix E) and the hospital (Approval number: 273/07) (Appendix F). The ethical issues associated with the research program were patient safety and burden and consent to participate. Maintenance of confidentiality of information and anonymity of patients were additional considerations.

3.5.1 Patient safety and burden

There was the potential to observe unsafe clinical practice during the naturalistic observation data collection period. If the researcher detected activities or hazards that placed patients at risk during the data collection period, which were not identified by clinicians, the researcher would have intervened to limit or prevent the danger. This may have involved providing direct assistance to patients and/or reporting the hazard to clinical staff. This situation did not occur during the data collection period.

Participants may have been inconvenienced by the interviews and/or observations. The researcher endeavoured to minimise any inconvenience for
participants by negotiating the time of the interview so that it did not cause any significant interruption to planned care activities. If patients stated that they were experiencing pain or concern regarding their understanding of their care they were advised to inform the nurse responsible for their care or, if they gave permission, the researcher informed the patients’ nurse.

3.5.2 Consent

Competence to give consent was determined by the researcher on the basis of each potential participant’s ability to verbalise their understanding of the study and what was required in order to participate. An interpreter was used for participants who did not speak English.

Information about the study was provided on a written participation information sheet and explained verbally to patients in the preadmission clinic. Written consent from patients was requested by the researcher at this time if they were willing to participate in either the interviews or observation or both. Nursing staff were individually approached by the researcher and provided with a written participatory information sheet and consent form and asked to participate in the study for the naturalistic observations and focus group interviews. Prior to commencing the observation period with the patient, written consent from the nurse was established. If other clinicians
interacted with patients during the observation period they were made aware of the study and verbal consent was gained to continue with the observation.

### 3.5.3 Confidentiality and anonymity

Confidentiality of information derived from patients and their medical records was maintained by restricting access to the data and ensuring all data were stored in locked facilities. Although confidentiality could not be assured following the focus group interviews, it was mentioned at the start of each focus group that what was discussed in the focus group should remain within the group. Total anonymity was not possible because interviews, observations and focus group interviews took place on the cardiac surgery ward. However, participants could not be identified by stored or reported characteristics or findings. Patients were assigned a code number so that names were not used on data collection tools. A record of patients’ details was kept in a study ledger according to their Unit Record (UR) number. A coding sheet that matched the patients’ code numbers with their UR numbers was stored separately and accessed only by the research team. Data collection tools and data files were kept in locked facilities for the duration of the study and are stored at the School of Nursing and Midwifery, Deakin University, indefinitely.
3.5.4 Privacy

The procedures for data collection and storage were based on requirements detailed in the Information Privacy Act 2000 and the Health Records Act 2001. In consenting to participate in the study, patients provided consent for their medical records to be accessed by the researchers.

3.6 Summary

The research program was designed to explore the enactment of patient participation during an episodic admission to the acute care environment. The research program, associated objectives, approach and expected outcomes are summarised in Table 3.3. The research findings are presented in the next five chapters. Analyses and discussion of the findings relating to patient characteristics and the environment for the case study are described in Chapter 4. The findings related to patient participation in the four specific recovery goals of care are presented separately in Chapters 5, 6, 7 and 8.
Table 3.3 Overview of the research program and presentation of results

| Purpose of research | Explore the current status of patient participation in meeting the goals of care during an episodic admission to the acute care environment, that integrated:  
|                     | 1) How patient participation was understood and enacted by patients and nurses, and  
|                     | 2) The barriers and facilitators of patient participation within this setting. |
| Study design        | Mixed Methods Case Study |
| Context             | Post-operative cardiac surgical |
| Sample              | 130 cardiac surgical patients and 40 registered nurses |

| Study propositions | Patients' preference for participation in the recovery goals of care varies based on the demands each goal places on patients | Barriers to the enactment of patient participation in recovery goals of care are multi-faceted and include patient, clinician and environmental factors |
| Patient Knowledge  | Preference for participation | Preference versus reported involvement | Nurse facilitation |
| Chapter 5 questions| Does patients' ability to provide a complete list and state the purpose and side effects of their current medications change as a function of surgical admission? | What is patients' preference for participation in medication management? | Is patients' experience of medication management commensurate with their preferred participation in medication management? | How do nurses facilitate patient participation in medication management? |
| Chapter 6 questions| Does patients' understanding of their pain management change as a function of surgical admission? | What is patients' preference for participation in pain management? | Is patients' experience of pain management commensurate with their preferred participation in pain management? | How do nurses facilitate patient participation in pain management? |
| Chapter 7 questions| Do patients know the importance of deep breathing and coughing exercises, the technique for performing deep breathing and coughing exercises, and the need for adequate pre-exercise analgesia? | What is patients' preference for participation in deep breathing and coughing exercises? | Is patients' experience of deep breathing and coughing exercises commensurate with their preferred participation in deep breathing and coughing exercises? | How do nurses facilitate patient participation in deep breathing and coughing exercises? |
| Chapter 8 questions| Does patients' ability to state their discharge destination, their intention to participate in cardiac rehabilitation and the benefits of cardiac rehabilitation change as a function of a surgical admission? | What is patients' preference for participation in discharge planning? | Is patients' experience of discharge planning commensurate with their preferred participation in discharge planning? | How do nurses facilitate patient participation in discharge planning? |
| Procedure          | Patient interviews | Patient interviews | Patient interviews | Naturalistic observation Focus group interviews Medical record audit |
Chapter Four

Case study selection: Patient characteristics and the environment

In health care, it is widely understood that patients vary in their ability and willingness to participate in care. Certain patient characteristics have been identified to affect patients’ preference for, and actual involvement in their care. Several factors within the acute care environment are also known to act as barriers to the enactment of patient participation.

In this chapter, patient characteristics and the environment where the study was conducted are described. Patient and nurses’ perceptions of the notion of patient participation in care are also reported. These descriptions allow assessment of the systematic generalisability of the study findings to the wider cardiac surgical population.

4.1 Methods

The methodological approach of the research program is described in detail in Chapter Three, Section 3.3. Patient characteristics, the environment description and patient and nurses’ perceptions of patient participation as a concept were acquired through patient interviews, naturalistic observations and focus group interviews.
4.2 Results

In this chapter, the findings are reported in three main sections. The first section contains a description of patients’ characteristics. A report of the environment where the study was conducted is then detailed. The final section, presents patients’ and nurses’ perceptions of the notion of patient participation in care.

4.2.1 Patient characteristics

The sample for analyses consisted of 130 patients. The sample represents 30% of all patients undergoing cardiac surgery between April 2008 and April 2009 at a major tertiary referral, metropolitan hospital in Melbourne. The average age of patients was 65.59 (SD=11.87) years, minimum age 25 years and maximum 87 years. For more than 50% of the sample, age was within a range of 17 years; between 57 and 74 years. The majority of patients were male (63%). Gender differences within categories of age are presented in Table 4.1. Overall, women (M=67.2, SD=13.0) were older than men (M=64.7, SD=11.1).

The naturalistic observations were undertaken over a nine month period from May 2008 to January 2009. Thirty seven per cent (n=48) of patients participated in these observations. The observation cohort was purposively stratified according to age and sex in order to achieve an even distribution of males and females and patient age. The average age of the observed cohort was 65.35 (SD=11.08) years, with a 50% male/female distribution.
Table 4.1 Patient age categories according to sex (N=130)

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Male (n = 82, 63.1%)</th>
<th>Female (n=48, 36.9%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29</td>
<td>1 (1.2)</td>
<td>2 (4.2)</td>
</tr>
<tr>
<td>30-39</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>40-49</td>
<td>7 (8.5)</td>
<td>2 (4.2)</td>
</tr>
<tr>
<td>50-59</td>
<td>19 (23.2)</td>
<td>7 (14.6)</td>
</tr>
<tr>
<td>60-69</td>
<td>21 (25.6)</td>
<td>12 (25.0)</td>
</tr>
<tr>
<td>70-79</td>
<td>29 (35.4)</td>
<td>19 (39.6)</td>
</tr>
<tr>
<td>80-89</td>
<td>5 (6.1)</td>
<td>6 (12.5)</td>
</tr>
</tbody>
</table>

As illustrated in Figure 4.1, the most frequently performed operation for patients was coronary artery bypass grafts (CABGs) (48.5%). Aortic valve replacement surgery (30.8%) and mitral valve replacement surgery (10.8%) were the next most frequently performed operations. The main difference between the observed and non-observed patient groups was the reported percentage of coronary artery bypass grafts (CABGs) and aortic valve replacements (AVRs). A higher proportion of patients underwent CABGs in the non-observed group.
Figure 4.1 Type of cardiac surgery for patients who did (n=48) and did not participate (n=82) in the naturalistic observations

Definition of Abbreviations: CABGS = coronary artery bypass graft surgery; AVR = aortic valve replacement; MVR = mitral valve replacement.
The majority of patients (63%) had an education level less than successful completion of high school (Table 4.2). For the majority of patients (85%) the main language spoken at home was English. There was minimal difference between the observed (85%) and the non-observed patient (84%) groups in regards to patients who mainly spoke English at home (Table 4.3).

Table 4.2 Education level for patients who did (n=48) and did not participate (n=82) in the naturalistic observations

<table>
<thead>
<tr>
<th>Education level</th>
<th>Observed</th>
<th></th>
<th>Not observed</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than VCE*</td>
<td>33</td>
<td>68.8</td>
<td>49</td>
<td>59.8</td>
</tr>
<tr>
<td>VCE* or equivalent</td>
<td>6</td>
<td>12.5</td>
<td>7</td>
<td>8.5</td>
</tr>
<tr>
<td>Tertiary</td>
<td>4</td>
<td>8.3</td>
<td>16</td>
<td>19.5</td>
</tr>
<tr>
<td>Tafe or trade</td>
<td>2</td>
<td>4.2</td>
<td>8</td>
<td>9.8</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>6.3</td>
<td>2</td>
<td>2.4</td>
</tr>
</tbody>
</table>

*Victorian Certificate of Education. Equivalent to successful completion of high school

Table 4.3 Main language spoken at home for patients who did (n=48) and did not participate (n=82) in the naturalistic observations

<table>
<thead>
<tr>
<th>Language spoken</th>
<th>Observed</th>
<th></th>
<th>Not observed</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>41</td>
<td>85.4</td>
<td>69</td>
<td>84.1</td>
</tr>
<tr>
<td>Greek</td>
<td>3</td>
<td>6.3</td>
<td>7</td>
<td>8.5</td>
</tr>
<tr>
<td>Other*</td>
<td>2</td>
<td>8.4</td>
<td>6</td>
<td>7.3</td>
</tr>
</tbody>
</table>

*Includes Mandarin, Cantonese, Russian and German
Figure 4.2 presents patients’ region of birth. Over half of the patients were born in Australia. Europe and the United Kingdom were the next most frequently cited region of birth. In patients who were born overseas there was less than a two year difference in the average age of arrival to Australia for observed (n=20, M=30, SD=15.9) and non-observed patients (n=41, M=28.8, SD=12.2). Overall, fourteen patients (10.7%) required an interpreter, of which four (8.3%) were part of the observed cohort.

Patients’ living arrangements are displayed in Figure 4.3. While the majority (62.3%) of patients lived with a partner, nearly 40% of patients lived alone.
Figure 4.2 Region of birth for patients who did (n=48) and did not participate (n=82) in the naturalistic observations.
Figure 4.3 Living arrangement for patients who did (n=48) and did not participate (n=82) in the naturalistic observations.
Thirty nine patients (30%) had experienced a previous surgical procedure requiring recovery and rehabilitation. The Charlson co-morbidity index (CCI) reflects the cumulative increased likelihood of one-year mortality (Charlson et al., 1994); the higher the score, the more severe the burden of comorbidity.

Table 4.4 shows approximately 50% of patients had a CCI of zero, meaning they did not have an increased likelihood of one-year mortality when compared to the general population.

<table>
<thead>
<tr>
<th>CCI</th>
<th>Observed</th>
<th>Not observed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>0</td>
<td>27</td>
<td>56.2</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>4.2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>8.3</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>12.5</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>6.3</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td>4.2</td>
</tr>
<tr>
<td>7</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt;7</td>
<td>3</td>
<td>6.3</td>
</tr>
</tbody>
</table>

*Age adjusted

Depending on the urgency for surgery, the time between patients’ preadmission appointment and surgical intervention varied and not all
patients who attended the preadmission clinic went on to have surgery in
the case study hospital. Consequently, 75% of patients (n=98) at
preadmission were interviewed following surgery. Patients who were not
interviewed had either undergone surgery at another hospital (n=13), were
still waiting for surgery (n=16), or had withdrawn from surgery (n=3).

Prior to conducting the pre-discharge interview, patients’ cognitive status
was assessed using the Six-Item-Screener (Callahan et al., 2002). Patients’
ability to answer each item of the Six-Item-Screener is presented in Table
4.5.

<table>
<thead>
<tr>
<th>Temporal orientation item</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year</td>
<td>95</td>
<td>96.9</td>
</tr>
<tr>
<td>Month</td>
<td>96</td>
<td>97.9</td>
</tr>
<tr>
<td>Day</td>
<td>93</td>
<td>94.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recall item</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apple</td>
<td>91</td>
<td>92.8</td>
</tr>
<tr>
<td>Table</td>
<td>73</td>
<td>74.5</td>
</tr>
<tr>
<td>Money</td>
<td>86</td>
<td>87.7</td>
</tr>
</tbody>
</table>

Patients’ ability to recall items was less than patients’ ability to reply
accurately to questions relating to temporal orientation. Of the 98 patients,
12.2% (n=12) were considered to have cognitive impairment according to
the six-item-screener. Approximately 10% (n=5) of the observed patient
cohort was considered to have cognitive impairment according to the six-item screener prior to the pre-discharge interview.

### 4.2.2 The case study environment

The cardiac surgery ward where the study was conducted accommodated 54 beds. The average number of cardiac surgical patients received per week throughout the study period was 10.3 patients. Ninety seven equivalent full time registered nurses were employed within the unit to provide care for patients during their recovery and rehabilitation from cardiovascular conditions including heart failure and cardiac surgery.

Primary nursing was the model of care operating within the ward. Of the registered nurses employed in the ward, 41% (n=40) were observed during the 48 (two-hour duration) observation periods. Table 4.6, presents the number of times each nurse was observed.

<table>
<thead>
<tr>
<th>Number of observations</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>38</td>
<td>95</td>
</tr>
<tr>
<td>2</td>
<td>7</td>
<td>17.5</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>2.5</td>
</tr>
</tbody>
</table>

Patients’ median length of stay was 8 days (Q1= 7, Q3= 14, Min 5, Max 41).

The average length of hospital stay was 11.9 (SD= 6.47) days. The median time between the preadmission appointment and surgery was 61 days.
(Q1= 33, Q3= 93, Min 2, Max 130). The majority of nurses (75%) cared for three patients per shift (Table 4.7). Nurse and patient interactions were observed for a total of 96 hours. Most observations (90%) occurred within 48 hours of a patient’s transfer to the ward from the Intensive Care Unit (ICU). The remaining observations (n=5) were conducted between Day 2 and Day 6 after ICU transfer. Over half of the 48 observation periods (58.3%) were conducted during nursing handover and double staff time with 10.4% of handovers carried out at the patient’s bedside.

Table 4.7 Number of patients nursed per shift (n=48)

<table>
<thead>
<tr>
<th>Number of patients</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>6</td>
<td>12.5</td>
</tr>
<tr>
<td>3</td>
<td>36</td>
<td>75</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>12.5</td>
</tr>
</tbody>
</table>

4.2.2.1 Recovery goals of care

The four a priori recovery goals of care were validated by nurses during the first and second focus group interviews. There was unanimous agreement from nurses in both focus groups that key recovery goals in patients’ recovery and rehabilitation following cardiac surgery were medication management, pain management, pulmonary management and discharge planning.

The number of these key recovery goals discussed with each patient during the observation period is shown in Table 4.8. During the observations, 10
patients (20.8%) missed opportunities to discuss any key recovery goal with nursing staff. Only five (10.4%) patients discussed all four key recovery goals with nursing staff.

Table 4.8 Number of key recovery goals discussed with each patient (n=48)

<table>
<thead>
<tr>
<th>Number of key goals</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>10</td>
<td>20.8</td>
</tr>
<tr>
<td>1</td>
<td>11</td>
<td>22.9</td>
</tr>
<tr>
<td>2</td>
<td>13</td>
<td>27.1</td>
</tr>
<tr>
<td>3</td>
<td>9</td>
<td>18.8</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>10.4</td>
</tr>
</tbody>
</table>

Of the key recovery goals mentioned, medication management (n=29, 60.4%) and deep breathing and coughing exercises (n=23, 47.9%) were most often discussed followed closely by pain management (n=22, 45.8%) (Figure 4.4).
Figure 4.4 Specific recovery goals mentioned (n=48)

Table 4.9 displays the person who initiated the interaction regarding the four goals of care. During the observation period a medication related activity occurred with 29 of the 48 patients (60.4%). Medication related activity constituted any sort of exchange between a nurse and patient about medications. For these 29 patients, 33 separate medication-related activities were observed. Twenty nine (87.8%) of these activities were initiated by nursing staff and 4 (12.1%) were initiated by patients.

Pain related activity was observed with 22 of the 48 patients (45.8%). Pain related activity constituted any sort of exchange between a nurse and patient about a patients’ pain or pain treatment. For these 22 patients one
pain-related activity was observed for each patient. All of these activities were initiated by nursing staff.

Pulmonary management-related activity was observed with 23 of the 48 patients (47.9%). Pulmonary management-related activity constituted any sort of exchange between the nurse and patient about deep breathing and coughing exercises or pulmonary hygiene in general. For these 23 patients, 24 separate pulmonary management-related activities were observed. Twenty two (91.7%) of these activities were initiated by nursing staff and 2 (8.3%) were initiated by patients.

During the observation period discharge planning-related activity was observed with 10 of the 48 patients (20.8%). Discharge planning activity constituted any sort of exchange between the nurse and patient about discharge planning including arrangements for discharge, medications after discharge and cardiac rehabilitation. For these 10 patients, 10 separate discharge related activities were observed. Six (60.0%) of these activities were initiated by nursing staff and 4 (40.0%) were initiated by patients.

| Table 4.9 Person initiating interaction regarding each recovery goal (n=89) |
|-------------------------------------------------|-----------------|-----------------|-----------------|------------------|
|                                                | Medication      | Pain            | Pulmonary       | Discharge        |
|                                                | management      | management      | management      | planning         |
|                                                | n (%)           | n (%)           | n (%)           | n (%)            |
| Nurse                                          | 29 (87.9)       | 22 (100.0)      | 22 (91.7)       | 6 (60.0)         |
| Patient                                        | 4 (12.1)        | 0 (0.0)         | 2 (8.3)         | 4 (40.0)         |
On average, nurses spent 17.4 (SD=12.9) minutes in a patient’s room during the two-hour observation periods (Figure 4.5). Of that time, an average of 3.8 (SD=3.5) minutes was spent in nurse and patient interaction (Figure 4.6). Nurses entered patients’ rooms on 119 separate occasions during the total observation period, a mean of 2.5 times per patient.
Figure 4.5 Mean length of time (%) spent in patients’ room during observation (time = 120 minutes)

Figure 4.6 Mean length of time (%) spent in nurse and patient interaction during observation (time = 120 minutes)
Nurses spent minimal time interacting with patients about any recovery goal (Table 4.10). Of the 96 hours spent observing nurse and patient interactions the maximum time a nurse spent with a patient discussing one goal of care was 2.02 minutes. Activities nurses undertook in patients rooms when they were not interacting with patients included managing equipment such as the cardiac monitor and completing paper work.

Table 4.10 Time (minutes) spent interacting with patients’ regarding each recovery goal of care

<table>
<thead>
<tr>
<th>Recovery goal</th>
<th>M (SD)</th>
<th>Minimum, Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication management</td>
<td>0.20 (0.41)</td>
<td>0, 2.02</td>
</tr>
<tr>
<td>Pain management</td>
<td>0.12 (0.30)</td>
<td>0, 1.46</td>
</tr>
<tr>
<td>Deep breathing and coughing exercises</td>
<td>0.13 (0.29)</td>
<td>0, 1.47</td>
</tr>
<tr>
<td>Discharge planning</td>
<td>0.04 (0.15)</td>
<td>0, 1.01</td>
</tr>
</tbody>
</table>

4.2.3 Patient and nurses’ perceptions of the concept of patient participation in care

Patient perceptions of participation were initially explored from an overall health care perspective. Patients’ desire to participate in decisions about their health and their reported participation is displayed in Table 4.11.

While the majority of patients (70.4%) had a desire to participate, less than half (47.8%) believed they actually participated in decisions about their health during hospitalisation.
Table 4.11 Patients’ preference for participation in decisions about their health care and reported participation in decisions about health care (n=98)

<table>
<thead>
<tr>
<th>Preference for participation</th>
<th>Reported participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinicians solely made decisions</td>
<td>Patient involved in decisions</td>
</tr>
<tr>
<td>Clinicians solely made decisions</td>
<td>(n=57)</td>
</tr>
<tr>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Clinicians solely made decisions</td>
<td>19 (70.4)</td>
</tr>
<tr>
<td>Patient involvement in decisions</td>
<td>36 (52.2)</td>
</tr>
<tr>
<td>Not sure</td>
<td>2 (100.0)</td>
</tr>
</tbody>
</table>

Despite discrepancy between patients’ preference to participate and reported participation, 96.9% (n=98) of patients were satisfied with their level of involvement in decisions about their health.

**4.2.3.1 Patient perceived facilitators of their participation in care**

Thirty two per cent of patients identified a factor that would make participation in their care easy prior to (n=42) and following surgery (n=31). The remaining patients could not identify any factors when asked. These results are displayed in Table 4.12. Prior to surgery at the preadmission clinic, patients most frequently cited clear communication (50%) and adequate knowledge (19%) as the main facilitators to participation in care. Following surgery, encouragement from clinicians (38%) was the most cited facilitator of patient participation. Patients also identified clear
communication (28%) and adequate information provision (22%) as facilitators prior to discharge.

Table 4.12 Factors patients considered facilitators to participation in health care decisions

<table>
<thead>
<tr>
<th>Factor</th>
<th>Preadmission (N=130)</th>
<th>Pre-discharge (n=98)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Clear communication</td>
<td>21</td>
<td>16.2</td>
</tr>
<tr>
<td>Encouragement from clinicians</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Physical ability</td>
<td>6</td>
<td>4.6</td>
</tr>
<tr>
<td>Adequate knowledge</td>
<td>8</td>
<td>6.2</td>
</tr>
<tr>
<td>Adequate information provision</td>
<td>4</td>
<td>3.0</td>
</tr>
<tr>
<td>No facilitators</td>
<td>88</td>
<td>67.7</td>
</tr>
</tbody>
</table>

4.2.3.2 Patient perceived barriers of their participation in care

Prior to admission only one quarter of patients (n=33) could identify a factor that would make participation in their care difficult. At discharge only 20% of patients identified a factor that would make participation difficult. These results are displayed in Table 4.13. In both the preadmission (39%) and pre-discharge (50%) interviews physical incapability including pain and fatigue was the most cited barrier to participation. Difficulty with understanding language was the second most cited barrier to participation by patients at both preadmission (18%) and pre-discharge (20%). Lack of
information was considered a barrier to participation at preadmission (13%) but was not identified as a barrier following surgical recovery. Poor clinician attitude was a perceived barrier to participation prior to admission (13%) but it was the perception of clinicians’ busyness (15%) and not their attitude that was identified as a barrier prior to discharge.

Table 4.13 Factors patients considered barriers to participation in health care decisions

<table>
<thead>
<tr>
<th>Factor</th>
<th>Preadmission (N=130)</th>
<th>Pre-discharge (n=98)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Lack of information</td>
<td>4</td>
<td>3.0</td>
</tr>
<tr>
<td>Language barrier</td>
<td>6</td>
<td>4.6</td>
</tr>
<tr>
<td>Physical incapability</td>
<td>13</td>
<td>10.0</td>
</tr>
<tr>
<td>Preference to not participate</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Poor clinician attitude</td>
<td>4</td>
<td>3.0</td>
</tr>
<tr>
<td>Clinicians’ too busy</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Inadequate knowledge</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Physical environment</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>No barriers</td>
<td>97</td>
<td>74.7</td>
</tr>
</tbody>
</table>
4.2.3.3 Nurse perceived facilitators for patient participation in care

In the first nursing focus group interview, nurses (n=4) were asked to discuss the meaning of patient participation. Nurses agreed upon the importance of patient involvement,

That’s the common goal isn’t it? Just to get the patient well enough to get home or wherever they are coming from so patients should definitely participate in their care. (nurse 4)

I think it (patient participation) also gives them back a sense of empowerment and you know that independence while they are in hospital. They might have tubes and things in but it is about what they can do to optimise their recovery post-surgery. (nurse 2)

And also when they go back into the community they can be responsible for their own health. So they can identify what signs they need to look out for and put the onus on them. They go from an acute area which is foreign to them and then back into the community so get them involved from day one to manage their own health. (nurse 3)

Nurses directly discussed how they engaged patients to participate in their care,

We keep them informed and explain the process of why we are doing certain interventions so then they are agreeable and they know what is going on. (nurse 1)

Usually you discuss what is going on for them for the day and what they need to do to ensure they are optimising their ability and also they are actually going to get out day 5 or 6 for discharge. (nurse 2)

We do have a schedule to keep up to but it is about including them in that schedule. (nurse 4)
The way information provision was delivered to patients was described by nurses in the focus groups as,

Well I certainly give or make sure they have their education booklet that they get in pre admission clinic as well as make sure they read through again when they have had surgery because it is usually more relevant to them then so that if there are any questions from that we can say well these are your expectations here and you know just discussing what they see as I guess their main treatment goals as well but I also tell them what I need to do what they need to do to optimise their recovery.

I've told patients you’re going to be on a pathway and this is what we expect at the end of each day, so, by day 7 you might be out of here, so that they can know what to expect as well.  

(nurse 2)

(nurse 8)

4.2.3.4 Nurse perceived barriers of patient participation in care

In the second nursing focus group interview all nurses (n=12) discussed time as a barrier to facilitating patients to participate in their care. One nurse described this as ‘how it is’ with no scope for modification,

Sometimes you just don’t have time to be in the patients’ room as much as you would like. Unfortunately that is just how it is. 

(nurse 4)

Other nurses believed the issue of not enough time could be addressed by increasing efficiency.

I think that there is more time we could be spending..... I think there is a lot of things that we do that probably aren’t really efficient so you know you are chasing up and down the corridor for the history or the notes but if you had it right
there and then you would have that extra time with the patient. I think there are a lot of things that we could do better so we could spend more time with patients.

I think the other thing too that might take you away (from the patient) is, ineffective management of where documentation is done. So often things are not done in the patients’ rooms, so just rethinking how things could be done differently to improve more time with patients. So addressing ineffective use of time.

(nurse 5)

Nurses acknowledged that in order to optimise patient outcomes it is necessary to organise care away from the patient’s room,

Looking after the patient doesn’t necessarily mean being at their bedside all of your shift, it comes from working with other people from outside the room. I sort of think we’ve joined them (health care professionals) all together. We have to have knowledge on every department. You know we’re physiotherapists and we’re Occupational Therapists and we’re Social Workers but we’re Nurses as well.

(nurse 8)

Usually it is the nurse who becomes coordinator and advocate for the patient and ends up pretty much sorting out everything.

(nurse 2)

When nurses were questioned about where the majority of time during a shift was spent three main activities emerged: searching for equipment, following up on clinician and patient requests and documentation.

Just following up on things you know. Some days things are nice and follow-up is just routine but sometimes it just doesn’t. You get phone calls and you have to follow them up and that takes you away from giving patient care.

(nurse 4)

I think also documentation that could have been filled out earlier by colleagues which you end up

(nurse 2)
doing on the day of discharge when you could be spending that time educating patients.

*Looking for stuff, medications or charts.*  
*Equipment, looking for stuff I find I spend a lot of time and it’s so frustrating.*

(nurse 8)

Interestingly, in the above discussion the day of discharge appeared to be the time when nurses formally engaged patients in post-operative education. Time and patient bed moves were also identified by nurses as specific barriers to patient education.

*I wouldn’t say [patient education] is in-depth. Probably say it wouldn’t be discussed as much as it could be but then it all comes back to those constraints such as time.*

(nurse 2)

*I think some things like bed moves, when there is pressure to have empty beds, nurses just start building up rapport with the patients so they know where they’re up to with education and then they are moved as their condition improves and then those questions are probably re-asked, if they haven’t had the same nurses for a while, then it’s reassessing where they’re at and maybe not the same reinforcements from the same nurse which they build up a rapport with.*

(nurse 5)

*Continuity, being changed around patients definitely affects us being able to deliver good care. It obviously impacts on the patient to get the right information delivery consistently.*

(nurse 8)

### 4.3 Discussion

The purpose of the discussion in this chapter was to describe patient characteristics and the case study environment where the study was conducted in particular in relation to patients’ and nurses’ perceptions of the concept of patient participation in care. The findings provide a
contextual basis for the analyses in subsequent chapters where patient participation is examined according to recovery goals of care.

Numerous patient characteristics were presented in this chapter. Characteristics were chosen based on their potential effect on patients’ participation in care as described in detail in Chapter 2, section 2.2.1.1.1. The effect these characteristics have on patient participation for each of the four key recovery goals of care are explored in the following Chapters 5-8. However, some important findings in relation to patient characteristics are discussed below.

The average patient age of 65.59 (SD=11.87), is consistent with the average age of patients undergoing cardiac surgery in other public hospitals in the State of Victoria (Tran et al., 2011) where the study was conducted. The sex distribution of patients was also similar to other hospitals within Victoria in that the majority of patients were male. However, the overall percentage of males in this study was lower (63.1%) when compared to the Victorian average of 70% (Australasian Society of Cardiac and Thoracic Surgeons, 2009). The ratio of coronary artery bypass grafts to valve replacement was also lower (1:2) when compared with other Victorian hospitals (1:3.8) (Australasian Society of Cardiac and Thoracic Surgeons, 2009).

Nearly 40% of patients having cardiac surgery lived alone. For this cohort there are greater health concerns following discharge from acute care. Patients living alone are more likely to be socially isolated and may not
have the support of immediate family members in their recovery to endorse adherence to discharge instructions (Mahoney, Eisner, Havighurst, Gray, & Palta, 2000; Schmaltz et al., 2007). It is essential for these patients to be fully aware of their discharge medications, pain management and other care needs prior to discharge in order to optimise their recovery. In previous studies, patients who lived alone were more likely to prefer an active role in their care (Florin et al., 2006; Florin et al., 2008). This may relate to their perceived need to self-manage their care without immediate support once discharged.

Cognitive deficit following cardiac surgery has been reported to occur in 53% of patients at hospital discharge (Newman et al., 2001) and 41% of patients six weeks following discharge (Phillips-Bute et al., 2006). Discrepancies in the percentage of patients that experienced cognitive impairment in this study (12%) and previous studies may relate to variation in the tools used to measure cognitive status. Both Newman (2001) and Phillips-Bute (2006) used a battery of five neurocognitive tests as cognitive impairment was the focus of their studies. Patients’ capacity to recall items on the six-item-screener is considered an assessment of their ability to learn new things (Callahan et al., 2002) and has implications for patients’ capability to retain new information during their hospital stay. At least 7.2% of patients were unable to recall one item in the recall section of the six-item-screener.
Patients’ average length of hospital stay was 11.9 (SD= 6.47) days. This is greater than the average length of stay reported in other cardiac surgical cohorts where the average length of stay ranged between 5.0 and 9.4 days (Aggarwal et al., 2006; Leegard et al., 2008; Yared et al., 2000). The increased length of stay may reflect the setting of this case study within a major tertiary referral hospital where patients tend to have higher acuity that may result in an extension of patients’ in-hospital recovery.

In the state of Victoria, nurse to patient ratios are legislated. The ratio is one nurse to four patients in medical and surgical units with a separate ‘in charge’ nurse for morning and afternoon shifts (Victorian Government, 2007). The higher staff-to-patient ratio in this study may reflect that patients who have recently returned from intensive care require more vigilant monitoring (Elliott, Worrall-Carter, & Page, 2012).

The model of care practiced on the unit where the study was conducted was primary nursing. As discussed in Chapter 2, the opportunities for patients to participate in their own care should amplify as a result of a primary nursing model. The extended period in which the nurse is the direct caregiver allows for increased opportunities for information provision and assessment of patients’ knowledge and understanding of their illness, collaboration and coaching to increase participation (Tiedman & Lookinland, 2004). The realisation of these aspects of primary care nursing within the unit was contradicted in the second focus group. Nurses
discussed the frustration of establishing a relationship with patients in
order to provide education only to have the patient moved from their area
as soon as they were considered to be stable.

While bedside handovers were endorsed by nursing leadership, only 10.4%
of handovers were carried out at the patients’ bedside. Bedside handover
has the potential to give patients an opportunity to actively participate in
their care by discussing their health and asking questions to improve the
consistency and continuity of patient care (Timonen & Sihvonen, 2000).
The lack of bedside reporting in this unit may be considered missed
opportunities for patients to participate in recovery goals and the quality
and safety of their care.

Patient perceived facilitators of participation were clear communication,
encouragement from clinicians, physical ability, adequate information
provision and knowledge. All these factors have previously been identified
as facilitators of patient participation in health care (Ashworth et al., 1992;
Belcher et al., 2006; Hack, Degner, & Dyck, 1994; Heisler, Bouknight,
Hayward, Smith, & Kerr, 2002; Ramfelt & Lutzen, 2005) and interestingly all
but one (physical ability) relate to roles clinicians must facilitate. The little
time nurses spent in patients’ rooms and the minimal time nurses spent
communicating with patients can be considered missed opportunities to
facilitate patients’ participation in their care, as time is required for nurses
to provide patients with education about their recovery goals, establish
patients’ role in these goals and encourage patients to participate. This is especially important for patients who identify language difficulties as barriers to participation.

The lack of education provision from nurses to patients was highlighted in nearly half (43.7%) of the observation periods as no or only one key goal of recovery was mentioned. The timing of the observation periods may not have coincided with the timing nurses felt was appropriate to provide education to patients. However, according to the focus groups, in particular, Focus Group 2, it is likely that nurses were busy searching for equipment, following up requests and filling out documentation. Locating patient care supplies and health care documentation are tasks that have previously been identified to decrease the time nurses spend with patients (Duffield, Gardner, & Catling-Paull, 2008; Ferenc, 2010). This busyness was perceived by some patients who reported clinicians’ busyness as a barrier of participation in care and has previously been noted as a barrier to participation (Fraenkel & McGraw, 2007; Sainio et al., 2001; Timonen & Sihvonen, 2000; Wellard et al., 2003).

Given the lack of congruity between patients’ desired participation and their reported participation in this study, clinicians do not appear to successfully achieve patients’ desired involvement in care. A mismatch between patients’ preference for participation and actual participation is not uncommon. Florin and colleagues (2006) found patients reported
participation equalled their preference for participation only 20% of the
time. Similarly, Ford et al., (2003) reported 61% of patients perceived they
achieved their preferred decision-making role.

Despite this, most patients (96.9%) were satisfied with their level of
involvement in their care. The distribution of patient satisfaction scores in
health care is frequently skewed toward the highly satisfied end of rating
scales (Coyte et al., 1994; Lee, Tu, Chong, & Alter, 2008; Strassels, Chen, &
Carr, 2002) regardless of inconsistencies in the quality of care delivered
and clinical outcomes achieved. Patients’ reported satisfaction with their
involvement may more likely reflect their prior personal experience,
knowledge and expectations of care (Lee et al., 2008; Strassels et al., 2002).

4.4 Conclusion

The limited time nurses spent with patients was a clear barrier to patients
receiving adequate information and education to participate in care.
Nurses described feelings of being busy undertaking tasks and limitations
in their ability to carry out the primary nursing model of care. Patients
were satisfied with their achieved level of involvement despite preferring
more.

Specific findings for each recovery goal of care are presented in the
following four chapters.
Chapter Five

Patient participation in medication management during an acute hospital admission

Within acute care settings, medication error and medication adherence are major and longstanding quality and safety problems (Barker, Flynn, Pepper, Bates, & Mikeal, 2002; Dean, Schachter, Vincent, & Barber, 2002; Ho, Bryson, & Rumsfeld, 2009; Kale, Keohane, Maviglia, Gandhi, & Poon, 2012; Kalisch, et al., 2012; Morimoto et al., 2011; Roughead & Semple, 2009; Runciman, Roughead, Semple, & Adams, 2003; Sabaté, 2003). In Australia, adverse events as a consequence of medication error affect 2-3% of all patients admitted to hospital (Roughead & Semple, 2009). Further, the rate of medication-related hospital admissions is reported as 20% (Kalisch et al., 2012) with the majority of these admissions relating to non-adherence of patients with medication regimens once they are discharged from hospital. The problem of in-hospital medication errors and post discharge medication adherence is not limited to the Australian context. Similar issues have been reported in other developed countries (Barton et al., 2012; Flynn, Liang, Dickson, Xie, & Suh, 2012; Franklin, Reynolds, Shebl, Burnett, & Jacklin, 2011; Kale et al., 2012; Kripalani et al., 2012; Morimoto, et al., 2011). Patient participation in medication management during hospitalisation has been proposed as a defence against medication errors (Aspden, Wolcott, Boorman, & Cronenwett, 2007) and, as a means of
improving patients’ adherence to medications once discharged from hospital (Chewing & Sleath, 1996).

In health care, the focus on patient participation has been predominately in the areas of treatment decisions and chronic illness management. More recently, the concept of patients as active participants in their care has been incorporated into health care policy as an important element in achieving quality patient outcomes. Patient participation in health care has been reported to improve patient outcomes (Deakin et al., 2005; Gibson et al., 2002; Guevara et al., 2003; Loh et al., 2007) and is proposed to play an important role in improving the quality and safety of health care (Longtin et al., 2010). There is however limited understanding of how patients participate, or are facilitated to participate, in their management while hospitalised. In relation to medication management, indicative behaviours of patient participation are not entirely clear.

Gruman and colleagues (2010) identified behaviours indicative of active patient engagement in health care, some of which apply specifically to patient participation in medication management. These behaviours relate to patients knowing the purpose and side effects of their medications in order to monitor their effectiveness, being prepared to discuss their medications with clinicians and effectively manage the procurement, storage and continuity of medications. The Joint Commission, ‘Speak Up’ program is a nationwide campaign in the United States urging patients to
take a role in preventing health care errors by becoming active, involved and informed participants in the health care team (The Joint Commission, 2007). This initiative also attempts to identify behaviours indicative of patient participation in medication management recommending that patients know the name and purpose of each medication they are prescribed and have the dose, route, frequency, and duration of each medication documented and readily accessible. Implicit in the initiatives of both Gruman et al. and The Joint Commission is that patients must understand their medications in order to actively engage in their medication management to prevent error and improve therapeutic outcomes. The nurse and patient interface during medication administration activities in hospital represents an opportunity for assessing and assisting patients’ understanding of their medication management plan.

In this chapter, the findings presented relate to patient participation in the context of medication management during recovery from surgery in the acute care environment. An acute hospital admission provides an opportunity for patients to engage with multiple clinicians in relation to their medication management plan. This opportunity is expected to enhance, through participation, patients’ knowledge of their medications, incorporating changes to their medication regimen after surgery. The specific research questions were:
a) Does patients’ ability to provide a complete list and state the purpose and side effects of their current cardiovascular medications change as a function of a surgical admission?

b) What is patients’ preference for participation in medication management?

c) Is patients’ experience of medication management commensurate with their preferred participation in medication management?

d) How do nurses facilitate patient participation in medication management?

5.1 Methods

The methodological approach used to explore patient participation in medication management is described in detail in chapter 3. Semi-structured patient interviews before surgery and prior to discharge from hospital, provided data regarding patients’ knowledge of their medications and their preference for and actual participation in medication management. The decision was made to focus on cardiovascular medications as it was expected that clinicians should have good understanding of these domain specialty drugs. The Control Preference Scale (CPS) was used to elicit patient preference for participation in medication management. A modified version of this tool was used to elicit patients’ reported participation in medication management. Naturalistic observations based on the tenets of qualitative exploratory descriptive research were used for data collection and analyses to elicit the clinical
practices surrounding medication management. A premise of this exploration was that informing patients about new medications and reinforcing their knowledge of existing medications is part of routine medication management. Focus group interviews explored nurses’ perceptions of how they facilitate patient participation in medication management and supported the data derived from the naturalistic observations. In the following section, the procedure and data collection relating to the description of patient participation in medication management is outlined.

5.1.1 Procedure and data collection

To elicit knowledge of medications, patients were interviewed twice: during the preadmission period and prior to discharge from hospital after their surgery. Pre-discharge interviews were conducted on the day of planned discharge. In most instances this occurred following the routine review of discharge medications that occurs between the patient and hospital pharmacist at the time that discharge medications are dispensed. This was considered important as the pharmacy review prior to discharge was another opportunity for patients to receive information about their medications.

At preadmission the patient interviews were semi-structured and were guided by three main topics:

1. Current list of medications
2. The purpose of medications

3. Side effects of medications

At the pre-discharge interview, these three general topics were explored again. For both the preadmission and pre-discharge interviews, patients’ medications were verified using reconciliation documents in their medical record. Where there were discrepancies in terms of a higher number of reported medications compared to documented medications further verification was sought. When there were lower numbers of reported medications compared to documented medications verification was not possible without consulting patients’ General Practitioners. In this case, the assumption was made that patients had missed medications.

Using the CPS, patients’ preference for participation in medication management was based on the question:

Who decides what medications and when to take them?

Once patients ranked their preference for medication management they were asked:

Why did you rank your preference in this way?

This question was asked in order to understand the reason/s why patients chose a certain role to identify barriers and facilitators of patient participation in medication management. A similar question was asked to elicit patients’ reported participation. Patients were asked to choose one statement from the modified CPS that best described their involvement in
medication management. Once patients reported their perception of who made the decisions they were asked either a, b or c depending on their CPS result:

a) Why did the clinicians make the decisions?

b) Why did you make the decisions together?

c) Why did you make the decisions?

For example if patients’ reported they made the decisions about medication management they were asked, “Why did you make the decisions?”

5.1.2 Statistical and qualitative analyses

Descriptive analyses explored patients’ preference for and reported participation and knowledge of their medication management and where appropriate inferential statistics were used with chi-square comparisons. Patients’ preference for and reported participation in medication management displayed small numbers in some categories. As a result when comparing patient characteristics with patients’ preference for and reported participation in medication management patients’ preference for and reported participation was collapsed into two main categories: a) ‘clinicians solely make/made decisions’, and b) ‘patient involvement/involved in decisions’. The two categories ‘clinicians make/made decisions but consider/considered my opinion’, ‘I make/made decisions but consider/considered clinicians opinion’ and ‘I make/made
decisions’ were collapsed into ‘patient involvement/involved in decisions’ as these three categories all require patient involvement in decision making. This procedure was repeated for the results in the following three chapters.

The Charlson co-morbidity index (CCI) used to measure patients’ illness severity also displayed small numbers in some categories and were collapsed into three main categories as described by Birim and colleagues (2003). Each patient was categorised to one of the three co-morbidity grades: 0 = no risk; 1-4 = moderate risk; and 5 or more = high risk. Again this procedure was repeated for the results in the following three chapters.

Content analysis was undertaken to count, cluster and describe the frequency, duration and initiators of interactions between nurses and patients in relation to medication management during the observation period. Thematic analysis based on qualitative description was used to identify themes in the observational data and nursing focus group interviews. The research questions and data collection are summarised in Table 5.1.
Table 5.1 Summary of medication management research questions and data collection

<table>
<thead>
<tr>
<th>Research question</th>
<th>Data collected</th>
<th>Timing of collection</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does patients’ ability to provide a complete list, state the purpose and side effects of their cardiovascular medications change as a function of a surgical admission?</td>
<td>Patients stated medications&lt;br&gt;Patients stated purpose of medications&lt;br&gt;Patients stated side effects of medications</td>
<td>Preadmission (prior to hospitalisation for surgery) and Pre-discharge (within 24 hours prior to discharge)</td>
<td>Semi-structured patient interview</td>
</tr>
<tr>
<td>What is patients’ preference for participation in medication management?</td>
<td>Patient preference for participation in medication management&lt;br&gt;Patients’ reported reasons for their chosen preference and reported participation in medication management&lt;br&gt;Patients’ characteristics and knowledge of medication management at preadmission and their relationship with patient preference for participation in medication management</td>
<td>Preadmission (prior to hospitalisation for surgery)</td>
<td>Semi-structured patient interview-Control Preference Scale</td>
</tr>
<tr>
<td>Is patients’ experience of medication management commensurate with their preferred participation in medication management?</td>
<td>Patient reported participation in medication management&lt;br&gt;Patients stated reasons for their reported participation in medication management&lt;br&gt;Patients’ characteristics and knowledge of medication management pre-discharge and their relationship with patient reported participation in medication management</td>
<td>Pre-discharge (within 24 hours prior to discharge)</td>
<td>Semi-structured patient interview-Modified Control Preference Scale</td>
</tr>
<tr>
<td>How do clinicians facilitate patient participation in medication management?</td>
<td>All interactions between nurse and patient regarding medication management and Nurses perceptions of how they facilitate patient participation in medication management</td>
<td>Midway through data collection and Following data collation</td>
<td>Naturalistic observation and Nurse focus group interviews</td>
</tr>
</tbody>
</table>
5.2 Results

The primary aim of the analyses in this chapter was to explore patient participation in the context of medication management during a hospital admission for a cardiac surgical intervention. Patients’ knowledge of their cardiovascular medications is presented in 5.2.1. In section 5.2.2, patients’ preference for and reported participation in medication management are displayed. The way clinicians facilitate patient participation in medication management is described in 5.2.3.

5.2.1 Patients’ knowledge of their medications

All patients (n=98) had changes made to their pre-operative cardiovascular medications as a consequence of surgery. Prior to surgery 90.8% of patients were prescribed medications for the treatment or prevention of a cardiovascular condition. All patients (100%) were prescribed cardiovascular medications prior to discharge after surgery. The average number of cardiovascular medications prescribed were relatively constant between preadmission 3.4 (Min 0, Max 8) and at discharge 3.7 (Min 1, Max 7). Figure 7.1 displays the number of patients’ prescribed specific cardiovascular medications at preadmission and pre-discharge.

Following surgery patients were likely to have received new prescriptions for anti-platelet, anti-arrhythmic, cholesterol lowering, beta blocker, diuretic and anti-coagulant medications. Whereas prescriptions for ace
inhibitor, anti-angina, sartan and calcium channel blocker medications were more likely to be ceased.

Figure 5.1 The number of patients prescribed cardiovascular medications at preadmission and pre-discharge (n=98).

Pre-discharge there was minimal difference in prescribed cardiovascular medications as a function of type of surgery except for anti-coagulant medication. Following heart valve replacement surgery the majority of patients (84%, n=26) were prescribed an anti-coagulant. In contrast only five patients (16%) were prescribed anti-coagulant medication following coronary artery bypass graft surgery.
Table 5.2 displays patients’ knowledge of cardiovascular medications at preadmission and pre-discharge and, in the case of pre-discharge medications, according to whether prescriptions were new or pre-existing. More patients were able to list, state the purpose and side effects of their medications at preadmission than prior to discharge from hospital. Knowledge of side-effects was low at preadmission and, with three exceptions, patients could not state any side effects pre-discharge. Of the patients who could list their medications pre-discharge 59.6% (n=31) were patients continuing with the same medication and 40.3% (n=21) were patients commencing a new medication. Similarly, 57.4% (n=27) of patients could state the purpose of their medications when these medications were the same as their preadmission medications compared to 42.5% (n=20) of patients commencing a new medication. Importantly, of the 98 patients who were interviewed prior to discharge 12.2% (n=12) were considered to have cognitive impairment according to the six-item-screener.
Table 5.2 The proportion of patients who knew their cardiovascular medications according to status of prescription (existing or new) (n=98)

<table>
<thead>
<tr>
<th>Medication</th>
<th>Pre-admission</th>
<th>Pre-discharge</th>
<th>Knowledge of medication</th>
<th>Purpose</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-platelet</td>
<td>69 (70.4)</td>
<td>77 (78.6)</td>
<td>97.1</td>
<td>78.2</td>
<td>13.0</td>
</tr>
<tr>
<td>Cholesterol lowering</td>
<td>67 (68.4)</td>
<td>69 (70.4)</td>
<td>98.5</td>
<td>67.1</td>
<td>4.5</td>
</tr>
<tr>
<td>Beta blocker</td>
<td>47 (47.9)</td>
<td>67 (68.4)</td>
<td>93.6</td>
<td>59.5</td>
<td>0.0</td>
</tr>
<tr>
<td>Ace inhibitor</td>
<td>41 (41.8)</td>
<td>40 (40.8)</td>
<td>97.5</td>
<td>48.7</td>
<td>0.0</td>
</tr>
<tr>
<td>Anti-angina</td>
<td>36 (36.7)</td>
<td>5 (5.1)</td>
<td>91.6</td>
<td>61.1</td>
<td>16.6</td>
</tr>
<tr>
<td>Sartan</td>
<td>22 (22.4)</td>
<td>7 (7.1)</td>
<td>100</td>
<td>72.7</td>
<td>4.5</td>
</tr>
<tr>
<td>Calcium channel blocker</td>
<td>19 (19.4)</td>
<td>13 (13.2)</td>
<td>100</td>
<td>73.6</td>
<td>10.5</td>
</tr>
<tr>
<td>Diuretic</td>
<td>18 (18.3)</td>
<td>52 (53.0)</td>
<td>88.8</td>
<td>50.0</td>
<td>11.1</td>
</tr>
<tr>
<td>Anti-coagulant</td>
<td>12 (12.2)</td>
<td>31 (31.6)</td>
<td>91.6</td>
<td>75.0</td>
<td>33.3</td>
</tr>
<tr>
<td>Anti-arrhythmic</td>
<td>10 (10.2)</td>
<td>20 (20.4)</td>
<td>90.0</td>
<td>70.0</td>
<td>0.0</td>
</tr>
</tbody>
</table>
5.2.2 Patients’ preference for and reported participation in medication management

In this section, patients’ preference for and actual participation in medication management are displayed. Patients’ preference for participation was not compared with their actual participation as patient reports of who made the decisions in medication management were the same.

5.2.2.1 Patients’ preference for participation in medication management

Over three-quarters (75.3%, n=98) of patients’ preferred clinicians to make the decisions about their medication management, with most of the remaining patients (20.7%, n=27) preferring shared participation in decisions about their medication management (Figure 5.2).

Figure 5.2 Patients’ preference for participation in medication management (N=130)
Patients who preferred clinicians to make the decisions about their medication management (75.3%, n=98) described a lack of knowledge to participate. They stated,

- *My knowledge of medicines is nil.* (patient 11)
- *I’m not a chemist.* (patient 33)
- *If I knew that I wouldn’t need their help.* (patient 37)
- *I don’t know enough about it.* (patient 53)
- *I wouldn’t know to me they are all the same.* (patient 77)
- *They have better knowledge.* (patient 81)

Other patients in this category felt it should be left to the clinicians who know or whose role it is. Statements from these patients included,

- *They are the experts.* (patient 18)
- *Better listen as they are the experts.* (patient 21)
- *They know.* (patient 45)
- *...guided by the experts.* (patient 60)
- *They know medicines it’s their job.* (patient 22)
- *That is their job.* (patient 36)
- *They have to earn their pay.* (patient 50)
- *They have to, don’t they?* (patient 107)
Patients who preferred to share responsibility for decision making with clinicians (n= 27) described wanting to know more and be informed.

Like to know a little bit more. (patient 23)

I’d like to know what I am taking and why. (patient 72)

Want explanation if medications change. (patient 127)

Patients who preferred to make decisions about their medication management (n=3) described taking responsibility and maintaining a sense of control by following routine. These patients responded that,

They are my medicines so I have to take responsibility for them. (patient 27)

I’d rather handle my own. I’ve been doing it for years but in hospital they lock it in draws and you can’t touch them. (patient 62)

I know better what I take and when I take it. It makes it safer... (patient 65)

The relationship between patient characteristics and patients’ preference for participation in medication management were explored in order to determine if there were patterns in patients’ characteristics that may explain their preference for participation. These findings are presented in Table 5.3.

The majority (85%, n=20) of the non-English speaking patients’ preferred to leave decisions about medication management to clinicians ($X^2 (1, N = 130) = 6.1, p = 0.01$). Other findings relating to patient characteristics and
preference for participation in medication management were unremarkable.

Table 5.3 Patient characteristics and preferred participation in medication management (N=130)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Clinicians solely make decisions n=78</th>
<th>Patient involvement in decisions n=52</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>χ², df, p value</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td>1.08, 1, 0.29</td>
</tr>
<tr>
<td>Male (n=82)</td>
<td>52 (63.4)</td>
<td>30 (36.6)</td>
<td></td>
</tr>
<tr>
<td>Female (n=48)</td>
<td>26 (54.2)</td>
<td>22 (45.8)</td>
<td></td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
<td>0.20, 1, 0.65</td>
</tr>
<tr>
<td>≥ VCE* (n=47)</td>
<td>27 (57.4)</td>
<td>20 (42.6)</td>
<td></td>
</tr>
<tr>
<td>&lt; VCE* (n=83)</td>
<td>51 (61.4)</td>
<td>32 (38.6)</td>
<td></td>
</tr>
<tr>
<td>Language spoken at home</td>
<td></td>
<td></td>
<td>6.1, 1, 0.01</td>
</tr>
<tr>
<td>English (n=110)</td>
<td>61 (55.5)</td>
<td>49 (44.5)</td>
<td></td>
</tr>
<tr>
<td>Non English (n=20)</td>
<td>17 (85.0)</td>
<td>3 (15.0)</td>
<td></td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
<td></td>
<td>1.48, 1, 0.22</td>
</tr>
<tr>
<td>Australia (n=69)</td>
<td>38 (55.1)</td>
<td>31 (44.9)</td>
<td></td>
</tr>
<tr>
<td>Other (n=61)</td>
<td>40 (65.6)</td>
<td>21 (34.4)</td>
<td></td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
<td></td>
<td>0.34, 1, 0.55</td>
</tr>
<tr>
<td>Alone (n=49)</td>
<td>31 (63.3)</td>
<td>18 (36.7)</td>
<td></td>
</tr>
<tr>
<td>With partner (n=81)</td>
<td>47 (58.0)</td>
<td>34 (42.0)</td>
<td></td>
</tr>
<tr>
<td>Previous surgery</td>
<td></td>
<td></td>
<td>0.02, 1, 0.88</td>
</tr>
<tr>
<td>Yes (n=39)</td>
<td>23 (59.0)</td>
<td>16 (41.0)</td>
<td></td>
</tr>
<tr>
<td>No (n=91)</td>
<td>55 (60.4)</td>
<td>36 (39.6)</td>
<td></td>
</tr>
<tr>
<td>Charlson co-morbidity index</td>
<td></td>
<td></td>
<td>0.38, 2, 0.83</td>
</tr>
<tr>
<td>0 (n=63)</td>
<td>39 (61.9)</td>
<td>24 (38.1)</td>
<td></td>
</tr>
<tr>
<td>1-4 (n=41)</td>
<td>23 (56.1)</td>
<td>18 (43.9)</td>
<td></td>
</tr>
<tr>
<td>≥5 (n=26)</td>
<td>16 (61.5)</td>
<td>10 (38.5)</td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>66.5 (11.2)</td>
<td>64.1 (12.7)</td>
<td>1.09, 128, 0.27</td>
</tr>
</tbody>
</table>

*Victorian Certificate of Education. Equivalent to successful completion of high school; ≥, greater than or equal to; <, less than.
In order to explore if patients’ preference for participation in medication management was affected by their knowledge of medication management, as determined by their ability to provide a complete list, state the purpose and side effects of their current cardiac medications, these variables were compared (Table 5.4). Patients’ knowledge of their medications showed no statistically significant effect on patients’ preference for participation in medication management.

Table 5.4 Patients’ knowledge of medication management at preadmission and preference for participation in medication management (n=120)

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Clinicians solely make decisions n=74</th>
<th>Patient involvement in decisions n=46</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>List medications</td>
<td></td>
<td></td>
<td>X², df, p value</td>
</tr>
<tr>
<td>Yes (n=109)</td>
<td>65 (59.6)</td>
<td>44 (40.4)</td>
<td>2.08, 1, 0.14</td>
</tr>
<tr>
<td>No (n=11)</td>
<td>9 (81.8)</td>
<td>2 (18.2)</td>
<td></td>
</tr>
<tr>
<td>Purpose of medications</td>
<td></td>
<td></td>
<td>0.56, 1, 0.45</td>
</tr>
<tr>
<td>Yes (n=60)</td>
<td>35 (58.3)</td>
<td>25 (41.7)</td>
<td></td>
</tr>
<tr>
<td>No (n=60)</td>
<td>39 (65.0)</td>
<td>21 (35.0)</td>
<td></td>
</tr>
<tr>
<td>Side effects of medications</td>
<td></td>
<td></td>
<td>1.63, 1, 0.20</td>
</tr>
<tr>
<td>Yes (n=15)</td>
<td>7 (46.7)</td>
<td>8 (53.3)</td>
<td></td>
</tr>
<tr>
<td>No (n=105)</td>
<td>67 (63.8)</td>
<td>38 (36.2)</td>
<td></td>
</tr>
</tbody>
</table>
5.2.2.2 Patients’ reported participation in medication management

Pre-discharge, patients’ perception of who made decisions relating to medication management is reported in Figure 5.3. In response to the question “who made the decisions about medication management?” all patients (n=98) stated clinicians made decisions relating to medication management.

![Figure 5.3 Patients’ reported participation in medication management (n=98)](image)

Again, patients considered clinicians to have made the decisions about medication management because ‘they know’ and ‘they are the experts.’

- They are the experts. (patient 10)
- Leave it to the doctors and nurses. (patient 21)
- They are the academy. (patient 54)
- I’m not a doctor. (patient 115)
Patient characteristics and pre-discharge knowledge of medication management could not be compared with patients’ report of participation in medication management as all patients reported clinicians made decisions about their medication management. For this reason no further analysis of the data could be performed.

5.2.3 Nurses’ facilitation of patient participation in medication management

The average number of patients cared for by each nurse per shift was 3 (SD=0.5, Range, 2-4). Nurse and patient interactions were observed for a total of 96 hours. Most observations (90%) occurred within 48 hours of a patient’s transfer to the ward from the Intensive Care Unit. The remaining observations (n=5) were conducted between day 2 and day 6 of transfer. On average, nurses spent 17.4 (SD=13) minutes in a patient’s room. Of that time, an average of 3.8 (SD=3.5) minutes were spent in nurse and patient verbal interaction. Nurses entered patients’ rooms on 119 separate occasions during the observation period.

During the observation period medication related activity occurred in 29 of the 48 patients (60.4%). Medication related activity constituted any sort of exchange between a nurse and patient about medications. For these 29 patients, 33 separate medication-related activities were observed. Twenty nine (87.8%) of these activities were initiated by nursing staff and 4 (12.1%) were initiated by patients.
The naturalistic observations and the focus group interviews were designed to provide valuable contextual data to enhance understanding of patient participation in medication management. Data from these two sources, though limited, revealed a lack of engagement by nurses to involve patients in medication management. Nurses generally took a procedural, task-orientated approach to administration of medications missing opportunities to educate and promote patients’ participation. The nurses in the focus groups appeared to be disconcerted and surprised by the notion that they could do more to provide patients with meaningful information regarding their medication.

The major theme to emerge from these data identified a missing culture of care surrounding patient involvement in medication management.

5.2.3.1 Missed opportunities

Data from the observation phase were sparse but highlighted the limited time nurses interact with patients, and demonstrated many lost opportunities for effectively involving patients’ in their medication management. The majority of interactions confirmed that the task of administering prescribed medication was at the forefront of the nurses’ interactions. Little attention was given to educating or involving patients in their medications beyond the actual name or superficial purpose of the medicine:
...I have just got some lactulose for your bowels... (nurse 6)

Here’s some panadol to make you not feel too bad. (nurse 9)

I’m giving your potassium and metformin. (nurse 27)

The process was essentially task focused. As seen above, at times cursory explanations of the medication’s purpose were provided but patient understanding was not examined and there was no opportunity given for questions to be asked or concerns to be expressed. The same process held true even for those medications that would form the ongoing treatment plan for these patients once they were discharged:

I have one tablet for you. It’s only a little one, but don’t take it if you are still feeling nauseated. (nurse 30)

Ok. (patient 83)

It’s the fluid one, the Lasix. (nurse 30)

I have a small blue tablet for you. This is the one which helps the heart rate because it’s still a little bit fast. Alright? (nurse 17)

(Patient nods and takes tablet) (patient 73)

This is a small dose of the beta blocker that you were on. (nurse 40)

Yep. (patient 96)
You know they are just slowly reintroducing that now to help control the blood pressure a little bit.

(nurse 40)

Aha.

(patient 96)

While simple explanations were given at times, patients’ understanding of the information was rarely checked or time allowed for questions:

I’ve withheld your heparin dose this morning. We give you a little dose of heparin, ... a sort of blood thinner, and in simple terms just to stop any clots, DVTs (Deep Vein Thrombosis).

(nurse 27)

Mmmmm.

(patient 53)

Heard of DVTs? People on flights?

(nurse 27)

Mmmmm.

(patient 53)

Well, the heparin injection is there to.....just a prophylaxis to prevent that basically, until we get the drains and things out, so we withhold that, so I’ll give you that injection when I get back from my other patient.

(nurse 27)

On only one occasion in the observed period did a nurse attempt to confirm the patient’s level of understanding regarding his medication:

I know you said you have a fair idea of what warfarin is?

(nurse 7)

Yes, I’ve got the leaflet and the pharmacist said she would come back and see me this afternoon.

(patient 15)

Oh, good.

(patient 7)
Once a degree of understanding was confirmed however, the interaction was completed without further examination of the extent of the patient’s knowledge. The nurse in this interaction seemed satisfied that further education would be undertaken by the pharmacist. This willing transfer of responsibility to the pharmacist was accompanied by the notion that discussion of medications only occurred immediately prior to discharge:

*Should I have these things at home? (referring to tablets and medication script)*

(patient 88)

*A medication script? The pharmacist will do that when you are ready to go home.*

(nurse 16)

*The pharmacist will go through all your tablets, you will have changes to them now you’ve had surgery.*

(nurse 40)

*Yes, we’ll sort it all out and we’ll send you home with a list.*

(nurse 29)

The practice of waiting until discharge to engage patients in their medication management was also highlighted in the findings of chapter 4.

### 5.2.3.2 Failure to recognise opportunity

On the occasions that patients sought further information nurses appeared to not recognise the opportunity presented to inform and engage them in participatory medication management:
What is it? [referring to injection]  
*It is an antibiotic.*  
(nurse 1)

What’s the name?  
*Metoprolol, have you ever been on that? Or betaloc is its other name?*  
(nurse 27)

Hmmm.  
(patient 53)

What is potassium for?  
*It assists cells in the heart to contract. You look tired have a rest.*  
(nurse 3)

These data identify that the process of medication management was focused on administration and that little attempt was made to include patients in the process either by providing education or facilitating questions.

The observational data from the nurse-patient interactions were supported by two focus group interviews with nurses. In response to the direct question: How do you facilitate patient participation in medication management? The nurses in the first focus group described the process used to engage patients in medication management. These descriptions demonstrated an understanding that the process involved interaction and discussion with patients but also highlighted that patient participation was not a planned focused activity.
5.2.3.3 Ambivalence towards facilitating participation

When doing something like medication you say ‘this is your medication’ and ‘do you know what that is for’ because then it shows they are part of the process and shows their understanding. (nurse 3)

And also not just giving them medication and say ‘here take this just because’...hopefully they have an understanding of it and will hopefully carry on at home. (nurse 4)

So with a particular drug we will have a conversation of what it is and why it is important to know how much to take to control x, y, or z and when you go to the doctors they will want to know x, y and z. [We explain to them] why people would look to them for that information. So demonstrating why they need to be responsible for their own knowledge. (nurse 2)

The nurses outlined instances that supported patient participation in maintaining safe medication yet in doing so seemed unaware that they identified gaps in their own medication practices:

They could say I don’t take that tablet. They know their tablets for example and there’s a different one in there and they’ll say ‘what’s that? That’s not mine.’ Then that will make you double check, so it can improve it (their safety). (nurse 4)

And with allergies, I find myself saying we’ll give you this and they say no I’m allergic to that and we can try something else. (nurse 2)
Prior to the second focus group the nurses were provided with the preliminary findings of the study. The nurses appeared to be surprised by the data. In response to the study finding that only 8.2% of patients could list all their prescribed cardiovascular medications prior to admission and following surgery they discussed ideas that could facilitate patients’ involvement in medication management. It was clear that nurses did not normally consider patient participation in medication management as integral to their daily goals of care.

Indeed the discussions indicated ambivalence with words such as ‘maybe’ ‘could’ and ‘sometimes’ leading most responses:

*Maybe we should be more encouraging of them getting involved with their medications, because they’re the ones that are going to be managing it at home instead of us just taking over (medication management).* (nurse 5)

*Could they be doing it themselves (medication administration) with us just supervising?* (nurse 8)

*Sometimes the change in medications isn’t really communicated to the patient as well. Sometimes you might bring up, oh, this dose has been changed or you’ve been put on this medication and they (patients) have no idea.* (nurse 11)

*Also think about how we educate patients and how we do medications, are we actually going through the packaging with them by the bedside or are we just handling them a little container of pills and going this is for* (nurse 5)
this, this is for this, and this is for this. I’d probably forget what was what too if I just had heart surgery as well.

Nurses were then asked to consider other potential barriers to patients’ participating in their medication management. Nurses found several reasons to explain why the process of encouraging patients to participate was absent from their routine care delivery:

- A lot of them don’t remember (their medications). (nurse 1)
- A lot of them don’t realise why they are on something. And this may be the first time they have had the pressure of someone asking them to understand. (nurse 3)
- With the effects of bypass surgery they may not take everything in. (nurse 5)
- There is always a change in medications and the use of generic names versus brand names. Because there were some patients that we had that were used to the brand names and we were using generic names so that’s a major thing. (nurse 10)
- I’m not sure if there is a relationship between language barrier and medication knowledge as well. Because some patients would, if you were to discuss medications, not understand and explaining the medications would just highlight their difficulty in that area. So patients would just say ok, I’ll just leave it to the experts, rather than highlighting the reality that they’ve got difficulty in that area. (nurse 9)
Despite the fact that the patient group under discussion had a chronic cardiac condition that would require them to manage their own medications effectively once discharged, the nurses in this study did not appear to consider that there may be strategies that could be employed to assist patients overcome the identified barriers.
5.2.4 Summary of findings

Medication changes following surgery

Opportunity for in hospital education and participation to enhance post discharge adherence and therapeutic outcomes

Missed opportunities for participation

Facilitation by clinicians

Patients’ readiness for education and participation

Time
Low frequency, low duration interactions

Failure to recognise opportunity related to medication

Ambivalence towards facilitating

Preference for participation

Cognitive status

Physiological impact of major surgery

Figure 5.4 Model of medication management findings
5.3 Discussion

In this chapter, patient participation in the context of medication management during a hospital admission for cardiac surgery was explored. The purpose of the analyses reported in this chapter was to identify patients’ knowledge of medication management. Patients’ preferences for and experience of participation in medication management and the way clinicians facilitate patient participation in medication management was also examined.

All patients had changes to their cardiovascular medications as a function of their surgical admission. This involved commencing new and ceasing old medications. As a result their ability to provide a complete list, state the purpose and side effects of their current cardiac medications was lower than their preadmission knowledge. While medication change after cardiac surgery is not surprising, patients’ lack of knowledge and understanding about the change is unexpected given the many opportunities available to multiple clinicians to engage actively with patients regarding their medication management plan.

In relation to patient preference, over half of the patients preferred clinicians to solely make decisions about medication management. The majority of patients who preferred clinicians to solely make decisions did not speak English at home (85%). Despite 25% of patients preferring participation in medication management no patients reported involvement
in medication management. Findings indicate that clinicians did not
routinely take advantage of these opportunities to facilitate patient
participation in medication management while hospitalised and that
interactions that did take place were for the most part task focused.

Patients who preferred clinicians to make decisions about medications
described a lack of knowledge to participate or deference to the expertise
of the clinicians caring for them. This finding reflects an earlier study
investigating patients’ view of participation in medication related decisions
(Belcher et al., 2006), where patients described a trust and confidence in
the expertise of the doctor and an expectation that doctors should know
what they are doing. While some patients preferred to participate in
medication management, patients did not experience participation in a
way they could perceive or recognise it. A substantial mismatch between
stated preference and perceived role in treatment decision making has
previously been reported (Ford, Schofield, & Hope 2003).

Patients’ lack of knowledge about their prescribed medications and side
effects at the time of discharge is concerning given the chronic nature of
cardiovascular disease. This patient group is highly likely to require long
term medication treatment following discharge and are to be responsible
for managing their medications on a daily basis. The problem of inadequate
knowledge is two-fold. First, knowledge of medications has been identified
as an important factor in adhering to medications (Auyeung, Patel,
McRобbie, Weinman, & Davies, 2011; Cochrane, Mandal, Ledger-Scott, & Walker, 1992; Nikolaus et al., 1996) and second, poor knowledge of discharge medications may lead to hospital readmissions related to medication mismanagement (Cochrane et al., 1992; Edwards & Elwyn, 2006; Parkin, Henney, Quirk, & Crooks, 1976).

Two explanations for patients’ poor knowledge of their cardiovascular medications following surgery are possible. Patients may have received information regarding their discharge medication plan but at a time when they were not ready or were unable to comprehend the information as a result of cognitive and memory alterations that occur following this type of surgery. It is also possible they were never adequately informed of their planned discharge cardiovascular medications.

Patients’ readiness for information about their medications during hospitalisation requires careful deliberation as to timing and frequency of the information exchange. Several factors impinge on patients’ ability to retain information about their medications particularly during the early stages of recovery. Cardiac surgery is major and during the recovery period patients commonly report concerns about their comfort, specifically pain, sleep and anxiety (Doering, McGuire, & Rourke, 2002; Gardner, Elliott, Gill, Griffin, & Crawford, 2005; Goodman, 1997). The urgent need to focus on comfort needs may limit patients’ ability to receive and process information adequately during the acute phase after a surgical procedure.
Although cognitive decline following cardiac surgery has been reported (Newman et al., 2001; Phillips-Bute et al., 2006; Selnes et al., 1999) patients in this study demonstrated capacity to understand their medications at both preadmission and pre-discharge. At the time of their preadmission the majority of patients were able to list and state the purpose of their cardiovascular medications. The results of the cognitive assessment administered pre-discharge indicated that the majority of patients had no cognitive impairment suggesting that these patients may have been able to understand and remember their medications. Although patients received an individualised pharmacist review immediately prior to discharge, the majority of patients were unable to provide a complete list or state the purpose and side effects of their current cardiovascular medications at this time. It would seem that one review of medications with a pharmacist is insufficient for adequate patient understanding. A review of the literature indicates that a variety of interventions have been used to provide education to patients about their discharge medication yet inadequate knowledge has continued to be reported (Cline, Björck-Linné, Israelsson, Willenheimer, & Erhardt, 1999; Cumbler, Wald, & Kutner, 2010; Franks, Burton, & Simpson, 2005; Kripalani et al., 2012; Toren, Kerzman, Koren, & Baron-Epel, 2006; Ulfvarson, Bardage, Wredling, Von Bahr, & Adami, 2007). This anomaly indicates that the timing of such interventions must correspond with patients’ readiness to receive education. This aspect of patient participation in medication management is vital and requires
further investigation including comparison of an in-hospital and home-based interventions.

Likewise, the ability of clinicians to facilitate effective patient participation in medication management requires consideration. While nurses’ demonstrated understanding of the ways they could engage patients in medication management and appeared to appreciate the role patients could play in maintaining their own medication safety there was little evidence of nurses routinely engaging patients in their medication management or reinforcing their current knowledge. This mismatch between nurses’ discursive accounts of their practice and their practical demonstration of this activity is not an uncommon finding. Baker and colleagues (2001) found clinicians rated themselves highly in seeking to involve patients in physical therapy goal setting, however observations of practice indicated that few clinicians actually engaged patients in collaborative goal setting at any time.

An apparent barrier to nurses’ facilitation of medication management is the time they spent with patients. The reduced-length of stay associated with cardiac surgery limits the time available for education (Cowper et al., 2006). The way in which nurses interact with patients during this time may also be considered a barrier. Nurses spent little time interacting with patients despite entering patient rooms at least twice during the observation period. These factors impact on the provision of effective,
timely information and education. Time constraints have been identified as a major barrier to patient participation (Gravel et al., 2006; Timonen & Sihvonen, 2000). When constrained by time, nurses are likely to give priority to immediate physical care over psychosocial needs (Williams, 1998).

While nurses in this study did not identify time constraint as a barrier to the facilitation of patient participation in medication management they did outline a number of other perceived barriers to effective education and knowledge transfer. The effect of major surgery on memory retention was considered to be an obstacle to patient participation in medication management. There was no evidence to suggest the nurses ‘tested’ this assumption and it may be that they chose to omit attempts to facilitate patient participation in medication management based on either their assumption or experience that patients were physically or mentally unable to participate. According to the nurses in this study changes to medications and confusion created by medication trade and generic names posed another significant barrier to patient participation. Medication changes are not unexpected for patients who experience acute care, particularly following cardiac surgery (Grimmsmann, Schwabe, & Himmel, 2007). Rather than a barrier to patient participation in medication management, these changes can be considered an opportunity for patients to engage with multiple clinicians to learn more about their medication management so as to use medications therapeutically and safely. Given that medication
administration usually occurs three times each day in hospital and, based on median length of stay of eight days, there are at least 24 opportunities for clinicians to facilitate patients’ participation in their medication management. These interactions constitute opportunities or missed opportunities for nurses to take an explicit role in facilitating participation for long term health promotion. Nurses could therefore effectively partner with patients to optimise medication safety, assure medication accuracy and improve long term medication adherence at time of discharge.

5.4 Conclusion

Every patient had changes made to their prescribed medications as a function of their surgical admission. The time spent in acute care following surgical intervention presents patients with opportunities to learn about these changes to their medications in order to safely manage medications once discharged from hospital. Preadmission, the majority of patients were able to list and state the purpose of their cardiovascular medications whereas prior to discharge few patients were able to achieve this.

Several factors were identified that may affect the opportunity for patients to participate in medication management during hospitalisation. These were patients’ preference for participation, the short periods of time nurses spent with patients, the focus on the task of medication administration rather than on provision of education and promotion of independence, and nurses’ ambivalence about the benefits of providing
this education while patients are hospitalised. Indeed, further research is
needed to explore patients’ readiness and ability to learn about their
discharge medications at this time.

Increasing opportunities for patients to participate in medication
management is considered an important strategy for improving the safety
and quality of medication management. To achieve this strategy, a
fundamental shift in the way clinicians provide post-operative care is
required, specifically the involvement of patients in routine medication
administration. In Chapter 6, the results from the exploration of patient
participation in pain management are presented.
Chapter Six

Patient participation in pain management during an acute hospital admission

The under treatment of acute pain in hospital is a worldwide phenomenon and inadequate pain control following surgical procedures in particular has been reported consistently over the past several decades (Apfelbaum, Chen, Mehta, & Gan, 2003; Gramke et al., 2007; Maier et al., 2010; McKinley & Botti, 1991; Sommer et al., 2008). Inadequate pain control has been estimated to affect 75% of post-operative patients (Phillips, 2000). The under treatment of acute pain following surgery can lead to immediate post-operative complications (De Cosmo, Aceto, Gualtieri, & Congedo, 2009; Hanna, Murphy, Kumar, & Wu, 2009) and progression of acute to chronic pain (Lavand’homme, De Kock, & Waterloos, 2005; Şentürk et al., 2002). The problem of post-operative pain management is multi-factorial, however patient participation in the assessment and management of pain is a major element of strategies found to improve the quality of pain management (Gordon et al., 2005; Macintyre, Scott, Schug, Visser, & Walker, 2010).

Pain management is a particular aspect of acute care where patient participation is fundamentally linked to the accuracy of assessment and effectiveness of treatment. This aspect of care is poorly understood and
further, patient behaviours indicative of patient participation in pain management are not entirely clear.

In relation to pain management, The Joint Commission ‘Speak Up’ initiative recommends patients report pain, understand the different pain management treatments available including pharmacological and non-pharmacological and discuss concerns regarding pain treatment including reporting unrelieved pain (The Joint Commission, 2008). Implicit in this initiative is that patients should, at the very least, report their pain and understand treatment regimens available to them.

Behaviours indicative of facilitation of participation in pain management have been identified. These are the importance of educating patients about the value of their involvement in pain management, communicating aspects of pain and treatment effectiveness, such as presence of pain, severity and side effects of treatment, and providing patients with a degree of control over pain treatment (Gordon et al., 2005; Macintyre et al., 2010).

In this chapter, the findings presented relate to patient participation in the context of post-operative pain management during a hospital admission. Within this context, it was expected that clinicians would use interactions with patients as an opportunity to explain pharmacological treatment, the importance of pain control and the expected patient role of reporting the presence and severity of pain and the effectiveness of treatment. This opportunity is expected to enhance, through participation, patients’
knowledge of their pain management in order to facilitate participation in management in hospital and prepare patients to self-manage their pain following discharge. The specific research questions were:

a) Does patients’ understanding of their pain management change as a function of a surgical admission?

b) What is patients’ preference for participation in pain management?

c) Is patients’ experience of pain management commensurate with their preferred participation in pain management?

d) How do nurses facilitate patient participation in pain management in the post-operative context?

6.1 Methods

The methodological approach used to explore patient participation in pain management was described in detail in Chapter Three. Semi-structured patient interviews before surgery and prior to discharge from hospital provided data regarding patients’ knowledge of their pain management following surgery and their preference for and reported role in pain management. The Control Preference Scale (CPS) was used to elicit patients’ preference for participation in pain management. A modified version of this tool was used to elicit patients’ reported participation in pain management. Naturalistic observations based on the tenets of qualitative exploratory descriptive research were to elicit the clinical
practices and interactions between patients and clinicians that occur during pain management in the recovery period after surgery. Focus group interviews with nurses in the cardiac surgery ward explored their perceptions of the way patient participation in pain management is and can be facilitated in the post-surgical context. In the following section, the procedure and data collection relating to the description of patient participation in pain management is outlined.

6.1.1 Procedure and data collection

At preadmission the patient interviews were semi-structured and were guided by three main topics:

1. The importance of reporting pain
2. The importance of controlling pain
3. Pharmacological and non-pharmacological treatments available to manage pain

At the pre-discharge interview, these three general topics were explored again. Using the CPS, patients’ preference for participation in pain management was based on the question:

Who decides when and how to report, assess and treat pain?

Once patients ranked their preference for pain management they were asked:

Why did you rank your preference in this way?
This question was asked in order to understand the reason/s why patients chose a certain role. A similar question was asked to elicit patients reported participation. Patients were asked to choose one statement from the modified CPS that best described their involvement in pain management. Once patients reported their perception of who made the decisions they were asked either a, b or c depending on their CPS result:

d) Why did the clinicians make the decisions?
e) Why did you make the decisions together?
f) Why did you make the decisions?

For example if patients’ reported they made the decisions about pain management they were asked, “Why did you make the decisions?”

6.1.2 Statistical and qualitative analyses

Patients’ preference for and reported participation and knowledge of their pain management were explored using descriptive analyses. Where appropriate inferential statistics were used with chi-square comparisons.

Like medication management in the previous chapter, patients’ preference for and reported participation in pain management displayed small numbers in some categories. The categories were collapsed in the same manner as described in section 5.1.2 in chapter 5. Content analysis was undertaken to count, cluster and describe the frequency, duration and initiators of interactions between nurses and patients in relation to pain management during the observation period. Thematic analysis based on
qualitative description was used to identify themes in the observational data and nursing focus group interviews. The research questions and data collection are summarised in Table 6.1.
<table>
<thead>
<tr>
<th>Research question</th>
<th>Data collected</th>
<th>Timing of collection</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does patients’ understanding of pain management change as a function of a surgical admission?</td>
<td>Patients understanding of reporting pain</td>
<td>Preadmission (prior to hospitalisation for surgery) and Pre-discharge (within 24 hours prior to discharge)</td>
<td>Semi-structured patient interview</td>
</tr>
<tr>
<td></td>
<td>Patients understanding of the importance to control pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patients understanding of the pharmacological and non-pharmacological treatments available to manage their pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How do clinicians facilitate patient participation in pain management in the post-operative context?</td>
<td>All interactions between nurse and patient regarding pain management and Nurses perceptions of how they facilitate patient participation in pain management</td>
<td>Midway through data collection and Following data collation</td>
<td>Naturalistic observation and Nurse focus group interviews</td>
</tr>
<tr>
<td>What is patients’ preference for participation in pain management?</td>
<td>Patient preference for participation in pain management and Patients’ reported reasons for their chosen preference and reported participation in pain management and Patients’ characteristics and knowledge of pain management at preadmission and their relationship with patient preference for participation in pain management</td>
<td>Preadmission (prior to hospitalisation for surgery)</td>
<td>Semi-structured patient interview-Control Preference Scale</td>
</tr>
<tr>
<td>Is patients’ experience of pain management commensurate with their preferred participation in pain management?</td>
<td>Patient reported participation in pain management and Patients stated reasons for their reported participation in pain management and Patients’ characteristics and knowledge of pain management pre-discharge and their relationship with patient reported participation in pain management</td>
<td>Pre-discharge (within 24 hours prior to discharge)</td>
<td>Semi-structured patient interview-Modified Control Preference Scale</td>
</tr>
</tbody>
</table>
6.2 Results

The primary aim of the analyses in this chapter was to explore patient participation in the context of pain management during a hospital admission for cardiac surgery. Patients’ understanding of pain management and how clinicians facilitate patient participation in pain management is separated into two parts: the assessment of pain and the treatment of pain. As such, patients’ understanding of and the way clinicians perceive and facilitate patient participation in pain assessment is reported in 6.2.1. Patients’ understanding of and the way clinicians perceive and facilitate patient participation in the treatment of pain is displayed in 6.2.2. In section 6.2.3 patients’ preference for and reported participation in pain management are presented.

6.2.1 The assessment of pain

During the observation period, pain related activity was observed with 22 of the 48 patients (45.8%). Pain related activity constituted any sort of exchange between a nurse and patient about a patients’ pain or pain treatment. For these 22 patients one medication-related activity was observed for each patient. All of these activities were initiated by nursing staff.

Reporting pain is an aspect of pain management where patients should be encouraged to play an active role. The proportion of patients who would
and did report pain, reasons for reporting pain, participation in reporting pain and attitude related to reporting pain at preadmission and pre-discharge are displayed in Table 6.2. Patient reporting of pain remained constant between preadmission and pre-discharge. At preadmission all patients (100.0%) stated they would report their pain to a clinician. Pre-discharge, most patients reported pain to clinicians (96.0%). The four patients (4.1%) who did not report their pain following surgery stated they did not experience pain. Comfort was the main reason why patients would report (98.9%) and did report their pain (82.6%). At preadmission one patient stated he would report pain in order to avoid complications. Following surgery, pre-discharge, 17.3% of patients stated they reported pain to avoid complications relating to untreated pain. At preadmission the majority of patients stated they would actively report their pain by using their call bell (67.3%). In contrast, following surgery the majority of patients (74.5%) described reporting their pain by waiting for clinicians to ask them about their pain.

Over a quarter of patients (28.6%) verbalised reasons for not reporting pain at preadmission with statements such as ‘I will just put up with it’ and ‘I don’t want to complain.’ At this time 23.5% of all patients stated their pain would have to be very bad to report it. In comparison, prior to discharge less patients verbalised reasons for not reporting pain with 7.1% of patients’ verbalising ‘I don’t want to complain’, however 3% of patients still stated they waited for their pain to be very bad to report it.
Table 6.2 Patients’ knowledge of reporting pain at preadmission and pre-discharge (n=98)

<table>
<thead>
<tr>
<th></th>
<th>Preadmission (n=98)</th>
<th>Pre-discharge (n=98)</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Report pain</td>
<td>98 (100.0)</td>
<td>94 (95.9)</td>
</tr>
<tr>
<td>Reason for reporting pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comfort</td>
<td>97 (98.9)</td>
<td>81 (82.7)</td>
</tr>
<tr>
<td>Avoid complication</td>
<td>1 (1.1)</td>
<td>17 (17.3)</td>
</tr>
<tr>
<td>Participation in reporting pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>66 (67.3)</td>
<td>25 (25.5)</td>
</tr>
<tr>
<td>Passive</td>
<td>32 (32.7)</td>
<td>73 (74.5)</td>
</tr>
<tr>
<td>Attitude toward reporting pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stoic</td>
<td>28 (28.6)</td>
<td>7 (7.1)</td>
</tr>
<tr>
<td>Pain must be very bad to report</td>
<td></td>
<td>23 (23.5)</td>
</tr>
</tbody>
</table>

6.2.1.1 Nurses’ facilitation of patient participation in pain assessment

Despite equal questions about pain assessment and pain treatment in the nursing focus group interviews more discussion was generated from questions relating to pain assessment. Nurses highlighted the importance of patients’ involvement in their pain assessment:

*Patients need to explain the nature of pain, how it is radiating and the frequency of pain. I like patients to know and be aware of what kind of pain they are going through and informing them of the right person to tell, like the nursing staff.* (nurse 9)
There was also acknowledgement that patients may not voluntarily report pain despite being in pain. Encouraging patients to report their pain to staff was agreed by all nurses in the first focus group (n=4) to be an important role of the nurse in facilitating patients to participate in their pain management:

*Having patients engaging in their own pain management is really important because some patients will sit there in immense pain and not want to bother the nurse. You have to explain to patients that their role is to let us know that it is time for their tablets or let us know they are getting some pain and we need to give them something extra.* (nurse 2)

Facilitation of patients to report pain was illustrated by nurses during the observation period. Information provision from the nurse to the patient was observed twice. This information included,

*There is no point in being really stoical (about pain) and not saying anything to us because we will look at the drug chart and see what you need for pain relief. We don’t want you to get home and have problems with pain, so it is important to have a handle on your pain before we get to the discharge stage.* (nurse 3)

*What we need to do is make sure your pain medication is enough so you can do a good strong cough without fear every hour or so.* (nurse 4)
Most interactions (n=20) between nurse and patient regarding pain management during the observation period related to the assessment of pain. All interactions appeared purposeful with the majority of interactions (95.4%) beginning by nurses asking the patient if they had pain. An example of this was,

Have you got pain at the moment? (nurse 3)

Five times during the observation period nursing staff questioned patients in a more in depth manner to gain a clearer understanding of the patient’s pain at rest. This was achieved through use of the numeric pain rating scale (McCaffery & Pasero, 1999). Patients were asked to rate their pain on a scale of zero to ten. Zero = no pain, and ten = worst pain imaginable. As an example:

If zero is no pain and 10 the worst, where would you put yourself between zero and ten? (nurse 19)

Reference to patients’ previous pain rating was not observed. During pain interactions less than one-third of patients (n=7) were questioned about the relationship between their pain level and their ability to deep breath and cough. Although the numeric pain rating scale was the recommended tool for pain assessment in the pain management guidelines for the hospital where data collection was conducted it was not routinely used to assess patients’ pain.
6.2.2 The treatment of pain

Pharmacological intervention is the main treatment for pain following cardiac surgery. The proportion of patients who could state the use of and reason for multi-modal analgesia at preadmission and pre-discharge are displayed in Table 6.3. Approximately, one quarter of patients (28%) could state the use of multi-modal analgesia at preadmission whereas following surgery over half the patients could state the use of multi-modal analgesia (64%). In addition, patients displayed a higher level of understanding of the reason for multi-modal analgesia prior to discharge when compared with their preadmission understanding.

Table 6.3 Patients’ knowledge of multi-modal analgesia at preadmission and pre-discharge (n=98)

<table>
<thead>
<tr>
<th>Multi-modal analgesia for pain management</th>
<th>Preadmission (n=98)</th>
<th>Pre-discharge (n=98)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multi-modal analgesia for pain management</td>
<td>27 (27.6)</td>
<td>63 (64.3)</td>
</tr>
<tr>
<td>Reason for multi-modal analgesia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Analgesia works in different ways</td>
<td>11 (11.2)</td>
<td>28 (28.6)</td>
</tr>
<tr>
<td>Find what suits me</td>
<td>10 (10.2)</td>
<td>9 (9.2)</td>
</tr>
<tr>
<td>So I don’t exceed dose limit</td>
<td>1 (1.0)</td>
<td>3 (3.1)</td>
</tr>
</tbody>
</table>

Non-pharmacological treatments for pain play an important adjunct role in managing pain following surgery. Patients’ knowledge of the use of non-pharmacological interventions for pain at preadmission and pre-discharge is displayed in Table 6.4. The majority of patients were unable to state non-
pharmacological interventions at both preadmission (71.4%) and pre-discharge (70.3%). Prior to surgery, meditation/prayer (9.2%) and positioning (7.1%) were the most cited non-pharmacological interventions for the management of pain. Following surgery, patients reported positioning (12.2%) and a rolled towel for chest support (8.2%) as the main interventions to manage pain.

Table 6.4 Patients’ knowledge of non-pharmacological interventions for pain at preadmission and pre-discharge (n=98)

<table>
<thead>
<tr>
<th>Type of non-pharmacological intervention</th>
<th>Preadmission (n=98)</th>
<th>Pre-discharge (n=98)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-pharmacological interventions for pain management</td>
<td>28 (28.6)</td>
<td>29 (29.7)</td>
</tr>
<tr>
<td>Rolled towel for chest support</td>
<td>1 (1.0)</td>
<td>8 (8.2)</td>
</tr>
<tr>
<td>Music/Television</td>
<td>3 (3.1)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Heat</td>
<td>3 (3.1)</td>
<td>3 (3.1)</td>
</tr>
<tr>
<td>Positioning</td>
<td>7 (7.1)</td>
<td>12 (12.2)</td>
</tr>
<tr>
<td>Massage/touch</td>
<td>3 (3.1)</td>
<td>3 (3.1)</td>
</tr>
<tr>
<td>Meditation/prayer</td>
<td>9 (9.2)</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>Sleep</td>
<td>2 (2.0)</td>
<td>1 (1.0)</td>
</tr>
</tbody>
</table>

6.2.2.1 Nurses’ facilitation of patient participation in pain treatment

Nurses’ facilitation of patient participation in pain treatment was limited to two comments by one nurse during the first focus group interview. The nurse highlighted the importance of patients’ involvement in their pain treatment:
For pain they should know their analgesic regime, so they understand what they need and how long they’ll need it and what to do if they don’t have pain.

This nurse further explained how she specifically involves patients in their pain treatment:

I would usually give them one medication but say they’ve got two available (oxycontin and paracetamol). I would let them know how long it will take to work and if they’ve still got pain after that then explain you’ve got extra things they can take. So they know they have that option.

6.2.3 Patients’ preference for and reported participation in pain management

In this section, patients’ preference for and actual participation in pain management are displayed. Patients’ preference for participation was compared with their actual participation to examine if patients’ preference for involvement was achieved.

6.2.3.1 Patients’ preference for participation in pain management

Patients’ preference for participation in pain management was measured using the Control Preference Scale (CPS) (Degner, Sloan & Venkatesh, 1997). Many patients (63.8%) preferred to share the decisions about their
pain management with clinicians (Figure 6.1). A minority of patients (n=8, 6.1%) preferred to make their own decisions relating to pain management.

![Pain management chart](attachment:chart.png)

Figure 6.1 Patients’ preference for participation in pain management (N=130)

Patients who preferred clinicians to make all the decisions about their pain management appeared to interpret the term ‘pain management’ to be exclusively ‘medication administration’ for pain. As such, they described a lack of knowledge to participate and believed clinicians were the experts whose role it was to make the decisions.

- *My knowledge of controlling pain is nil.* (patient 11)
- *Don’t know how much I need and if I need it.* (patient 30)
- *What would I know?* (patient 14)
- *For me to start demanding stuff and not knowing what I am talking about....* (patient 33)
Patients who preferred to share responsibility for decision making with clinicians about their pain management described wanting to know more and be informed. Patients described this as,

- *Cos it’s my pain I’d like to be involved* (patient 37)
- *….like to know what’s going on and know what I feel like* (patient 12)
- *Like to discuss with health care professionals* (patient 61)
- *Want to be included* (patient 15)

Patients who preferred to make decisions about their pain management described taking responsibility and maintaining a sense of control by following routine. These patients responded that,

- *I know what pain I have.* (patient 22)
- *I have a good knowledge of own pain.* (patient 126)
- *I know when I’m in pain.* (patient 94)
- *Want to be included.* (patient 15)
- *I know what is best for me.* (patient 116)
- *I understand better.* (patient 53)
Patient characteristics were compared with patients’ preference for participation in pain management in order to determine if patients’ preference was affected by their characteristics. These findings are presented in Table 6.5.

Patients’ co-morbid illness severity, as measured by the Charlson co-morbidity index, revealed a statistically significant ($X^2 (1, N = 130) = 12.6$, $p=0.002$) association with patients’ preference for participation in pain management. The majority of patients’ with no (85.7%) or a low to medium (90.2%) co-morbidity index preferred involvement in decisions regarding their pain management. In contrast close to half of patients (42.8%) with a high co-morbidity index preferred to leave clinicians to solely make decisions about pain management.
Table 6.5 Comparison of patient characteristics with preferred participation in pain management (N=130)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Clinicians solely make decisions n=24</th>
<th>Patient involvement in decisions n=106</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>X², df, p value</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td>0.76, 1, 0.38</td>
</tr>
<tr>
<td>Male (n=82)</td>
<td>17 (20.7)</td>
<td>65 (79.3)</td>
<td></td>
</tr>
<tr>
<td>Female (n=48)</td>
<td>7 (14.6)</td>
<td>41 (85.4)</td>
<td></td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
<td></td>
<td>0.01, 1, 0.75</td>
</tr>
<tr>
<td>≥ VCE* (n=47)</td>
<td>8 (17.0)</td>
<td>39 (83.0)</td>
<td></td>
</tr>
<tr>
<td>&lt; VCE* (n=83)</td>
<td>16 (19.3)</td>
<td>67 (80.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Language spoken at home</strong></td>
<td></td>
<td></td>
<td>0.67, 1, 0.41</td>
</tr>
<tr>
<td>English (n=110)</td>
<td>19 (17.3)</td>
<td>91 (82.7)</td>
<td></td>
</tr>
<tr>
<td>Non English (n=20)</td>
<td>5 (25.0)</td>
<td>15 (75.0)</td>
<td></td>
</tr>
<tr>
<td><strong>Country of birth</strong></td>
<td></td>
<td></td>
<td>0.11, 1, 0.73</td>
</tr>
<tr>
<td>Australia (n=69)</td>
<td>12 (17.4)</td>
<td>57 (82.7)</td>
<td></td>
</tr>
<tr>
<td>Other (n=61)</td>
<td>12 (19.7)</td>
<td>49 (80.3)</td>
<td></td>
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<tr>
<td><strong>Living arrangement</strong></td>
<td></td>
<td></td>
<td>0.19, 1, 0.65</td>
</tr>
<tr>
<td>Alone (n=49)</td>
<td>10 (20.4)</td>
<td>39 (79.6)</td>
<td></td>
</tr>
<tr>
<td>With partner (n=81)</td>
<td>14 (17.3)</td>
<td>67 (82.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Previous surgery</strong></td>
<td></td>
<td></td>
<td>0.78, 1, 0.37</td>
</tr>
<tr>
<td>Yes (n=39)</td>
<td>9 (23.1)</td>
<td>30 (76.9)</td>
<td></td>
</tr>
<tr>
<td>No (n=91)</td>
<td>15 (16.5)</td>
<td>76 (83.5)</td>
<td></td>
</tr>
<tr>
<td><strong>Charlson co-morbidity index</strong></td>
<td></td>
<td></td>
<td>12.6, 2, 0.002</td>
</tr>
<tr>
<td>0 (n=63)</td>
<td>9 (14.3)</td>
<td>54 (85.7)</td>
<td></td>
</tr>
<tr>
<td>1-4 (n=41)</td>
<td>4 (9.8)</td>
<td>37 (90.2)</td>
<td></td>
</tr>
<tr>
<td>≥5 (n=26)</td>
<td>11 (42.8)</td>
<td>15 (57.7)</td>
<td></td>
</tr>
</tbody>
</table>

|                                | Mean (SD)                             | Mean (SD)                             | t, df, p value |
|                                |                                       |                                       | 1.8, 128, 0.07 |
| Age (n=130)                    | 69.5 (10.5)                           | 64.7 (12.0)                           |           |

*Victorian Certificate of Education. Equivalent to successful completion of high school; ≥, greater than or equal to; <, less than.
In order to determine if patients’ preference for participation in pain management was affected by their understanding of pain management, these variables were compared (Table 6.6). Patients’ understanding of their pain management showed no statistically significant effect on patients’ preference for participation in pain management.

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Clinicians solely make decisions n=24</th>
<th>Patient involvement in decisions n=106</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Importance of pain control to avoid complication</td>
<td></td>
<td></td>
<td>0.22, 1, 0.63</td>
</tr>
<tr>
<td>Yes (n=1)</td>
<td>0 (0.0)</td>
<td>1 (100.0)</td>
<td></td>
</tr>
<tr>
<td>No (n=129)</td>
<td>24 (18.6)</td>
<td>105 (81.4)</td>
<td></td>
</tr>
<tr>
<td>Report pain</td>
<td></td>
<td></td>
<td>1.90, 1, 0.16</td>
</tr>
<tr>
<td>Yes (n=122)</td>
<td>24 (19.6)</td>
<td>98 (80.4)</td>
<td></td>
</tr>
<tr>
<td>No (n=8)</td>
<td>0 (0.0)</td>
<td>8 (100.0)</td>
<td></td>
</tr>
<tr>
<td>Non-pharmacological management</td>
<td></td>
<td></td>
<td>1.1, 1, 0.27</td>
</tr>
<tr>
<td>Yes (n=33)</td>
<td>4 (12.1)</td>
<td>29 (87.9)</td>
<td></td>
</tr>
<tr>
<td>No (n=97)</td>
<td>20 (20.6)</td>
<td>77 (79.4)</td>
<td></td>
</tr>
</tbody>
</table>
6.2.3.2 Patients’ reported participation in pain management

Patients’ perception of who made decisions relating to pain management is reported in Figure 6.2. The majority of patients (64.3%) stated they shared responsibility for decisions relating to pain management.

Figure 6.2 Patients’ reported participation in pain management (n=98)

While the majority of patients reported shared responsibility for decisions about pain management, this involvement appeared to be related to being involved in reporting the level of their pain but not in the timing of pain relief and what medication they received. This is evidenced by statements such as,

*They would ask pain level; but just tell me what they will give me.* (patient 83)

*They asked level of pain but made decision about what to have.* (patient 34)

*They have asked me about level of pain not asked me what I would like.* (patient 54)
Patients’ experience of pain management was compared with their preferred participation in pain management (Table 6.7). For patients who preferred clinicians to make all decisions regarding pain management, 68.2% (n=15) reported involvement in decisions. The majority of patients who preferred participation in pain management decisions, 84.2% (n=64) experienced participation in pain management. However 12 patients (15.8%) preferring involvement in decisions reported no involvement.

Table 6.7 Patients’ preference for participation in pain management and reported participation in pain management (n=98)

<table>
<thead>
<tr>
<th>Preference for participation</th>
<th>Reported participation</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Clinicians solely made decisions (n=19)</td>
<td>Patients involved in decisions (n=79)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td>Clinicians solely make decisions</td>
<td>7 (7.1)</td>
<td>15 (15.3)</td>
<td></td>
</tr>
<tr>
<td>Patient involvement in decisions</td>
<td>12 (12.2)</td>
<td>64 (65.3)</td>
<td></td>
</tr>
</tbody>
</table>

Patient characteristics were compared with patients’ reported participation in pain management in order to determine if patients’ reported involvement was affected by their characteristics. These findings are presented in Table 6.8.
Patients born overseas were more likely to report clinicians solely made decisions regarding their pain management (34.1%) than patients who
were born in Australia (7.4%). The majority of patients who spoke English at home reported involvement in decisions with clinicians (85.7%). In contrast, only half of non-English speaking patients (50.0%) reported involvement in decisions with clinicians.

In order to determine if patients’ reported participation in pain management was affected by their understanding of pain management pre-discharge these variables were compared (Table 6.9). Patients’ understanding of their pain management showed no statistically significant effect on patients’ reported participation in pain management.
Table 6.9 Comparison of patients’ knowledge of pain management pre-discharge with reported participation in pain management (n=98)

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Clinicians solely made decisions n=19</th>
<th>Patient involved in decisions n=79</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>X², df, p value</td>
</tr>
<tr>
<td>Importance of pain control to avoid complication</td>
<td></td>
<td></td>
<td>0.04, 1, 0.84</td>
</tr>
<tr>
<td>Yes (n=17)</td>
<td>3 (17.6)</td>
<td>14 (82.4)</td>
<td></td>
</tr>
<tr>
<td>No (n=81)</td>
<td>16 (19.7)</td>
<td>65 (80.3)</td>
<td></td>
</tr>
<tr>
<td>Report pain</td>
<td></td>
<td></td>
<td>0.08, 1, 0.77</td>
</tr>
<tr>
<td>Yes (n=94)</td>
<td>18 (19.1)</td>
<td>76 (80.9)</td>
<td></td>
</tr>
<tr>
<td>No (n=4)</td>
<td>1 (25.0)</td>
<td>3 (75.0)</td>
<td></td>
</tr>
<tr>
<td>Non-pharmacological management</td>
<td></td>
<td></td>
<td>2.1, 1, 0.14</td>
</tr>
<tr>
<td>Yes (n=29)</td>
<td>3 (10.3)</td>
<td>26 (89.7)</td>
<td></td>
</tr>
<tr>
<td>No (n=69)</td>
<td>16 (23.1)</td>
<td>53 (76.9)</td>
<td></td>
</tr>
</tbody>
</table>
6.2.4 Summary of findings

Patients experience pain following surgery

Opportunity for in hospital education and participation to enhance quality of pain management both during admission and post discharge

Majority of patients prefer involvement and have cognitive ability to participate in pain management

Facilitation of pain management by nurses

Nurses involve patients in pain assessment via patient report of pain but not in the treatment of pain

Time
Low frequency, low duration interactions

Figure 6.3 Model of pain management findings
6.3 Discussion

In this chapter, patient participation in the context of pain management during a hospital admission for a cardiac surgery was explored. The purpose of the analyses reported in this chapter was to identify patients’ understanding of pain management and the way clinicians facilitate patient participation in pain management. Patients’ preferences for and experience of participation in pain management was also examined.

Most patients preferred and reported some level of involvement in their pain management albeit that this was largely limited to pain assessment. Generally, patients’ knowledge of pain management was higher after their surgical admission suggesting that they had participated in their management to some extent. There were many instances where opportunities to participate in pain management were missed either because clinicians failed to facilitate participation or patients did not actively seek involvement.

The time nurses spend with patients provides a window of opportunity for patients to gain knowledge and understanding about their pharmacological treatment, the importance of pain control and the expected patient role of reporting the presence and severity of pain and the effectiveness of treatment. Nurses entered patients’ rooms an average of 2.4 times in the two-hour observation periods. This represented 15% of the total observed time, however only 3% of the observation time was spent in actual nurse-
patient interactions. These low frequency, low duration interactions are a clear barrier to patient participation in pain management. The limited time clinicians spend with patients is consistently reported to constrain patient involvement in care (Fraenkel & McGraw, 2007; Gravel et al., 2006; Sainio, et al., 2001; Timonen & Sihvonen, 2000; Wellard et al., 2003).

The importance of this small window of opportunity for patient involvement is heightened when viewed in conjunction with patients’ knowledge and behaviours relating to pain management. Especially since most patients (75%) did not actively report pain but waited for nurses to ask them if they were experiencing pain. Overall, patients displayed a greater understanding of their role in pain management following their surgical admission in terms of reporting pain, attitude to reporting pain and the use of multi-modal analgesia. However, the majority of patients still did not know the importance of actively reporting pain to avoid complications (83%) and could not describe the use of non-pharmacological interventions (70%). Failure to understand the importance of controlling pain to prevent complications may deter patients from actively reporting pain especially when patients had the propensity to wait for pain to be severe before reporting it.

Patients’ understanding of their care has previously been linked to their involvement in care (Belcher et al., 2006; Jerant et al., 2005; O’Leary et al., 2010). Inadequate understanding of pain management during
hospitalisation may impede patients’ ability to participate in pain management and lead to the under treatment of their pain. Poorly controlled pain in the context of cardiac surgery increases the risk of in-hospital surgical complications manifesting as ineffective breathing patterns and pulmonary morbidity (Milgrom et al., 2004; O'Connor, 1999) impeded mobility and prolonged recovery (Mueller et al., 2000). While it is assumed that following discharge patients will manage their own pain (Leegard, et al., 2008) poorly controlled pain in the immediate post-surgery period and ongoing inadequate treatment may increase the risk of developing irreversible chronic pain (Lahtinen et al., 2006).

In relation to who decides when and how to report, assess and treat pain the majority of patients preferred to share responsibility for decisions about pain management. While there is increased interest in patients’ preferences regarding specific aspects of pain management (Borders, Xu, Heavner, & Kruse, 2005; Gan et al., 2004; Martin & Spirig, 2006) no other studies were identified examining patients’ preference for participation in general decisions about pain management. Studies from other contexts support the findings of this study where the majority of patients preferred to share responsibility for decision making in the contexts of hypertension, chronic illness, and breast cancer (Charles, Gafni, & Whelan, 2004; Clark et al., 2009; Strull, Lo, & Charles, 1984). What remains unclear is patients’ preference for participation in the varying aspects of pain management.
Patients’ interpretation of what is meant by pain management may influence their preference for involvement.

Patients may have preferred involvement in reporting pain when they could identify and understand the role they could play in this aspect of pain management. Patients who preferred clinicians to make decisions about pain management appeared to interpret pain management to mean ‘choice of medication’ for pain as they described a lack of knowledge as the reason for not participating. Further investigation is required to explore patients’ preference for participation in different aspects of pain management such as self-administration of analgesics.

The majority of patients reported sharing responsibility for pain management. In total, 72% of patients perceived they achieved their preferred role in pain management decisions, noting that this involvement was largely limited to pain assessment. This is similar to previous findings examining patients’ preference for and reported participation in treatment decisions where 61% of patients achieved their preferred involvement (Ford et al., 2003). Unique to this study, of the patients who preferred clinicians to make all the decisions about pain management, 68% reported some involvement in decisions suggesting that the very nature of pain requires patients to be involved.

Patients with a high co-morbidity illness severity were more likely to prefer to leave decisions about pain management to clinicians. Patients with a
higher illness severity have consistently preferred a more passive role in participation in health care (Arora & McHorney, 2000; Beaver et al., 1996; O'Donnell & Hunskaar, 2007; O'Donnell et al., 2007). This may relate to their inability to participate or their confidence in clinicians from previous exposure to health care.

Patients born overseas and who did not speak English at home were also more likely to report clinicians made the decisions about pain management. These factors are indicators of a persons’ cultural background. People considered to be from the cultural minority have previously preferred and demonstrated a more passive role in treatment decisions than the cultural majority (O'Donnell et al., 2007; Schouten et al., 2007; Street et al., 2005). This may account for less involvement reported by patients who speak non-English and are born overseas.

Despite the limited time clinicians spent with patients, the nature of these interactions is important to our understanding of how clinicians perceive and facilitate patient participation in pain management. Pain assessment involved use of the numerical pain rating scale in less than 25% of the assessments observed. These findings are not unique, Ene and colleagues (Ene, Nordberg, Bergh, Johansson, & Sjöström, 2008) revealed similar findings in a cross sectional descriptive study of 218 patients and 41 nurses evaluating pain levels reported by patients with those documented by
ward nurses. They found that 40% of nurses did not use a validated tool to assess patients’ pain or assess pain at both rest and during activity.

When clinicians facilitated patient involvement in pain management it appeared to be focused on assessment of pain and not in the treatment of pain. Patient participation in decisions about pain treatment has been shown to result in decreased reports of moderate to severe pain (Hanucharurnkui & Vinya-nguag, 1991), frequency of pain (Borders et al., 2005) and promote effective pain control (Manias & Williams, 2008) leading to a quicker and less complicated recovery. Clinicians may not involve patients in decisions about the treatment of pain because this aspect of pain management has traditionally been considered a role of the clinician (Leegard et al., 2008).

Patients have the potential to play a clearer role in the treatment of pain through self-management of pain medications during hospitalisation. Self-administration of pain medicines following labour has been shown to reduce women’s use of medications and increase satisfaction with pain relief (East, Dubé, & Perreault, 2007). Self-administration of pain medicines following surgical intervention is an option requiring further exploration.

If medication administration for pain occurred at least four times every day while patients were hospitalised then, based on the median length of stay, this could equate to at least 32 opportunities for clinicians to facilitate patient participation in pain management. Specifically, these were
opportunities for educating patients about when and how to use analgesics in order to adequately control pain and should extend to the use of non-pharmacological methods to treat pain. Failure to have these discussions are missed opportunities to partner with patients to optimise pain outcomes, ensure patients have adequate knowledge of pain treatment once they go home and could have long term consequences.

6.4 Conclusion

Most patients preferred and reported involvement in pain management during their hospital admission. Patients’ preference for involvement for the majority of patients was commensurate with their experience of participation. Overall patients’ knowledge of pain management increased as a function of surgical admission however they continued to display deficits relating to the need to report pain to avoid complications and non-pharmacological interventions. Participation in pain management was limited to pain assessment. Nurses appeared to involve patients in the assessment of pain but not in the treatment of pain. This restriction in participation in pain management was reported by patients and noted in the observation periods.

The findings of this study suggest there are missed opportunities to facilitate patient participation in pain management with consequences for the preparation of patients to manage their pain following discharge where they are responsible for making decisions about what pain treatment to
implement. In the following chapter, patient participation in post-operative pulmonary management is explored.
Cardiac surgery, that requires bypass, is associated with decreased pulmonary residual capacity, diaphragmatic dysfunction, impaired gas exchange and alteration in pulmonary defence mechanisms exposing patients to an increased risk of pulmonary complications (Duggan & Kavanagh, 2005). Pulmonary complications include atelectasis and pneumonia and account for a substantial increase to length of stay, associated cost and morbidity and mortality (Shander et al., 2011).

Pulmonary complications are considered modifiable adverse events and the incidence of pulmonary complications is used as a measure of the quality and safety of care (Eber, Laxminarayan, Perencevich, & Malani, 2010; Shander et al., 2011). Eber and colleagues (2010) estimated attributable hospital length of stay, hospital costs and crude in-hospital mortality of pneumonia from 69 million discharge records using a multivariate matched analysis. The outcomes were calculated as the difference between outcome of the case and the mean outcome in all matched controls. Eber et al. (2010) found attributable mean length of stay was 14 days, hospital costs were US$46,400 and crude in-hospital mortality was 11.4% for pneumonia cases.
Various interventions have been recommended to decrease the risk of pulmonary complications following surgery (Lawrence, Cornell, & Smetana, 2006; Shander et al., 2011). One intervention is patient-performed pulmonary exercises in the form of deep breathing and coughing where the goals are the improvement of pulmonary function via lung expansion and enhanced mucous clearance (Temporelli & Ambrosetti, 2011). In recent years, the benefit of performing prophylactic, voluntary pulmonary exercises had been questioned (Brasher, McClelland, Denehy, Story, & Yang, 2003; Filbay, Hayes, & Holland, 2012; Johnson, Kelm, Thomson, Burbridge, & Mayers, 1996). In this context of uncertainty about effectiveness, yet a long tradition and strong physiological rationale for treatment, there is needed greater clarity of how patients participate, or are facilitated to participate, in pulmonary exercises after surgery.

While deep breathing and coughing makes sense from a physiological perspective (Temporelli & Ambrosetti, 2011) the evidence to support pulmonary exercises in the post-operative context is equivocal, despite two comprehensive reviews (Slade, 2013; Pasquina et al., 2003) examining the use respiratory physiotherapy for reducing pulmonary complications following cardiac surgery.

The ambiguous findings are due to issues of rigour associated with the studies reviewed. These issues relate to small numbers of participants, variations in the actual intervention including the amount, timing and
depth of breathing and coughing, measurement of performance in the intervention and inconsistency in the definition of pulmonary complications as the outcome measure (Brasher et al., 2003; Mendes et al., 2010; Westerdahl et al., 2005).

Regardless of the equivocal evidence from a physiological perspective, deep breathing and coughing remains a common respiratory intervention following cardiac surgery worldwide (Agostini et al., 2012; Overend et al., 2010; Tucker et al., 1996; Westerdahl & Olsén, 2011). The performance of voluntary deep breathing and coughing necessitates patient participation in particular because of the high frequency of exercises that is required, and because the exercises can exacerbate wound pain. In this context, patients must assume responsibility to know how to correctly perform the exercises and commit to undertaking the exercises on a very frequent basis without regular clinician input. Patients must also ensure they have adequate pain relief in order to undertake the exercises.

Nurses facilitate deep breathing and coughing by explaining their importance, ensuring that patients use the correct technique, and by providing adequate pain relief (Agostini et al., 2012; Canet & Mazo, 2010; Overend et al., 2010; Westerdahl & Olsén, 2011). Facilitation of deep breathing and coughing exercises requires nurses to prioritise this intervention in care delivery within a context of ambiguity about its effectiveness. Another potential mediating factor is the blurred role
between nurses and physiotherapists in facilitating deep breathing and
coughing exercises in general, and in particular, after hours. Whether or
not patients are assisted to perform voluntary exercises is likely to vary
according to time of day, patients’ condition, staffing levels and expertise
(Stiller, 2000), role description and whether or not nurses believe that the
exercises are worthwhile.

Behaviours proposed to be indicative of patient participation in voluntary
pulmonary exercises and nurses’ facilitation of these exercises were: 1)
patients’ preference and reported participation in deep breathing and
coughing exercises; 2) patients’ knowledge of the importance of deep
breathing and coughing exercises; 3) demonstration by nurses, and use by
patients, of the correct technique when performing deep breathing and
coughing exercises, and 4) the administration of adequate analgesia by
nurses.

In this chapter, the findings presented relate to patient participation in the
context of voluntary deep breathing and coughing exercises during a
hospital admission for cardiac surgery. The specific research questions
were:

a) Do patients know the importance of deep breathing exercises
and coughing, the technique for performing deep breathing
exercises and coughing, and the need for adequate pre-exercise
analgesia?
b) What is patients’ preference for deciding the amount and frequency of deep breathing and coughing exercises?

c) Is patients’ experience of deep breathing and coughing exercises commensurate with their preferred participation in deep breathing and coughing exercises?

d) How do nurses facilitate patient participation in deep breathing exercises and coughing?

7.1 Methods

The methodological approach used to explore patient participation in pulmonary management was described in detail in Chapter Three. Semi-structured patient interviews before surgery and prior to discharge from hospital provided data regarding patients’ knowledge of deep breathing and coughing exercises and their preference for and reported role in these exercises. The Control Preference Scale (CPS) and a modified version were again used to elicit patients’ preference and reported participation in this aspect of pulmonary management. Naturalistic observations were used to understand the clinical practices surrounding pulmonary management. Focus group interviews explored nurses’ perceptions of how they facilitate patient participation in deep breathing and coughing exercises. In the following section, the procedure and data collection relating to the description of patient participation in deep breathing and coughing exercises is outlined.
7.1.1 Procedure and data collection

Questions that provided structure for the interviews were guided by three main topics:

1. The technique for deep breathing and coughing
2. The importance of deep breathing and coughing
3. The requirement for adequate pain relief in order to deep breathe and cough

Using the CPS, patients’ preference for participation in deep breathing and coughing exercises was based on the question:

Who decides the frequency and amount of deep breathing and coughing exercises to undertake?

Once patients ranked their preference for this aspect of pulmonary management they were asked:

Why did you rank your preference in this way?

This question was asked in order to understand the reason/s why patients chose a certain role to identify barriers and facilitators of patient participation in pulmonary management. A similar question was asked to elicit patients reported participation. Patients were asked to choose one statement from the modified CPS that best described their actual involvement in deep breathing and coughing exercises and provide a reason for their answer.
7.1.2 Statistical and qualitative analyses

The statistical and qualitative analyses used in the chapter were consistent with the analyses described in sections 5.1.2 and 6.1.2 in the previous two result chapters. The research questions and data collection are summarised in Table 7.1.
Table 7.1 Summary of research questions and data collection

<table>
<thead>
<tr>
<th>Research question</th>
<th>Data collected</th>
<th>Timing of collection</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do patients know the importance of deep breathing exercises and coughing, the technique for performing deep breathing exercises and coughing, and the need for adequate pre-exercise analgesia?</td>
<td>Technique for performing deep breathing and coughing exercises</td>
<td>Preadmission (prior to hospitalisation for surgery) and Pre-discharge (within 24 hours prior to discharge)</td>
<td>Semi-structured patient interview</td>
</tr>
<tr>
<td></td>
<td>Importance of deep breathing and coughing exercises following surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Requirement for analgesia prior to deep breathing and coughing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is patients’ preference for deciding the amount and frequency of deep breathing and coughing exercises?</td>
<td>Patient preference for participation in deep breathing and coughing exercises</td>
<td>Preadmission (prior to hospitalisation for surgery)</td>
<td>Semi-structured patient interview-</td>
</tr>
<tr>
<td></td>
<td>Patients’ reported reasons for their chosen preference and reported participation in deep breathing and coughing exercises</td>
<td></td>
<td>Control Preference Scale</td>
</tr>
<tr>
<td></td>
<td>Patients’ characteristics and knowledge of deep breathing and coughing exercises at preadmission and their relationship with patient preference for participation in deep breathing and coughing exercises</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is patients’ experience of deep breathing and coughing exercises commensurate with their preferred participation in deep breathing and coughing exercises?</td>
<td>Patient reported participation in deep breathing and coughing exercises</td>
<td>Pre-discharge (within 24 hours prior to discharge)</td>
<td>Semi-structured patient interview-Modified Control Preference Scale</td>
</tr>
<tr>
<td></td>
<td>Patients stated reasons for their reported participation in deep breathing and coughing exercises</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patients’ characteristics and knowledge of deep breathing and coughing exercises pre-discharge and their relationship with patient reported participation in deep breathing and coughing exercises</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How do clinicians facilitate patient participation in deep breathing exercises and coughing?</td>
<td>All interactions between nurse and patient regarding pulmonary management and Nurses perceptions of how they facilitate patient participation in pulmonary management</td>
<td>Midway through data collection and Following data collation</td>
<td>Naturalistic observation and Nurse focus group interviews</td>
</tr>
</tbody>
</table>
7.2 Results

The primary aim of the analyses in this chapter was to explore patient participation in the context of deep breathing and coughing exercises during a hospital admission for a cardiac surgery. In section 7.2.1 patients’ knowledge of deep breathing and coughing exercises is presented. Patients’ preference for and reported participation in deep breathing and coughing exercises are displayed in section 7.2.2. The way nurses facilitate patient participation in deep breathing and coughing exercises is shown in 7.2.3.

7.2.1 Patients’ understanding of deep breathing and coughing exercises

Table 7.2 displays the proportion of patients who could state the technique and importance of deep breathing and coughing exercises and the requirement for adequate pain relief in order to deep breathe and cough prior to and following surgery. Prior to admission, while less than half of patients knew the importance of deep breathing and coughing to avoid complications (37.8%) the majority of patients knew the technique for performing the exercises (63.3%). Patients displayed an increase in understanding in all aspects of pulmonary exercises following surgery. However, at this time less than half of patients (40.8%) could identify the requirement for adequate pain relief in order to deep breathe and cough.
Table 7.2 Patients who could state the technique and importance of pulmonary exercises and the requirement of adequate pain relief at preadmission and pre-discharge (n=98)

<table>
<thead>
<tr>
<th></th>
<th>Preadmission (n=98)</th>
<th>Pre-discharge (n=98)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>The technique for deep breathing and coughing</td>
<td>62 (63.3)</td>
<td>80 (81.6)</td>
</tr>
<tr>
<td>The importance of deep breathing and coughing to avoid complications</td>
<td>37 (37.8)</td>
<td>63 (64.3)</td>
</tr>
<tr>
<td>The requirement of adequate pain relief in order to deep breathe and cough</td>
<td>33(33.7)</td>
<td>40 (40.8)</td>
</tr>
</tbody>
</table>

7.2.2 Patients’ preference for and reported participation in deep breathing and coughing exercises

In this section, patients’ preference for and actual participation in deep breathing and coughing exercises are displayed. Patients’ preference for participation was compared with their actual participation to examine if patients’ preference for involvement was achieved.

7.2.2.1 Patients’ preference for participation in deep breathing and coughing exercises

Patients’ preference for participation in deep breathing and coughing exercises was measured using the Control Preference Scale (CPS) (Degner, Sloan & Venkatesh, 1997). More than half of the patients (55.4%, n=72) preferred to assume individual responsibility for making decisions about
this aspect of their pulmonary management (Figure 7.1). In relation to the remaining patients, 23 per cent (n= 30) preferred to share decisions and 22 per cent (n=28) preferred clinicians to make the decisions.

Figure 7.1 Patients’ preference for participation in deep breathing and coughing exercises (N=130)

Patients who preferred to leave all decisions about deep breathing and coughing exercises to clinicians felt it should be left to the clinicians who know more about, and whose role it is to manage, pulmonary recovery.

Statements from these patients included,

*Doctors and nurses know the job.* (patient 30)

*They are qualified to know when I need to do it.* (patient 27)

*Doctors and nurses know more about it than me.* (patient 12)
Patients who preferred to make decisions about deep breathing and coughing exercises described being able to do it and not wanting to bother clinicians or waste resources. These patients responded that,

*They don’t have to come and see me to remind me. Not to bother them I can do it myself.*  
(patient 21)

*I’d like to take responsibility because it is my own health.*  
(patient 22)

*Easier for me to do it.*  
(patient 66)

*Willing to listen to what they say but take ownership if I know what to do.*  
(patient 37)

*I take responsibility and if able to do it I don’t see anyone else’s involvement needed. Would be a wasted resource.*  
(patient 84)

*Whatever you can do for yourself is best.*  
(patient 46)

The relationship between patient characteristics and patients’ preference for participation in deep breathing and coughing exercises were explored in order to determine if there were patterns in patients’ characteristics that may explain preference for participation. These findings are presented in Table 7.3.

Older patients’ preferred clinicians to make decisions about deep breathing and coughing exercises (*t*, (128) = 2.3, *p*=0.02). Other findings relating to patient characteristics and preference for participation in deep breathing and coughing exercises were unremarkable.
Table 7.3 Comparison of patient characteristics with preferred participation in deep breathing and coughing exercises (N=130)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Clinicians solely make decisions n=26</th>
<th>Patient involvement in decisions n=104</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>X², df, p value</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td>0.07, 1, 0.78</td>
</tr>
<tr>
<td>Male (n=82)</td>
<td>17 (20.7)</td>
<td>65 (79.3)</td>
<td></td>
</tr>
<tr>
<td>Female (n=48)</td>
<td>9 (18.8)</td>
<td>39 (81.2)</td>
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</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
<td>0.75, 1, 0.78</td>
</tr>
<tr>
<td>≥ VCE* (n=47)</td>
<td>10 (21.3)</td>
<td>37 (78.7)</td>
<td></td>
</tr>
<tr>
<td>&lt; VCE* (n=83)</td>
<td>16 (19.3)</td>
<td>67 (80.7)</td>
<td></td>
</tr>
<tr>
<td>Language spoken at home</td>
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<td></td>
<td>1.47, 1, 0.22</td>
</tr>
<tr>
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<td>20 (18.2)</td>
<td>90 (81.8)</td>
<td></td>
</tr>
<tr>
<td>Non English (n=20)</td>
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<td>14 (70.0)</td>
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</tr>
<tr>
<td>Country of birth</td>
<td></td>
<td></td>
<td>0.12, 1, 0.72</td>
</tr>
<tr>
<td>Australia (n=69)</td>
<td>13 (18.8)</td>
<td>56 (81.2)</td>
<td></td>
</tr>
<tr>
<td>Other (n=61)</td>
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</tr>
<tr>
<td>Living arrangement</td>
<td></td>
<td></td>
<td>0.29, 1, 0.58</td>
</tr>
<tr>
<td>Alone (n=49)</td>
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<td>38 (77.6)</td>
<td></td>
</tr>
<tr>
<td>With partner (n=81)</td>
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<td>66 (81.5)</td>
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</tr>
<tr>
<td>Previous surgery</td>
<td></td>
<td></td>
<td>0.01, 1, 0.92</td>
</tr>
<tr>
<td>Yes (n=39)</td>
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<td>31 (79.5)</td>
<td></td>
</tr>
<tr>
<td>No (n=91)</td>
<td>18 (19.8)</td>
<td>73 (80.2)</td>
<td>2.3, 2, 0.30</td>
</tr>
<tr>
<td>Charlson co-morbidity index</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>0 (n=63)</td>
<td>11 (17.5)</td>
<td>52 (82.5)</td>
<td></td>
</tr>
<tr>
<td>1-4 (n=41)</td>
<td>7 (17.1)</td>
<td>34 (82.9)</td>
<td></td>
</tr>
<tr>
<td>≥5 (n=26)</td>
<td>8 (30.8)</td>
<td>18 (69.2)</td>
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</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>t, df, p value</td>
</tr>
<tr>
<td>Age (n=130)</td>
<td>70.4 (11.5)</td>
<td>64.3 (11.6)</td>
<td>2.3, 128, 0.02</td>
</tr>
</tbody>
</table>

*Victorian Certificate of Education. Equivalent to successful completion of high school; ≥, greater than or equal to; <, less than.
In order to explore if patients' preference for participation in deep breathing and coughing exercises was affected by their knowledge of these exercises these variables were compared (Table 7.4). Patients’ preferred clinicians to make decisions regarding deep breathing and coughing exercises when they did not understand the requirement of adequate pain relief in order to deep breathe and cough ($X^2 (1, N = 130) = 5.3, p=0.02$).

**Table 7.4 Patients’ knowledge of deep breathing and coughing exercises at preadmission and preference for participation in these exercises (N=130)**

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Clinicians solely make decisions n=26</th>
<th>Patient involvement in decisions n=104</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technique for exercises</td>
<td>n (%)</td>
<td>n (%)</td>
<td>$X^2$, df, p value</td>
</tr>
<tr>
<td>Yes (n=85)</td>
<td>13 (15.3)</td>
<td>72 (84.7)</td>
<td>3.3, 1, 0.65</td>
</tr>
<tr>
<td>No (n=45)</td>
<td>13 (28.9)</td>
<td>32 (71.1)</td>
<td></td>
</tr>
<tr>
<td>Importance of exercises</td>
<td></td>
<td></td>
<td>2.0, 1, 0.15</td>
</tr>
<tr>
<td>Yes (n=51)</td>
<td>7 (13.7)</td>
<td>44 (86.3)</td>
<td></td>
</tr>
<tr>
<td>No (n=79)</td>
<td>19 (24.1)</td>
<td>60 (75.9)</td>
<td></td>
</tr>
<tr>
<td>Adequate analgesia prior to exercises</td>
<td></td>
<td></td>
<td>5.3, 1, 0.02</td>
</tr>
<tr>
<td>Yes (n=45)</td>
<td>4 (8.9)</td>
<td>41 (91.1)</td>
<td></td>
</tr>
<tr>
<td>No (n=85)</td>
<td>22 (25.9)</td>
<td>63 (74.1)</td>
<td></td>
</tr>
</tbody>
</table>
7.2.2.2 Patients’ reported participation in deep breathing and coughing exercises

Patients’ perception of who made decisions relating to when and how frequently they undertook deep breathing and coughing exercises during their recovery is reported in Figure 7.2. Nearly three quarters of patients (73.4%) stated they made decisions relating to deep breathing and coughing exercises. Explanations that were provided revealed minimal encouragement from nurses to undertake respiratory exercises. They stated,

*I'm dobbing now but no one has prompted me except the physiotherapist.* (patient 83)

*Nurses haven’t been at me to do it. Only two nurses said, ‘do it in front of me’ and watched me do it.* (patient 34)

*No prompting has occurred.* (patient 54)

Some patients considered knowing the importance of preventing pulmonary complications as a motivating factor to undertake responsibility for this aspect of pulmonary management. Statements from these patients included,

*I know enough from the physiotherapist to take responsibility to do it.* (patient 83)

*Try to get back to good health.* (patient 34)

*My brother had same operation so I know it is important.* (patient 54)
Patients’ experience of deep breathing and coughing exercises was compared with their preferred participation in these exercises (Table 7.5). For patients who preferred clinicians to make all decisions regarding deep breathing and coughing exercises 65% (n=13) reported involvement in decisions. The majority of patients who preferred participation in pulmonary exercise decisions 88.5% (n=69) experienced participation in these decisions. However nine patients (11.5%) preferring participation reported no involvement. These patients may have not participated for a few reasons. They could have changed their preference for involvement or there may have been barriers within the acute care environment that prevented their ability to participate.
Table 7.5 Patients' preference for participation in deep breathing and coughing exercises and experienced participation in these exercises (n=98)

<table>
<thead>
<tr>
<th>Patients preference for participation</th>
<th>Clinicians solely make decisions</th>
<th>Patient involvement in decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Clinicians solely make decisions</td>
<td>7 (7.1)</td>
<td>13 (13.2)</td>
</tr>
<tr>
<td>Patient involvement in decisions</td>
<td>9 (9.1)</td>
<td>69 (70.4)</td>
</tr>
</tbody>
</table>

Patient characteristics were compared with patients’ reported participation in deep breathing and coughing exercises in order to determine if patients’ reported involvement was affected by their characteristics. These findings are presented in Table 7.6. Patients’ characteristics showed no statistically significant effect on patients’ reported participation in deep breathing and coughing exercises.
Table 7.6 Comparison of patient characteristics with reported participation in deep breathing and coughing exercises (n=98)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Clinicians solely made decisions n=16</th>
<th>Patient involved in decisions n=82</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>X², df, p value</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td>0.10, 1, 0.75</td>
</tr>
<tr>
<td>Male (n=64)</td>
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<td>53 (82.8)</td>
<td></td>
</tr>
<tr>
<td>Female (n=34)</td>
<td>5 (14.7)</td>
<td>29 (85.3)</td>
<td></td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
<td>1.3, 1, 0.25</td>
</tr>
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<td>4 (10.8)</td>
<td>33 (89.2)</td>
<td></td>
</tr>
<tr>
<td>&lt; VCE* (n=61)</td>
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<td>49 (80.3)</td>
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<tr>
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<td></td>
<td>1.7, 1, 0.18</td>
</tr>
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<td>72 (85.7)</td>
<td></td>
</tr>
<tr>
<td>Non English (n=14)</td>
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<td>10 (71.4)</td>
<td></td>
</tr>
<tr>
<td>Country of birth</td>
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<td></td>
<td>0.20, 1, 0.65</td>
</tr>
<tr>
<td>Australia (n=54)</td>
<td>8 (14.8)</td>
<td>46 (85.2)</td>
<td></td>
</tr>
<tr>
<td>Other (n=44)</td>
<td>8 (18.2)</td>
<td>36 (81.8)</td>
<td></td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
<td></td>
<td>0.19, 1, 0.65</td>
</tr>
<tr>
<td>Alone (n=38)</td>
<td>7 (18.4)</td>
<td>31 (81.6)</td>
<td></td>
</tr>
<tr>
<td>With partner (n=60)</td>
<td>9 (15.0)</td>
<td>51 (85.0)</td>
<td></td>
</tr>
<tr>
<td>Previous surgery</td>
<td></td>
<td></td>
<td>0.004, 1, 0.95</td>
</tr>
<tr>
<td>Yes (n=30)</td>
<td>5 (16.7)</td>
<td>25 (83.3)</td>
<td></td>
</tr>
<tr>
<td>No (n=68)</td>
<td>11 (16.2)</td>
<td>57 (83.8)</td>
<td></td>
</tr>
<tr>
<td>Charlson co-morbidity index</td>
<td></td>
<td></td>
<td>2.1, 2, 0.34</td>
</tr>
<tr>
<td>0 (n=53)</td>
<td>7 (13.2)</td>
<td>46 (86.8)</td>
<td></td>
</tr>
<tr>
<td>1-4 (n=27)</td>
<td>4 (14.8)</td>
<td>23 (85.2)</td>
<td></td>
</tr>
<tr>
<td>≥5 (n=18)</td>
<td>5 (27.8)</td>
<td>13 (72.2)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
<th>t, df, p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (n=98)</td>
<td>68.6 (10.9)</td>
<td>64.5 (12.3)</td>
<td>1.2, 96, 0.21</td>
</tr>
</tbody>
</table>

*Victorian Certificate of Education. Equivalent to successful completion of high school; ≥, greater than or equal to; <, less than.

In order to determine if patients’ reported participation in deep breathing and coughing exercises was affected by their understanding of deep
breathing and coughing exercises these variables were compared (Table 7.7). Patients’ who knew the technique for \((p<0.001)\) and importance of \((p<0.001)\) deep breathing and coughing exercises were more likely to report participation in these exercises.

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Clinicians solely made decisions (n=16)</th>
<th>Patient involved in decisions (n=82)</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Technique for exercises</strong></td>
<td></td>
<td></td>
<td>18.3, 1, &lt;0.001</td>
</tr>
<tr>
<td>Yes (n=80)</td>
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<td>73 (91.2)</td>
<td></td>
</tr>
<tr>
<td>No (n=18)</td>
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<td>9 (50.0)</td>
<td></td>
</tr>
<tr>
<td><strong>Importance of exercises</strong></td>
<td></td>
<td></td>
<td>9.0, 1, &lt;0.001</td>
</tr>
<tr>
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<td>5 (7.9)</td>
<td>58 (92.1)</td>
<td></td>
</tr>
<tr>
<td>No (n=35)</td>
<td>11 (31.4)</td>
<td>24 (68.6)</td>
<td></td>
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<td><strong>Adequate analgesia prior to exercises</strong></td>
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<td>1.9, 1, 0.15</td>
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<tr>
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<td>36 (90.0)</td>
<td></td>
</tr>
<tr>
<td>No (n=58)</td>
<td>12 (20.7)</td>
<td>46 (79.3)</td>
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</tr>
</tbody>
</table>

### 7.2.3 Nurses’ facilitation of patient participation in deep breathing and coughing exercises

During the observation period pulmonary management related activity was observed with 23 of the 48 patients (47.9%). Pulmonary management related activity constituted any sort of exchange between the nurse and patient about deep breathing and coughing exercises or pulmonary
hygiene in general. For these 23 patients, 24 separate pulmonary management related activities were observed. Twenty two (91.7%) of these activities were initiated by nursing staff and 2 (8.3%) were initiated by patients.

The naturalistic observations and the focus group interviews were designed to provide valuable contextual data to enhance understanding of patient participation in pulmonary management. Data from these two sources, though limited, revealed while there was an expectation from nurses that patients undertook deep breathing and coughing exercises, patients’ ability to undertake these exercises was not assessed in a systematic way. The manner in which nurses assessed patients’ ability to deep breathe and cough varied. A few nurses simply asked patients if they had been undertaking deep breathing and coughing exercises and did not assess patients’ ability to perform these exercises.

Have you been doing deep breathing and coughing exercises? (nurse 9)

Have you been doing your deep breathing and coughing? (nurse 20)

Many nurses asked patients to perform deep breathing and a cough. This was demonstrated as,

Can you cough for me? Can you cough? (nurse 11)

Can you take a deep breath for me please? (nurse 13)
During patient demonstration of deep breathing and coughing exercises nurses did not appear to assess patients’ ability to deep breathe and cough. At this time some nurses did not look at the patient and were preoccupied with medical documents. One nurse asked the patient to deep breathe and cough and then immediately left the room. When they returned the conversation was,

*How did you go?* (nurse 15)

*I don’t know* (patient 11)

No discussion regarding pulmonary management was entered into and the nurse left the room without further conversation. Minimal information about the importance of pulmonary exercises was discussed during the observation period. Patients were encouraged to cough up sputum but were not explained the purpose of doing this.

*Have you coughed up any sputum today?* (nurse 4)

*Did you cough up some phlegm?* (nurse 11)

*Yes I coughed some up.* (patient 6)

*I will get you some tissues and you keep* (nurse 11)
coughing it up as much as you can.

Well if you can do this (deep breathing and coughing) four times a day. And that’s not overdoing it.  

(nurse 15)

If you can do three deep breathes hourly and then a cough.  

(nurse 36)

Are you doing deep breathing and coughing hourly?  

(nurse 2)

In both focus groups nurses confirmed pulmonary management as a key goal of care during recovery from cardiac surgery. At this time one nurse noted the need to assess patients’ ability to deep breath and cough.

We have to check their breathing and chest physiotherapy.  

(nurse 4)

The importance of patients knowing the technique for deep breathing and coughing exercises and the reason for doing the exercises was also highlighted.

I say to patients you need to deep breathe and cough every hour and ask them do they know why? I explain to patients they deflate their lungs in surgery and they need to cough from the bottom or they will end up with pneumonia. I usually give them the worst case scenario.  

(nurse 2)

The requirement that patients have adequate pain relief for the exercises was also noted.
We need to make sure that patients know if it is pain stopping them from doing their exercises we can get on top of pain so that it doesn’t prevent them for doing the exercises. (nurse 4)

Nurses appeared to use an information tool in the form of a cardiac surgery booklet as the patients’ main source of information regarding their pulmonary management. It appeared that nurses relied heavily on the information booklet about cardiac surgery provided at preadmission to educate patients about the role they should play in their recovery. Nurses requested patients to read this booklet prior to and after surgery and then answer patients questions arising from their reading.

Well I certainly give like or make sure they have their education booklet that they get in preadmission clinic as well as make sure they read through it again when they have had surgery because it’s usually more relevant to them then so that if there are any questions from that well these are your expectations here. (nurse 2)

Times when the importance of pulmonary management was mentioned the conversations were brief or not explained clearly. Patients understanding did not appear to be checked. This was exhibited as,

I really, really need you to do those deep breathing and coughing exercises. You had a bit of breathing trouble in the Intensive Care Unit (ICU) and you don’t
want to delay your discharge because, you know.....

*I would just encourage you to stay up as much as you can during the day just to keep the lungs because when you are sitting up it is just much easier to sort of take nice deep big breathes and open up the bottom of those lungs.*

(nurse 7)

*Your chest x-ray looks great!*

(nurse 9)

*Does it?*

(patient 24)

*I had a look earlier on, and it was really good, so it’s working all that deep breathing and coughing that you’re doing.*

(nurse 9)

*You’re going to get a chest infection if you lie flat. I know I sound mean but.....*

(nurse 31)

While these comments encourage patients to undertake deep breathing and coughing exercise they fail to provide a clear explanation for the importance of deep breathing and coughing and the requirement for adequate pain relief.
7.2.4 Summary of findings

Patients undertake deep breathing and coughing exercises to prevent pulmonary complications.

Opportunity for in hospital education and participation to enhance quality of deep breathing and coughing exercises during admission.

Majority of patients prefer involvement and have cognitive ability to participate in this aspect of pulmonary management.

Facilitation of pulmonary management by nurses.

Nurses prompted patients to undertake deep breathing and coughing exercises but did not appear to assess ability to undertake exercises or clearly educate patients of importance.

Time: Low frequency, low duration interactions.

Despite lack of routinised facilitation of deep breathing and coughing exercises by nurses, patients controlled this aspect of pulmonary management.

Figure 7.3 Model of pulmonary management findings.
7.3 Discussion

In this chapter, patient participation in the context of deep breathing and coughing exercises during a hospital admission for cardiac surgery was explored. The purpose of the analyses reported in this chapter was to identify patients’ preferences for and experience of participation in deep breathing and coughing exercises. Patients’ knowledge of deep breathing and coughing exercises and the way clinicians facilitate patient participation in this aspect of pulmonary management was also examined.

In relation to patient preference, while over half of patients (55%) preferred to make decisions about deep breathing and coughing exercises, three-quarters of patients (75%) reported they made decisions about deep breathing and coughing during their surgical admission. In general, patients displayed a greater understanding of their role in deep breathing and coughing exercises following their surgical admission in terms of the technique, the importance to avoid complications and the requirement of adequate pain relief in order to deep breathe and cough. However, clear deficits in patients’ knowledge remained pre-discharge following surgical intervention. Specifically only 64% of patients were able to state the importance of deep breathing and coughing exercises at this time and less than half of patients (41%) were able to state the requirement for adequate pain relief in order to deep breathe and cough.
Nurses did not routinely facilitate patients to participate in deep breathing and coughing exercises. When nurses facilitated patient involvement in deep breathing and coughing exercises it appeared to focus on instructing the patients to commence the exercises. Little attempt was made to assess patients’ technique or ability to deep breathe and no education for this aspect of pulmonary management was observed.

Deficits in the understanding of the importance of deep breathing and coughing and the requirement of adequate pain relief to deep breathe and cough following surgery may impede patients’ ability to participate in these aspects of pulmonary management. Consequently, these deficits may contribute to pulmonary morbidity (O’Connor, 1999) and lead to an increased risk of mortality, length of stay and associated costs (Eber et al., 2010).

There are two possible reasons why nurses did not routinely engaged patients in deep breathing and coughing exercises following surgery. First, nurses may not have prioritised facilitation of deep breathing and coughing exercises because the evidence to support pulmonary exercises in the post-operative context is equivocal (Slade, 2013; Pasquina et al., 2003). However, during the observations and in the focus groups it was evident that nurses believed deep breathing and coughing exercises to be important.
Second, nurses may have been reliant on other sources to provide information and education to patients about deep breathing and coughing, namely the physiotherapist and written information. Physiotherapists are part of the health care team and within the cardiac surgical recovery setting are responsible for preventing pulmonary complications (Stiller, 2000). Based on the role physiotherapists play nurses may have either relinquished their role in pulmonary management or considered it a low priority when addressing patient care needs. The delineation of roles in relation to pulmonary management appears unclear and is not supported by previous research. Despite this nurses could play an important, if only supporting, role in improving patient outcomes in relation to deep breathing and coughing exercises based on their role in frontline patient management and 24-hour care delivery.

Written information is a tool commonly used to provide patients with details about their post-operative management (Coulter & Ellins, 2007; Johansson et al., 2005). At the study site all patients undergoing cardiac surgery were given a hospital specific education booklet titled, ‘Your cardiac surgery’ prior to admission. This booklet outlined the importance of reporting pain to staff in order to assist in patient comfort and ability to undertake deep breathing and coughing exercises. Regardless of provision of written information the majority of patients were unable to identify the importance of reporting pain in order to undertake these exercises.
Written information should be considered an adjunct to verbal information (Hartigan, Murphy, & Hickey, 2011) and not a stand-alone intervention.

Despite the lack of routinised engagement of patients in their deep breathing and coughing exercises by nurses patients assumed responsibility for this aspect of their recovery. Patients reported knowing what to do and described taking ownership of the task. This may relate to patients understanding of the role they can play in this aspect of treatment, the knowledge they have in order to undertake the exercises and the expectation by nurses that patients participate in these exercises.

### 7.4 Conclusion

Most patients’ preferred and reported making decisions about deep breathing and coughing exercises during their hospital admission. Overall patients’ understanding of deep breathing and coughing exercises increased as a function of surgical admission however patients continued to display deficits relating to the importance of deep breathing and coughing exercises and the requirement of adequate pain relief in order to deep breathe and cough.

One barrier to patients’ knowledge regarding deep breathing and coughing exercises may be the reliance on other sources for information provision and education by nurses. Despite this the majority of patients felt confident to co-ordinate their deep breathing and coughing exercises without input from nurses. This may relate to nurses and patients’
understanding of the role patients can play in this aspect of recovery. If deep breathing and coughing exercises continue to be considered an important aspect of pulmonary management following surgery nurses should ensure adequate information and education provision about these exercises is prioritised as part of routinised care. In Chapter 8, the results from the exploration of patient participation in discharge planning are presented.
Chapter Eight

Patient participation in discharge planning during an acute hospital admission

Discharge planning is the process of co-ordinating care to ensure a quality and safe transition from hospital to home (Bull, Hansen, & Gross, 2000). Inadequate discharge planning leaves patients ill-equipped to manage their care after hospitalisation (Boughton & Halliday, 2009; Bull & Roberts, 2001) and increases re-admission rates to hospital following discharge (Naylor et al., 1999; Phillips et al., 2004; Shepperd et al., 2010). Effective discharge planning is crucial within a context of shortening length of stay (Cowper et al., 2006) because an increased amount of care that was previously delivered in hospital is managed by patients and their families in their home environment (Bauer, Fitzgerald, Haesler, & Manfrin, 2009).

Hospital length of stay (Aggarwal et al., 2006; Lee et al., 2012; Leegard et al., 2008; Yared et al., 2000) and 30-day re-admission rates (Hannan et al., 2011; Lee et al., 2012; Li, Armstrong, Parker, Danielsen, & Romano, 2012) are routinely measured as indicators of quality care. In the context of cardiac surgery increased length of stay is attributed to complications developed following surgical intervention (Aggarwal et al., 2006; Lee, et al., 2012; Leegard et al., 2008; Yared et al., 2000). The average length of stay for cardiac surgical patients worldwide has variously been reported to range from 5 to 9 days (Aggarwal et al., 2006; Lee et al., 2012; Leegard et
The 30-day re-admission rate following cardiac surgery has recently been reported to occur in between 13.2% and 14.4% of patients (Hannan et al., 2011; Lee et al., 2012; Li et al., 2012).

Following cardiac surgery the trajectory of recovery requires discharge planning to be organised for three distinct phases of rehabilitation: immediate, intermediate and ongoing. In the immediate phase of rehabilitation the aim of quality discharge planning is a timely discharge from hospital (Shepperd et al., 2010). During the intermediate phase the aim of quality discharge planning is to reduce unplanned re-admission to hospital (Shepperd et al., 2010). The aim of quality discharge planning for the ongoing phase of rehabilitation is preparation of patients for long term self-management of health (Shepperd et al., 2010). Cardiac rehabilitation is recommended to optimise cardiac patients’ long-term recovery.

Improved patient outcomes have been reported as a consequence of patient participation in cardiac rehabilitation (Jiang, Sit, & Wong, 2007; Jolliffe et al., 2001; Lavie, Thomas, Squires, Allison, & Milani, 2009; Taylor et al., 2004; Tsai, Lin, & Wu, 2005) and include increased physical functioning (Jiang et al., 2007; Taylor et al., 2004; Tsai et al., 2005) and reduced mortality (Jolliffe et al., 2001; Taylor et al., 2004) and morbidity (Lavie et al., 2009). Attendance rates at cardiac rehabilitation have been particularly low with less than 15-30% of those eligible for cardiac rehabilitation attending worldwide (Neubeck et al., 2012). Within Australia,
37% of eligible cardiac surgical patients attend cardiac rehabilitation (Sundararajan, Bunker, Begg, Marshall, & McBurney, 2004).

While patient participation is recommended to ensure a safe transition for patients at the interface between acute and chronic care (Carroll & Dowling, 2007; Efraimsson et al., 2004; Goble, Worcester, Centre, & Services, 1999; Huber & McClelland, 2003) there is limited understanding of how patients participate or are facilitated to participate in their discharge plan during hospitalisation. Further, indicative behaviours of patient participation in discharge planning during acute episodic illness are not entirely clear.

In preparation for discharge, patients should be cognisant of the clinical pathway guiding their care and know their discharge date and destination. To self-manage care in the intermediate phase of rehabilitation, patients should know their discharge medications and pain treatment. Patients must also be aware of the signs and symptoms of post-operative infection. For the ongoing phase of rehabilitation patients should know the benefits of attending cardiac rehabilitation and lifestyle changes necessary to reduce future risk of cardiovascular events.

In this study the behaviours proposed to be indicative of patient participation in discharge planning were: 1) patients’ preference and reported participation in discharge planning; 2) patients’ understanding of their medications, pain treatment, the importance of deep breathing and
coughing exercises to prevent infection, the benefits of attending cardiac rehabilitation and their discharge destination.

Within this context, it was expected that clinicians would use interactions with patients as an opportunity to discuss their discharge plan and highlight the importance of understanding this plan to self-manage their care once discharged.

The specific research questions were:

a) What is patients’ preference for participation in discharge planning?

b) Is patients’ experience of discharge planning commensurate with their preferred participation in discharge planning?

c) How do nurses facilitate patient participation in discharge planning?

d) Does patients’ ability to state their discharge destination, their intention to participate in cardiac rehabilitation and the benefits of cardiac rehabilitation change as a function of a surgical admission?

Findings from previous chapters relating to medication and pain management considered essential for quality discharge planning were also incorporated into the discussion in this chapter.
8.1 Methods

The methodological approach used to explore patient participation in discharge planning was described in detail in Chapter Three. Semi-structured patient interviews before surgery and prior to discharge from hospital, provided data regarding patients’ knowledge of their discharge plan following surgery and their preference for, and reported role in discharge planning. The Control Preference Scale (CPS) was used to elicit patients’ preference for participation in discharge planning. A modified version of this tool was used to elicit patients’ reported participation in discharge planning. Naturalistic observations based on the tenets of qualitative exploratory descriptive research were conducted to elicit the clinical practices and interactions between patients and clinicians that occur during discharge planning in the recovery period after surgery. Focus group interviews with nurses in the cardiac surgery ward explored their perceptions of the way patient participation in discharge planning is and can be facilitated in the post-surgical context. In the following section, the procedures and data collection relating to the description of patient participation in discharge planning are outlined.

8.1.1 Procedure and data collection

Questions that provided structure for the interviews were guided by three main topics:

1. Knowledge of discharge destination
2. Benefits of attending cardiac rehabilitation following discharge

3. Intention to participate in cardiac rehabilitation following discharge

Using the CPS, patients’ preference for participation in discharge planning was based on the question:

Who decides when and where you go following discharge?

8.1.2 Statistical and qualitative analyses

The statistical and qualitative analyses were consistent with the analyses described in Sections 5.1.2 and 6.1.2 in Chapters 5 and 6. The research questions and data collection are summarised in Table 8.1.
<table>
<thead>
<tr>
<th>Research question</th>
<th>Data collected</th>
<th>Timing of collection</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is patients’ preference for participation in discharge planning?</td>
<td>Patient preference for participation in discharge planning&lt;br&gt;Patients’ reported reasons for their chosen preference and reported participation in discharge planning&lt;br&gt;Patients’ characteristics and knowledge of discharge planning at preadmission and their relationship with patient preference for participation in discharge planning</td>
<td>Preadmission (prior to hospitalisation for surgery)</td>
<td>Semi-structured patient interview-Control Preference Scale</td>
</tr>
<tr>
<td>Is patients’ experience of discharge planning commensurate with their preferred participation in discharge planning?</td>
<td>Patient reported participation in discharge planning&lt;br&gt;Patients stated reasons for their reported participation in discharge planning&lt;br&gt;Patients’ characteristics and knowledge of discharge planning pre-discharge and their relationship with patient reported participation in discharge planning</td>
<td>Pre-discharge (within 24 hours prior to discharge)</td>
<td>Semi-structured patient interview-Modified Control Preference Scale</td>
</tr>
<tr>
<td>How do clinicians facilitate patient participation in discharge planning?</td>
<td>All interactions between nurse and patient regarding discharge planning and&lt;br&gt;Nurses perceptions of how they facilitate patient participation in discharge planning</td>
<td>Midway through data collection and&lt;br&gt;Following data collation</td>
<td>Naturalistic observation and&lt;br&gt;Nurse focus group interviews</td>
</tr>
<tr>
<td>Does patients’ ability to state their discharge destination, their intention to participate in cardiac rehabilitation and the benefits of cardiac rehabilitation change as a function of a surgical admission?</td>
<td>Discharge destination&lt;br&gt;Importance of attending cardiac rehabilitation&lt;br&gt;Intention to attend cardiac rehabilitation</td>
<td>Preadmission (prior to hospitalisation for surgery) and&lt;br&gt;Pre-discharge (within 24 hours prior to discharge)</td>
<td>Semi-structured patient interview</td>
</tr>
</tbody>
</table>
8.2 Results

The primary aim of the analyses in this chapter was to explore patient participation in the context of discharge planning during a hospital admission for a cardiac surgical intervention. Patients’ knowledge of discharge planning is presented in section 8.2.1 and their preference for, and reported participation in discharge planning in section 8.2.2. This is followed by the analyses of clinicians’ facilitation of patient participation in discharge planning.

8.2.1 Patients’ knowledge of discharge planning

Table 8.2 displays the proportion of patients who could state their discharge destination; the benefits of cardiac rehabilitation and their intention to participate in cardiac rehabilitation recorded prior to and following surgery. Prior to admission (83.7%) and pre-discharge (86.7%), the majority of patients could state their discharge destination. While most patients intended to participate in cardiac rehabilitation following surgery (92.9%) only 74.5% could state at least one benefit of attending outpatient rehabilitation. Of the seven patients whose intention was to not attend rehabilitation pre-discharge, none could state the importance of attending rehabilitation at this time.
The reasons given for their intention to not attend rehabilitation were related to transport issues:

- *Too hard as I can’t drive.*
  - (patient 25)

- *I don’t have the transport.*
  - (patient 14)

Table 8.2 Patients’ knowledge of discharge destination, benefits of cardiac rehabilitation and intention to participate in rehabilitation at preadmission and pre-discharge (n=98)

<table>
<thead>
<tr>
<th></th>
<th>Preadmission (n=98)</th>
<th>Pre-discharge (n=98)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge destination</td>
<td>82 (83.7)</td>
<td>85 (86.7)</td>
</tr>
<tr>
<td>Benefits of cardiac rehabilitation</td>
<td>65 (66.3)</td>
<td>73 (74.5)</td>
</tr>
<tr>
<td>Intention to participate in cardiac rehabilitation</td>
<td>67 (68.4)</td>
<td>91 (92.9)</td>
</tr>
</tbody>
</table>

**8.2.2 Patients’ preference for and reported of participation in discharge planning**

In this section, patients’ preference for, and actual participation in discharge planning are presented. Patients’ preference for participation was compared with their actual participation to examine if patients’ preference for involvement was achieved.

**8.2.2.1 Patients’ preference for participation in discharge planning**

Prior to eliciting patients’ preference for participation in discharge planning, patients were advised this preference related to deciding when
and where they go following discharge. Close to half (47.3%) of patients’ preferred to share responsibility for discharge date and destination with clinicians (Figure 8.1). The remaining patients were divided with a similar number of patients preferring clinicians (n=31, 23.7%) to make decisions or make decisions themselves (n=29, 22.1%).

![Discharge planning](image)

**Figure 8.1** Patients’ preference for participation in discharge planning (N=130)

Patients who preferred to leave decisions about their discharge date and destination to clinicians felt they could not make these decisions and that clinicians know best. Statements from these patients included,

> They are the ones that have got me through it. I have trusted them this far I need to listen to them. (patient 22)

> I feel as if clinicians should advise if for my benefit to go ahead. With what doctors and nurses say. (patient 23)
The doctors know, like them to make the decisions.  
(patient 61)

They know better than me.  
(patient 82)

Patients who preferred to make decisions about their discharge (n=32) described knowing what was best for them in relation to when and where to go following discharge. Patients explained this as,

Expect clinicians to accept my decision as I know where I am most comfortable.  
(patient 11)

I know what I want and feel.  
(patient 12)

I feel in myself when I am ready to go home.  
(patient 26)

The decision is mine as far as I am concerned.  
(patient 27)

I know when I am ready to go.  
(patient 45)

Patient characteristics were compared with patients’ preference for participation in discharge planning in order to determine if patients’ preference was affected by their characteristics. These findings are presented in Table 8.3.

Patients’ age (t, (128) = 2.5, p=0.01), language spoken at home ($X^2 (1, N = 130) = 12.6, p<0.001$) and country of birth ($X^2 (1, N = 130) = 5.05, p=0.02$) revealed statistically significant effects on patients’ preference for participation in discharge planning. On average, older patients (M=70.1, SD=9.9) preferred clinicians to make decisions about discharge planning
while younger patients preferred to share responsibility for decisions with clinicians (M=64.1, SD=12.1).

The majority of patients who spoke English 81.8% preferred to share decisions with clinicians \( \chi^2(1, N = 130) = 12.6, p<0.001 \). In contrast, over half of non-English speaking patients (55.0%) preferred clinicians to make the decisions about discharge planning. Corresponding with the effect of language spoken at home, the majority of patients born in Australia preferred involvement in decisions (84.0%) when compared with patients who were born overseas (67.2%) \( \chi^2(1, N = 130) = 5.05, p=0.02 \).
Table 8.3 Patient characteristics associated with preferred participation in discharge planning (N=130)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Clinicians solely make decisions n=31</th>
<th>Patient involvement in decisions n=99</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>X², df, p value</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td>0.43, 1, 0.50</td>
</tr>
<tr>
<td>Male (n=82)</td>
<td>18 (22.0)</td>
<td>64 (78.0)</td>
<td></td>
</tr>
<tr>
<td>Female (n=48)</td>
<td>13 (27.1)</td>
<td>35 (72.9)</td>
<td></td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
<td>0.26, 1, 0.60</td>
</tr>
<tr>
<td>≥ VCE* (n=47)</td>
<td>10 (21.3)</td>
<td>37 (78.7)</td>
<td></td>
</tr>
<tr>
<td>&lt; VCE* (n=83)</td>
<td>21 (25.3)</td>
<td>62 (74.7)</td>
<td></td>
</tr>
<tr>
<td>Language spoken at home</td>
<td></td>
<td></td>
<td>12.6, 1, &lt;0.001</td>
</tr>
<tr>
<td>English (n=110)</td>
<td>20 (18.2)</td>
<td>90 (81.8)</td>
<td></td>
</tr>
<tr>
<td>Non English (n=20)</td>
<td>11 (55.0)</td>
<td>9 (45.0)</td>
<td></td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
<td></td>
<td>5.05, 1, 0.02</td>
</tr>
<tr>
<td>Australia (n=69)</td>
<td>11 (16.0)</td>
<td>58 (84.0)</td>
<td></td>
</tr>
<tr>
<td>Other (n=61)</td>
<td>20 (32.8)</td>
<td>41 (67.2)</td>
<td></td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
<td></td>
<td>0.51, 1, 0.47</td>
</tr>
<tr>
<td>Alone (n=49)</td>
<td>10 (20.4)</td>
<td>39 (79.6)</td>
<td></td>
</tr>
<tr>
<td>With partner (n=81)</td>
<td>21 (26.0)</td>
<td>60 (74.0)</td>
<td></td>
</tr>
<tr>
<td>Previous surgery</td>
<td></td>
<td></td>
<td>0.58, 1, 0.44</td>
</tr>
<tr>
<td>Yes (n=39)</td>
<td>11 (28.2)</td>
<td>28 (71.8)</td>
<td></td>
</tr>
<tr>
<td>No (n=91)</td>
<td>20 (22.0)</td>
<td>71 (78.0)</td>
<td></td>
</tr>
<tr>
<td>Charlson co-morbidity index</td>
<td></td>
<td></td>
<td>2.0, 2, 0.35</td>
</tr>
<tr>
<td>0 (n=63)</td>
<td>13 (20.6)</td>
<td>50 (79.4)</td>
<td></td>
</tr>
<tr>
<td>1-4 (n=41)</td>
<td>9 (22.0)</td>
<td>32 (78.0)</td>
<td></td>
</tr>
<tr>
<td>≥5 (n=26)</td>
<td>9 (34.6)</td>
<td>17 (65.4)</td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>t, df, p value</td>
<td>2.5,128, 0.01</td>
</tr>
<tr>
<td>Age (n=130)</td>
<td>70.1 (9.9)</td>
<td>64.1 (12.1)</td>
<td></td>
</tr>
</tbody>
</table>

*Victorian Certificate of Education. Equivalent to successful completion of high school; ≥, greater than or equal to; <, less than.
In order to explore if patients’ preference for participation in decisions about their discharge date and destination was affected by their knowledge of discharge planning these variables were compared (Table 8.4). When patients knew their discharge destination they were more likely to prefer involvement in decisions about discharge planning ($X^2 (1, N = 130) = 7.7, p=0.005)$.

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Clinicians solely make decisions n=31</th>
<th>Patient involvement in decisions n=99</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge destination</td>
<td></td>
<td></td>
<td>$X^2$, df, p value</td>
</tr>
<tr>
<td>Yes (n=109)</td>
<td>21 (19.3)</td>
<td>88 (80.7)</td>
<td>7.7, 1, 0.005</td>
</tr>
<tr>
<td>No (n=21)</td>
<td>10 (47.6)</td>
<td>11 (52.4)</td>
<td></td>
</tr>
<tr>
<td>Benefits of rehabilitation</td>
<td></td>
<td></td>
<td>0.29, 1, 0.58</td>
</tr>
<tr>
<td>Yes (n=89)</td>
<td>20 (22.5)</td>
<td>69 (77.5)</td>
<td></td>
</tr>
<tr>
<td>No (n=41)</td>
<td>11 (26.8)</td>
<td>30 (73.2)</td>
<td></td>
</tr>
<tr>
<td>Intention to participate in rehabilitation</td>
<td></td>
<td></td>
<td>0.58, 1, 0.44</td>
</tr>
<tr>
<td>Yes (n=91)</td>
<td>20 (22.0)</td>
<td>71 (78.0)</td>
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<tr>
<td>No (n=39)</td>
<td>11 (28.2)</td>
<td>28 (71.8)</td>
<td></td>
</tr>
</tbody>
</table>
8.2.2.2 Patients’ reported participation in discharge planning

Patients’ perception of who made decisions relating to their discharge date and destination is reported in Figure 8.2. Most patients (56.1%) stated clinicians made decisions relating to discharge date and destination. Some patients described ‘doing what they were told’ when reporting no involvement in decisions regarding discharge. They stated,

Just do as I’m told and give no lip. (patient 14)

Just told I am going, no asking “is that ok?” Not really any discussion. (patient 15)

Figure 8.2 Patients’ reported participation in discharge planning (n=98)

Patients’ experience of discharge planning was compared with their preferred participation in discharge planning (Table 8.5). For patients who preferred clinicians to make all decisions regarding discharge date and destination,
41.7% (n=10) reported involvement in decisions. However, the majority of patients who preferred participation in discharge decisions 55.4% (n=41) did not experience participation.

Table 8.5 Patients preference for participation in discharge planning and experienced participation in discharge planning (n=98)

<table>
<thead>
<tr>
<th>Patients preference for participation</th>
<th>Clinicians solely make decisions</th>
<th>Patient involvement in decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients preference</td>
<td>Clinicians solely make decisions</td>
<td>14 (58.3)</td>
</tr>
<tr>
<td>for participation</td>
<td>Patient involvement in decisions</td>
<td>41 (55.4)</td>
</tr>
</tbody>
</table>

Patient characteristics were compared with patients’ reported participation in discharge decisions in order to determine if patients’ reported involvement was affected by their characteristics. These findings are presented in Table 8.6. Patients’ language spoken at home (X² (1, N = 98) = 5.8, p=0.01) and country of birth (X² (1, N = 98) = 4.7, p=0.03) were patient characteristics to show statistically significant effects on patients’ reported participation in discharge planning. The majority of English (51.2%) and non-English (85.7%) patients reported clinicians as having made the decisions about discharge planning. However, patients who spoke English at home (48.8%) were more likely to have shared decisions with clinicians than non-English speaking patients (14.3%). Again, corresponding to language spoken at home, the majority of
patients born in Australia were more likely to report involvement in decisions (53.7%) than patients who were born overseas (31.8%) ($\chi^2 (1, N = 98) = 4.7$, $p=0.03$). While the difference was not statistically significant, there was a trend for older patients ($M=67.0$, $SD=11.4$) to report clinicians having made the decisions about discharge while younger patients reported involvement in decisions ($M=62.8$, $SD=12.7$).
### Table 8.6 Comparison of patient characteristics with reported participation in discharge planning (n=98)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Clinicians solely made decisions n=55</th>
<th>Patient involved in decisions n=43</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>$X^2$, df, p value</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td>0.21, 1, 0.64</td>
</tr>
<tr>
<td>Male (n=64)</td>
<td>37 (57.8)</td>
<td>27 (42.2)</td>
<td></td>
</tr>
<tr>
<td>Female (n=34)</td>
<td>18 (52.9)</td>
<td>16 (47.1)</td>
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<td>Education level</td>
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<td>0.88, 1, 0.34</td>
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<td>23 (62.2)</td>
<td>14 (37.8)</td>
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<td>&lt; VCE* (n=61)</td>
<td>32 (52.5)</td>
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<tr>
<td>Language spoken at home</td>
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<td>5.8, 1, 0.01</td>
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<tr>
<td>English (n=84)</td>
<td>43 (51.2)</td>
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<td>Non English (n=14)</td>
<td>12 (85.7)</td>
<td>2 (14.3)</td>
<td></td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
<td></td>
<td>4.7, 1, 0.03</td>
</tr>
<tr>
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<td>25 (46.3)</td>
<td>29 (53.7)</td>
<td></td>
</tr>
<tr>
<td>Other (n=44)</td>
<td>30 (68.2)</td>
<td>14 (31.8)</td>
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</tr>
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<td>16 (42.1)</td>
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<td>With partner (n=60)</td>
<td>33 (55.0)</td>
<td>27 (45.0)</td>
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<tr>
<td>Previous surgery</td>
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<td></td>
<td>1.5, 1, 0.21</td>
</tr>
<tr>
<td>Yes (n=30)</td>
<td>14 (46.7)</td>
<td>16 (53.3)</td>
<td></td>
</tr>
<tr>
<td>No (n=68)</td>
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<td>0.74, 2, 0.68</td>
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<td>28 (52.8)</td>
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</tr>
<tr>
<td>1-4 (n=27)</td>
<td>17 (63.0)</td>
<td>10 (37.0)</td>
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<tr>
<td>≥5 (n=18)</td>
<td>10 (55.6)</td>
<td>8 (44.4)</td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (n=98)</td>
<td>67.0 (11.4)</td>
<td>62.8 (12.7)</td>
<td>1.7, 96, 0.09</td>
</tr>
</tbody>
</table>

*Victorian Certificate of Education. Equivalent to successful completion of high school; ≥, greater than or equal to; <, less than.
In order to determine if patients’ reported participation in discharge date and destination was affected by their understanding of discharge destination these variables were compared (Table 8.7). Patients’ knowledge of discharge date and destination showed no statistically significant effect on patients’ reported participation in this aspect of discharge planning.

Table 8.7 Patients’ knowledge of discharge planning pre-discharge and reported participation in discharge planning (n=98)

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Clinicians solely made decisions n=55</th>
<th>Patient involved in decisions n=43</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>( \chi^2 ), df, p value</td>
</tr>
<tr>
<td>Discharge destination</td>
<td></td>
<td></td>
<td>0.60, 1, 0.43</td>
</tr>
<tr>
<td>Yes (n=85)</td>
<td>49 (57.6)</td>
<td>36 (42.4)</td>
<td></td>
</tr>
<tr>
<td>No (n=13)</td>
<td>6 (46.2)</td>
<td>11 (53.8)</td>
<td></td>
</tr>
<tr>
<td>Benefits of rehabilitation</td>
<td></td>
<td></td>
<td>0.20, 1, 0.65</td>
</tr>
<tr>
<td>Yes (n=73)</td>
<td>40 (54.8)</td>
<td>33 (45.2)</td>
<td></td>
</tr>
<tr>
<td>No (n=25)</td>
<td>15 (60.0)</td>
<td>10 (40.0)</td>
<td></td>
</tr>
<tr>
<td>Intention to participate in rehabilitation</td>
<td></td>
<td></td>
<td>2.6, 1, 0.10</td>
</tr>
<tr>
<td>Yes (n=91)</td>
<td>49 (53.8)</td>
<td>42 (46.2)</td>
<td></td>
</tr>
<tr>
<td>No (n=7)</td>
<td>6 (85.7)</td>
<td>1 (14.3)</td>
<td></td>
</tr>
</tbody>
</table>
8.2.3 Nurses’ facilitation of patient participation in discharge planning

Nurse and patient interactions regarding discharge planning related activity was observed in 10 of the 48 patients (20.8%) who participated in the naturalistic observation component of the research. Discharge planning activity constituted any sort of exchange between the nurse and patient concerning discharge planning. For these 10 patients, 10 separate discharge related activities were observed. Six (60.0%) of these activities were initiated by nursing staff and 4 (40.0%) were initiated by patients.

The naturalistic observations as well as the focus group interviews were designed to provide valuable contextual data to enhance understanding of patient participation in discharge planning. Data from the observations, though limited, revealed discussions initiated by patients about discharge planning were based on logistics of getting home - when they could go home or how to get home. All patient initiated interactions demonstrated concern about what was to happen next and indicated a lack of knowledge about their illness trajectory and their ability to manage at home. They made enquiries ranging from the need to organise physical transport to providing clues that they did not feel ready to be alone and nurses generally responded with short answers that did not allow for further exploration of patients’ feelings.

Can’t get home, will need transport to get home. (patient 3)
We will organise that for you when it is time to go. (patient 15)

Am I going home soon? (patient 11)

No, you are not ready to leave, maybe next week. (nurse 5)

Will they plan to send me home tomorrow? (patient 9)

Yes. (nurse 15)

They (family) want me to stay up here a couple of weeks instead of going home. (patient 55)

Is that what you want or what the family wants? (nurse 33)

In contrast, nurses initiated conversations focused on either encouraging patients by letting them know they were getting close to being discharged:

The way you are going I’m sure you’ll be home within 5 to 6 days. (nurse 27)

Getting better, should be going home soon. (nurse 17)

Or organising community based cardiac rehabilitation following discharge:

Did they talk to you about rehab? (nurse 5)

I’m just going to refer you to rehab. (nurse 40)
Now the other nurse has contacted the nurses at your local country hospital about rehab and we are just waiting for them to call her back. (nurse 11)

I’ve been discussing with the doctors the fact that your sister is away and you were staying with her so probably inpatient rehabilitation will be the way we’ll be going. So I’ll fill out the referrals today and start getting a place for you. (nurse 40)

While supportive, the information given tended to focus on the immediate post-discharge period. There was scant attention given to patients’ long-term treatment plan or their understanding of their chronic illness. Given that nurse-patient interactions were observed over a period of 96 hours the paucity of data related to discharge planning was instructive and thus specifically referred to during the second nurse focus group.

In the groups, nurses expressed frustration with what they perceived as inadequate communication from the medical team regarding discharge planning. This frustration related to what they perceived as a lack of interest by the medical staff in their patients’ readiness to be discharged:

I think very rarely they (doctors) will say are you right to get home? Or how are you going home? I don’t think I have ever heard that. Usually they say are you right to go? Yep! Ok well we will see you in two weeks time for a check-up. (nurse 1)
Yeah not really any questions about are you ready?  
(nurse 3)

Yeah very rarely do I hear are you ok?  
(nurse 1)

The lack of clear communication that involved both information giving and listening between the medical team, the patient and the nurse was also a source of dissatisfaction to some in the group.

I think it actually depends on the individual doctor because I have been on the rounds sometimes and even I’ve had to clarify so are they right to go home? It’s just not expressed across to the patient. I think it really is individualised to how the doctor’s bedside manner is. Because often I’ve found I have to stay around after the round and say you can actually go home are you ok about that.  
(nurse 2)

Just recently there was a concern over some patient. His concern was his wife going home. She wanted to go home but he didn’t want her to go home. There were some medical issues as well and I felt that they weren’t really being listened to. From their point of view they wanted to be involved and that was really frustrating.  
(nurse 3)

Although clearly frustrated by the medical team’s lack of communication regarding discharge planning it was not obvious from the data collected that nurses were willing to step in to fill the subsequent gap. They did not appear
to appreciate their role in the process, missing important verbal cues from patients who seemed uncertain of what lay ahead of them. While supportive and encouraging of the patient’s prospect of discharge they do not provide tangible advice about living with a chronic illness beyond the acute hospitalisation phase. The main source of interaction revolved around the administrative duty of organising post-discharge rehabilitation programs.
8.2.4 Summary of findings

- Patients discharged from hospital following surgery

  - Opportunity for in hospital education and participation to ensure quality and safe transition from hospital to home and prepare patients for long-term self-management of health

  - Majority of patients prefer involvement and have cognitive ability to participate in discharge planning

  - Nurse and patient interactions focused on the logistics of discharge and arranging cardiac rehabilitation

  - Nurses missed opportunities to oversee care and partner with patients to ensure patients receive a quality and safe transition from hospital to home

- Nurses

  - Nurses view of discharge planning limited to discharge date, destination and organising cardiac rehabilitation

  - Nurses felt frustrated by lack of communication with the health care team and to patients but did not take ownership of this aspect of care

Figure 8.3 Model of discharge planning findings
8.3 Discussion

In this chapter, patient participation in the context of discharge planning during a hospital admission for cardiac surgery was explored. In relation to patient preference, most patients’ preferred involvement in decisions about their discharge date and destination however most patients reported clinicians made all decisions relating to these aspects of discharge planning. Overall, patients displayed a greater understanding of their discharge destination, importance of cardiac rehabilitation and more were intending to attend cardiac rehabilitation as a function of their surgical admission. Nurses’ facilitation of discharge planning focused on the logistics of discharge and arranging cardiac rehabilitation.

As noted in the previous chapters, the mismatch between patients’ preference for participation in discharge planning and their reported involvement is not unique (Ford et al., 2003). However, patients who knew their discharge destination were more likely to prefer involvement in discharge planning decisions. Patients who prefer participation may want control of where they go and therefore seek participation in deciding their discharge destination.

Patients preferring clinicians to make decisions were more likely to be older, non-English speaking and born overseas. These patient characteristics were similar in patients who reported clinicians made the decisions, where again
non-English speaking patients and patients born overseas were less likely to report participation. Older patients have been shown to prefer a more passive role in participation in the contexts of clinical and treatment decision making (Arora & McHorney, 2000; Deber et al., 2007; Florin et al., 2006; O'Donnell et al., 2007).

As discussed in Chapter 6, patients’ region of birth and language spoken at home are indicators of a persons’ cultural background. People considered to be from a cultural minority have previously preferred and demonstrated a more passive role in treatment decisions than the cultural majority (O'Donnell et al., 2007; Schouten et al., 2007; Street et al., 2005). This may account for the decreased preference for, and reported participation by these groups of patients.

Discussions about patients’ discharge destination and referral to cardiac rehabilitation were evident in the observation periods. Of concern was the lack of understanding and missed opportunities by nurses to prepare patients for self-management of care following discharge. It appeared that patients’ trajectory in hospital was considered a surgical admission rather than an episode in a chronic illness. This was highlighted by the way nurses engaged patients in not only their discharge planning but in their medication and pain management during admission.
It appears from the observational data that the patients, the nurses and the medical team engage in conversations about discharge planning in a parallel rather than an integrated manner. Lack of communication in the process of discharge planning is not uncommon. Gaps in communication between health care professionals regarding discharge planning have been reported consistently (Bauer et al., 2009; Bull & Roberts, 2001; Efraimsson et al., 2004) and impede effective discharge planning (Bull & Roberts, 2001). The limited time clinicians spend in discussions about discharge planning is a known factor affecting communication in this context (Atwal, 2002; Lund, Tamm, & Bränholm, 2001). The minimal time nurses spend with patients to prepare them for long term self-management of their health is also a barrier to patients’ involvement in discharge planning. Time constraints have previously been identified as a major barrier to patient participation (Gravel et al., 2006; Timonen & Sihvonen, 2000) and when time constrained nurses give priority to immediate physical care over communication and documentation for patient discharge (McKenna, Keeney, Glenn, & Gordon, 2000; Payne, Hardey, & Coleman, 2000).

Frustration with the process of discharge planning and focus on the logistics of discharge planning by nurses appears to be reactive rather than proactive and impedes the role they could play in co-ordinating discharge planning. Further exploration of nurses’ understanding of the role they could play in discharge
planning is required along with systems of care that enhance facilitation of patient participation in discharge planning.

8.4 Conclusion

The findings of this study suggest the current system of care delivery does not support patient participation in discharge planning. This has implications for the quality and safety of care patients receive once discharged from hospital where patients are required to manage their own care and be responsible for making decisions about their care. In order to prepare patients to manage their care following discharge, patient involvement in their discharge planning while hospitalised must be optimised. This includes improving the communication between clinicians and patients and having a transparent process for involving patients (and their families) in their discharge planning.

Patient participation in discharge planning must be adopted as an important aspect of routinised care. The time nurses spend with patients and the information they provide in order to prepare patients for discharge are aspects of care delivery that require further investigation. Addressing these factors would require a fundamental shift in the way clinicians currently provide care related to discharge planning.
Chapter Nine

Conclusions

This study was designed to explore the current status of patient participation in meeting key recovery goals of care in the acute care context. The investigation of participation occurred during a hospital admission of patients experiencing an acute episode of a chronic illness who were admitted for a cardiac surgical intervention. In this context, a single institution, case study approach was used. Patient participation was described in terms of four *a priori* key recovery goals: medication management, pain management, pulmonary management and discharge planning.

In Chapter 2, patient participation was reviewed in terms of participation as a concept of patients’ interactions with health care and the operationalisation of patient participation within health care settings and contexts. It was argued that patient participation within acute care settings is likely to be affected by the unique characteristics of the acute environment that impact on patients’ knowledge and understanding of care processes and their willingness to participate. The complexity of patient participation as a concept and process, necessitated the development of a conceptual framework to build on understandings gained from previous research and this framework was
presented in Chapter 2 to provide clarity for the important concepts considered when designing the study.

Two key propositions emerged from the review of literature that relate to patient participation in the context of acute care:

1. Patients’ preference for participation in the recovery goals of care may vary based on the demands each goal places on patients in terms of perceived knowledge and role.

2. Barriers to the enactment of patient participation in achieving recovery goals of care are likely to be multi-faceted due to the complexity of patient participation in the acute care setting and include patient, clinician and environmental factors.

Participation in key goals of care allows patients to partner with clinicians to ensure high quality and safe care delivery and optimise their recovery following surgery. The notion of ‘patients as partners in care’ was introduced in the seminal publication, Crossing the Quality Chasm (Kohn et al., 2001) as a means of improving the safety and quality of health care. Fundamental to realising the aim of patients as partners in care is the quality of clinician and patient interactions to achieve the goals of care (Coulter, 1999).

The introduction of the notion of patients as partners into international, national and local policy documents was initiated, in part, through patients’
desire for more involvement in care (Biley, 1992; Coulter & Willis, 2004; Kennedy, 2003; Lober & Flowers, 2011). Widespread and easier access to literature regarding health has changed the way many patients present for health related consultations and treatment. Patients have greater health knowledge and seek involvement in care, including decisions that influence their health and quality of life (Biley, 1992; Coulter & Willis, 2004; Kennedy, 2003; Lober & Flowers, 2011). However, while patient participation has been incorporated into hospital policy documents, patient participation within the context of acute care is complex and there is little direction or clarity for how patients can participate in their care to increase the quality and safety of the care they receive.

In this last chapter, the findings of a study that has sought to explore 1) how patient participation was understood and enacted by patients and nurses, and 2) the barriers and facilitators of patient participation, within the acute care setting are integrated to inform clinical practice, education and future research agenda. The discussion begins with an integrated general synthesis of the findings in order to identify key learnings from the study. This is followed by a discussion of the significance of the research and recommendations for clinical practice, the strengths and limitations of the research and suggestions for future research directions.
9.1 Integration of research findings

The integrated analyses of the findings revealed two discernible patterns in care delivery that affected the way patient participation was observed and reported to be enacted in acute care practice. These differences in patient and nurse interactions were identified in relation to the four recovery goals of care after cardiac surgery. Care delivery was either nurse-centred or co-constructed between nurses and patients. Co-construction is defined as the joint construction of knowledge (Hausmann, Chi, & Roy, 2004). In health care, patients and clinicians need to co-construct the goals of care using clear communication in order to develop a shared understanding of their required roles to achieve patient participation in care. Figure 9.1 depicts a summary of the integration of research findings.

9.1.1 Nurse-centred care delivery

The first pattern of participation was evidenced by what could be described as nurse-centred care delivery. There was limited understanding by patients and nurses of the scope of a particular task in terms of patient participation and its function in overall health promotion, ambiguity by nurses and patients about the role patients could play in meeting recovery goals of care, and/or ambivalence by nurses about the value of engaging patients in the context of a busy acute care environment with complex care interventions.
Nurse-centric care delivery was most evident in medication management.

Both patients and nurses held very narrow interpretations of the routine task of medication administration and missed opportunities for ongoing patient education and involvement in safety processes.

Patients did not appear to understand the role they could play as a safety partner in medication management. Patients identified lack of knowledge as a barrier to participating and adequate knowledge as a facilitator to participating in their care both at preadmission and prior to discharge. Patients consistently described not knowing enough to participate as the main reason for preferring and reporting clinicians make/made all decisions in relation to medications. Perceived adequacy of knowledge is a recognised prerequisite for patients’ willingness to participate in care (Belcher, Fried, Agostini, & Tinetti, 2006; Biley, 1992; Jerant et al., 2005; O'Leary et al., 2010; Davis, Sevdalis, Jacklin, & Vincent, 2012).

Patients’ preference for participation in medication management was variable although most patients (75.3%) preferred clinicians to make the decisions without their input. Patients described not knowing enough to participate and that clinicians were the experts. This suggests that patients considered participation in medication management meant making decisions about medications as a therapeutic intervention and not using involvement in
medication management as a means of ensuring safety by checking they receive the right drug at the right time or to ensure that they had sufficient knowledge of their medications to allow safe self-management following discharge from hospital.

During focus groups, nurses did not spontaneously identify the role they could play in engaging patients as partners to optimise the quality and safety of medication management during and following hospitalisation. While nurses espoused the importance of patient involvement in care in general, there was little reflection on the processes of care delivery that may best facilitate participation. Analyses of the naturalistic observations revealed that nurses did not routinely use the interactions they had with patients as opportunities to provide patients with knowledge and understanding of their medications.

There was also evidence of limited engagement of patients in relation to some aspects of discharge planning. Interactions tended to focus on the logistics of discharge rather than on the importance of patients knowing and understanding their medications, ongoing care needs and secondary and tertiary rehabilitation. This finding of limited engagement of patients in discharge planning has been reported in many previous studies (Baumbusch et al., 2007; Hudson, Comer, & Whichello, 2012). The difference in patient engagement according to goal of care was evident in patient reports of
perceived involvement where no patients felt they had participated in medication management and 44% reported some participation in discharge planning when compared with pain management (81%) and pulmonary management (84%).

The nurse-centredness apparent in the management of medication administration and aspects of discharge planning exemplifies the focus on acuity rather than recognition of the chronicity of patients’ cardiovascular disease and the important role patients can play in the quality and safety of the care they receive both in hospital and after discharge.

**9.1.2 Co-construction of recovery goals of care**

When patients and nurses understood the role patients could play in the goals of care, ambivalence was reduced and co-construction of key recovery goals of care was evident. This was observed in pulmonary and pain management (pain assessment) and supported by patient reports of greater involvement in these aspects of care. Patient involvement in these goals of care is essential due to the nature of the task required, is well established and traditionally expected in post-operative environments (Agostini et al., 2012; Gordon et al., 2005; Macintyre et al., 2010; Overend et al., 2010; Tucker et al., 1996; Westerdahl & Olsén, 2011).
In pulmonary management there was an expectation from both patients and clinicians that patients would participate by undertaking regular deep breathing and coughing exercises and patients displayed a clear understanding of the deep breathing and coughing regimen. Also a high level of patient involvement in deep breathing and coughing exercises was displayed by patients’ preference for participation in this recovery goal. Patients were supported to participate in pulmonary exercises by nurses who understood how patients could participate in this aspect of care and regularly asked patients about their ability to deep breath and cough.

The recovery goal of pain management was unique in that there was co-construction of the assessment of pain but ambiguity about patients participating in the treatment of pain. Patients displayed a good understanding of the role they could play in the reporting and assessment of their pain with all patients stating they would report pain. Patients preferred (81%) and reported (81%) involvement in pain management but some patients acknowledged this was limited to the assessment of pain. Patients’ knowledge and involvement in the assessment of pain was supported by the actions of clinicians. Nurses were observed to routinely ask patients to report their pain level and the expectation that patients were involved in the assessment of pain was discussed by nurses in the focus group interviews. In contrast,
patients displayed less understanding of the treatment of pain and nurses were not observed to engage patients in this aspect of pain management.

The findings underpin the fundamental role clinicians play in engaging and facilitating patients to participate in the recovery goals of care. Knowledge and understanding of the role patients play in their recovery by both nurses and patients is clearly an important enabler of patient participation, however the culture of practice also appeared to play an important part in whether or not patients engaged in their care. There was evident ambivalence from nurses’ perspectives in balancing the priority of facilitating participation in the context of what are perceived to be higher value quality and safety interventions focused on immediate surgical recovery.
Co-construction of recovery goals of care

Collaboration Understanding Knowledge
- Pulmonary Management
- Pain Assessment

Nurse-centred care delivery of recovery goals of care

Task-focused Ambiguity Ambivalence
- Medication Management
- Discharge Planning
- Pain Treatment

Facilitators of Patient Participation

Barriers of Patient Participation

Culture of acute care environment

Figure 9.1 Model of integration of findings
9.2 Addressing the culture of acute care practice

The ways nurses prioritise care is very likely to be influenced by the environment in which they deliver care. The underpinning premise of the research reported in this thesis was that acute care environments present particular complexities that impact on the way nurses and patients interact and the way nurses carry out their work. The characteristics of these acute care environments create the ‘culture of care’ and encompass factors such as the structure and processes of care delivery, the choices made, interactions and habits and routines.

In 2009, Kalisch, Landstrom and Hinshaw, provided a concept analysis of the notion of ‘missed nursing care’ derived from data obtained via 25 focus groups with nurses who provide care for medical and surgical patients. They defined missing care as “…any aspect of required patient care that is omitted (either in part or whole) or delayed” (p.1510) and argued that this constitutes an error of omission. The ACSQHC (2012a) have identified ‘Consumers as Partners’ as one of the fundamental health care standards. Failure to engage patients in their care and facilitate participation is therefore deemed an error of omission. Nursing focus group data reported in this thesis, identified several gaps in the way nurses consider the opportunities inherent in some nursing tasks for engaging patients to participate however, in the main, nurses recognised the importance of patient participation but expressed frustration at the lack of available time.
to develop relationships with patients and engage them in care. Indeed the amount of time spent in patient interactions overall was very brief.

According to Kalisch et al. (2009), when faced with multiple demands and insufficient resources, nurses may make conscious decisions to abbreviate, delay or omit some aspects of care. In 2006, Kalisch identified nine elements of regularly missed care: ambulation, turning, delayed or missed feedings, patient teaching, discharge planning, emotional support, hygiene, intake and output documentation and surveillance. Reasons nurses gave for missing care included: too few staff, poor use of existing staff resources, time required for the nursing intervention, poor teamwork, ineffective delegation, habit and denial (Kalisch, 2006). Four factors that influence nurses’ choices to delay or omit elements of patient care were identified. These were: 1) team norms, 2) decision making processes, 3) internal values and 4) habits (Kalisch et al., 2009). Team norms, decision making processes and habits are derived from the culture of practice and bringing about change is difficult and requires changes to policy, commitment of stakeholders and substantial financial investment (Leape & Berwick, 2005).

Having to make choices about omission of aspects of care has implications for nurses. There was evidence of nurses’ ambivalence about the relative priority of engaging patients in their care given the competing demands of meeting patients’ physiological needs of recovery. There are implications for nurses when they make these choices. In several studies, the work
environment associated with acute care settings was investigated by evaluating nurses’ perceptions of their work. Reports of feeling rushed, busy and not having adequate time to deliver holistic care are consistent in the literature (Dunn, Wilson & Esterman, 2005; Hegney, Plank & Parker, 2006; Parker, Giles & Higgins, 2009). Nurses exhibit frustration and dissatisfaction with tasks such as locating patient care supplies and completing health care documentation, that take them away from delivering care to patients (Duffield, Gardner, & Catling-Paull, 2008; Ferenc, 2010). The tasks that take nurses away from the bedside diminish nurses’ ability to build relationships with patients (Dunn et al., 2005). Nurses describe the time they spend with patients as important in providing a sense of meaning in their work, and in contrast, a task-focused environment is seen as a barrier to extracting meaning from nursing (Pavlish & Hunt, 2012).

In 2006, Battles, in a paper advocating for a redesign of the healthcare system argued that the time has come to close the ‘quality chasm’. The Institute of Medicine in Crossing the quality chasm identified that: “Health care has safety and quality problems because it relies on outmoded systems of work. Poor designs set the workforce up to fail, regardless of how hard they try. If we want safer higher quality care, we will need to redesign systems of care...” (p.i1). To achieve this change in systems of care to facilitate patient participation there needs to be a shift from nurse-centred
care delivery to one that facilitates the co-construction of common goals of care. There are several aspects of the health care system that requires redesign. In high acuity environments there are workload and workforce issues, short patient length of stay and what Battles and Lilford (2003) describe as the clinical work systems involved in the processes of care. Health professional education and ongoing professional development is needed to prepare clinicians for a redesigned health care system where the patient is at the centre of care delivery. In addition, this education has to prepare clinicians for the “...break from the mythology of the independent professional model of work to embrace the reality of interconnected clinical work systems” (Battles, 2006, p. i3).

The perception of nurses that they work beside and not with other clinicians was evident in the focus group discussions related to discharge planning. Although it is widely recognised that collaboration and communication between interdisciplinary clinicians would decrease the risk of adverse events (Fewster-Thuente & Velsor-Friedrich, 2008), clinicians from different disciplines still tend to miss opportunities to collaborate with patients and other members of the interdisciplinary team (Bender, Connelly, Glaser & Brown, 2012). This ‘silo’ approach to care delivery stems from educational and socialisation processes within each health care discipline that have led to the development of discipline-specific own values, beliefs, attitudes, customs and behaviours (Hall, 2005).
What is required is a sustainable shift in the culture of practice to modify 1) team norms, 2) decision making processes, 3) internal values and 4) habits of clinicians. As with any initiative for quality improvement, health system redesign of this extent requires impetus to transform, leadership commitment to quality, improvement initiatives that actively engage clinicians in meaningful problem solving, and alignment to achieve consistency of organisation wide goals with appropriate resource allocation (Lukas et al., 2007).

The role that patients play in health care redesign has yet to be considered. For patients to navigate the complex environment of acute care and understand the structure and processes of care in that context, they need assistance (Sofaer, 2009). Lack of familiarity with the structure and processes of care is often coupled with patients’ fear of being labelled as difficult when attempting to assert their autonomy (Doherty & Stavropoulou, 2012). In these circumstances, a desire to perform in a way they perceive necessary to gain clinicians’ approval may cause them to assume a passive role in their care (Doherty & Stavropoulou, 2012). The lower participation in care by patients within cultural minority groupings identified in this research and the work of others (Schouten et al., 2007; Street et al., 2005) underscores the imperative to consider the varying needs of patients.
9.3 Strengths and limitations of the research

The research presented in this thesis has made a novel and important contribution to our understanding of patient participation in the context of acute care delivery. The design had a number of strengths. First, case study design is a comprehensive approach for exploring a phenomenon within a real-life context (LoBiondo-Wood & Haber, 1994; Yin, 2009). As such, case study design was the ideal method for exploring the enactment of patient participation within acute care.

The major strength of this approach was the use of data triangulation that encompasses the multiple environment, patient and clinician factors that impact on the enactment of patient participation (Polit & Hungler, 1997). In this study, triangulation was achieved using two methods: data triangulation and method triangulation. Triangulation of mixed methods including semi-structured interviews, naturalistic observation, medical record audit and focus group interviews enabled the multi-factorial influences on patient participation to be examined. Also, the inclusion of multiple groups as study informants allowed for both patients’ and nurses’ perceptions of patient participation to be explored.

Second, the repeated measures of knowledge of the key recovery goals of care showed that patients’ knowledge of these goals varied before and following surgical intervention and provided insight into the information patients received whilst hospitalised. The assessment of patients’
preference for participation across different key goals of care also showed
variation in patients’ preference for participation across recovery goals and
supports the proposition that patients’ preferences vary based on the
demands each goal places on patients in terms of perceived knowledge and
role. Third, the integration of findings from all the key recovery goals of
care provided a clear understanding of the issues surrounding the
enactment of patient participation in acute care and assists in developing
strategies to address these issues to optimise patient involvement in care.

Despite the identified strengths of this research program there are also
limitations that must be acknowledged. The external validity and
generalisability of case study design has previously been questioned (Yin,
2009). It is acknowledged that the use of a single centre case study limits
the degree to which findings of the study can be generalised to other
populations. This methodology has provided preliminary understandings of
the nature of patient participation in the post-operative cardiac context.
Further research is required using multiple case study methods. However,
the culture within the acute care setting explored in this study may be
transferable to similar clinical environments and assist in our
understanding of patient participation in these settings.

A potential limitation was that participants may act differently because of
the researcher’s presence, known as the Hawthorne effect. In order to limit
this phenomenon the researcher spent time in the ward prior to the
observations to promote familiarity to ward personnel and decrease awareness of staff. The use of two-hour observation periods provided a snap shot of clinical practice and may have missed interactions between nurses and patients where the key goals of care were discussed in a more in-depth manner. The brevity of actual data derived from the observations was unexpected as it was assumed the selected two-hour period would capture more interactions. Extending the data collection across several periods per patient may provide a more comprehensive evaluation of the facilitation of patient participation in post-operative recovery goals of care.

9.4 Future research directions

Knowledge of the current status of patient participation during an episodic admission to the acute care environment provides the foundation for future research in this context. This research should focus on interventions for supporting the structure and processes of care to optimise co-construction of key recovery goals of care in order for patients to partner with clinicians in achieving high quality and safe health care.

The study reported in this thesis, focused on patient and nurse perceptions of patient participation in recovery goals of care. A broader perspective that delves deeper into care-giver perspectives and the culture of practice should be the imperative for future research. Specifically, future research should address the best method to create a culture of care that facilitates
engagement of patients to participate in key care goals and develop processes of care that optimises patient participation in these goals.

As discussed earlier, ‘closing the quality chasm’ in relation to patient involvement requires a redesign of the system of care delivery in acute services. Future research agendas will necessarily be multi-faceted addressing the important interplay of factors that influence the quality and safety of care delivery in acute environments. The research agenda would focus on three interconnected programs: 1) redesigning acute care delivery systems towards patient centred care delivery; 2) the educational preparation of clinicians to provide the necessary skills to engage patients in their care that meets the varying needs and preferences of patients for participation, and the skills clinicians need to work in interconnected teams rather than independent disciplines; and 3) appropriate processes for informing patients about goals of care, skills in negotiating participation in environments that are unfamiliar to them, and a deeper understanding of the elements of care needs that determine patients’ preferences for participation in their care.

A further consideration that is fundamental to establishing and sustaining change in processes of care is the establishment of clear indicators of the quality of patient participation in key recovery goals of care to allow for continuous monitoring of patient participation, provide a feedback loop to
inform practice, and assess the effect of patient participation in recovery goals of care on the quality and safety of care.

9.5 Conclusions

The purpose of the research program reported in this thesis was to explore the current status of patient participation during an episodic admission to the acute care environment to inform change and future research directions. The case study design provided a means for describing fundamental aspects of the enactment of patient participation in the acute environment by allowing the examination of processes of care delivery. The repeated measures design provided insight into the impact of these care processes on patients’ preferences for participation and their knowledge of the key goals of recovery. The integrated analyses of the findings revealed two discernible patterns in care delivery that affected the way patient participation was observed and reported to be enacted in acute care practice. These patterns in care delivery reflected interactions that were either nurse-centred or involved the co-construction of goals of care between nurses and patients. The two patterns of care delivery identified the variable processes for involving patients in their care. Importantly, the findings revealed that involving patients in their care to promote a healthy post hospitalisation recovery and health maintenance was not a priority of care.
The findings underpin the fundamental role clinicians’ play in engaging and facilitating patients to participate in the recovery goals of care in acute care environments. Knowledge and understanding of the role patients play in their recovery by both nurses and patients is clearly an important enabler of patient participation, however the culture of practice appeared to play an important part in whether or not patients engaged in their care. These findings provide unique insights into care processes related to post-surgical management of patients and contribute to providing conceptual clarity about patient participation within the ‘real world’ clinical domain.

Substantial redesign of the acute health care system is required in order to achieve patient participation in this context. This redesign would require changes at a policy level, commitment from all stakeholders and sufficient financial investment to ensure sustainable change. Health care professional education would also require redesign to incorporate learnings that facilitate patient participation in care.

Future directions in research need to focus on the interplay of systems of care delivery, health professionals’ skills in facilitating participation and working within interdisciplinary work systems, and patient factors that impact on participation in complex, acute care environments.
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Appendix A Patient Plain Language Statement

Participant Information and Consent Form – Patient Observation and Interviews
Version 1 Dated 20th October 2007

Full Project Title: Defining patient participation in treatment in acute care contexts
Principal Researcher: Professor Mari Botti
Associate Researcher(s): Professor Maxine Duke
Ms Lauren McTier

This Participant Information and Consent Form is 6 pages long. Please make sure you have all the pages.

1. Your Consent
You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background
The purpose of this project is to explore the notion of patient participation following coronary artery bypass graft surgery. We want to gain a better understanding of the way patients participate in their care and how health professionals involve patients in their care. An additional purpose is to explore patients’ and health professionals’ preferences regarding patient participation in care.

Approximately 50 nurses and 200 patients will participate in this project.
Previous experience has shown that expanding involvement of patients in their care is associated with improved health outcomes (Kaplan, Greenfield & Ware, 1989; Kaplan, Gandek, Greenfield, Rogers & Ware, 1995; Kaplan, Greenfield, Gandek, Rogers & Ware, 1996; Wetzels, Harmsen, Van Weel, Grol, Wensing, 2007) whereas lack of patient involvement may have adverse consequences such as noncompliance resulting in negative outcomes (Schulman, 1979; Greenfield, Kaplan & Ware, 1985; Bibowski, 2001). The question of what roles are appropriate for patients to play in efforts to enhance their safety and how health care professionals should facilitate their contributions remains unclear in the acute care context where clinicians assume responsibility for 24-hour care. This study will provide recommendations on how patients can be active participants in their care following coronary artery bypass surgery to improve the quality and safety of care delivered.

You are invited to participate in this research project because you are planning to have coronary artery bypass graft surgery.

The results of this research may be used to help researcher Lauren McTier to obtain a Doctor of Philosophy.

3. Procedures

There are two separate data collection activities that you are invited to participate in as part of this research program. You can agree to participate in one or both of the data collection procedures. The first data collection method is observation. If you agree to participate in this part of the research, the researcher will observe activities related to your care for one 2 hour period within 24 hours following your return to the cardiac ward after surgery. The researcher/observer is a Registered Nurse, who will describe activities using a small microphone and may also make additional notes. Following the observation period the researcher will undertake a 15 minute interview to clarify your understanding regarding the interactions with health care professionals during the observation period.

The second data collection method that you are invited to participate in is two semi structured interviews with the researcher that will take approximately 45 minutes each to complete. The types of questions you will be asked during the interviews relate to your understanding and experience regarding participation in your care. If you agree to participate in this part of the study, the researcher will interview you two times during your hospital stay 1) at the preadmission clinic, and 2) within 12 hours prior to discharge from hospital.

The researcher will also access your medical record, to record your demographic information, medical history, and details relating to your management of pain, medications, pulmonary care and discharge planning. Prior to your second interview you will be asked six questions that test your memory and thinking.
4. **Possible Benefits**
While there may be no direct benefit to you from participating in this study, an improved understanding of how patients participate and their desired level of participation will potentially improve the quality and safety of health care.

5. **Possible Risks**
The interviews will not affect the care you receive. Should you be in any level of discomfort during the interview, the interview can be postponed until you are ready to continue.

6. **Privacy, Confidentiality and Disclosure of Information**
Any information obtained in connection with this project and that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law. If you give us your permission by signing the Consent Form, we plan to publish the results in a professional journal and submit the findings to Deakin University in the form of a thesis for examination.

In any publication, information will be provided in such a way that you cannot be identified.

7. **New Information Arising During the Project**
During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs and medical condition.

8. **Results of Project**
A summary of the results will be available for you on request.

9. **Further Information or Any Problems**
If you require further information or if you have any problems concerning this project you can contact the principal researcher Professor Mari Botti on (03) 94266565.

10. **Other Issues**
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name: Ms Rowan Frew

Position: Ethics Manager, Office of Ethics and Research, Alfred Hospital

Telephone: (03) 9076 3848
or

Name: Ms Sylvia Rametta
Position: Secretary, Deakin University Human Research Ethics Committee
Telephone: (03) 9251 7123

You will need to tell the contact person the name of the researcher given in section 10 above.

11. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with the Alfred Hospital.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

12. Ethical Guidelines

This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of this institution.

13. Reimbursement for your costs

You will not be paid for your participation in this project.
Consent Form
Version 1 Dated 20th October 2007
Full Project Title: Defining patient participation in treatment in acute care contexts

I have read, or have had read to me in my first language and I understand the Participant Information version 1 dated 20th October 2007.

I freely agree to participate in the observation component and/or interview component of the project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant’s Name (printed) ..............................................................
Signature
Date

Name of Witness to Participant’s Signature (printed)
..............................................................
Signature
Date

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher’s Name (printed) ..............................................................
Signature
Date

* A senior member of the research team must provide the explanation and provision of information concerning the research project.

Note: All parties signing the Consent Form must date their own signature.
REVOCATION OF CONSENT FORM

Revocation of Consent Form

Full Project Title: Defining patient participation in treatment in acute care contexts

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with the Alfred Hospital.

Participant’s Name (printed) .................................................................

Signature  Date
Appendix B Nurse Plain Language Statement

Participant Information and Consent Form – Nurses
Version 1 Dated 20th October 2007

Full Project Title: Defining patient participation in treatment in acute care contexts
Principal Researcher: Professor Mari Botti
Associate Researcher(s): Professor Maxine Duke
Ms Lauren McTier

This Participant Information and Consent Form is 6 pages long. Please make sure you have all the pages.

1. Your Consent
You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background
The purpose of this project is to explore the notion of patient participation following coronary artery bypass graft surgery. We want to gain a better understanding of the way patients participate in their care and how health professionals involve patients in their care. An additional purpose is to explore patients’ and health professionals’ preferences regarding patient participation in care.

Approximately 50 nurses and 200 patients will participate in this project.

Previous experience has shown that Expanding involvement of patients in their care is associated with improved health outcomes (Kaplan, Greenfield & Ware, 1989; Kaplan, Gandek, Greenfield, Rogers & Ware,
1995; Kaplan, Greenfield, Gandek, Rogers & Ware, 1996; Wetzels, Harmsen, Van Weel, Grol, Wensing, 2007) whereas lack of patient involvement may have adverse consequences such as noncompliance resulting in negative outcomes (Schulman, 1979; Greenfield, Kaplan & Ware, 1985; Bibowski, 2001). The question of what roles are appropriate for patients to play in efforts to enhance their safety and how health care professionals should facilitate their contributions remains unclear in the acute care context where clinicians assume responsibility for 24-hour care. This study will provide recommendations on how patients can be active participants in their care following coronary artery bypass surgery to improve the quality and safety of care delivered.

You are invited to participate in this research project because you work with patients undergoing coronary artery bypass graft surgery in an acute care setting.

The results of this research may be used to help researcher Lauren McTier to obtain a Doctor of Philosophy.

3. Procedures
There are two separate data collection activities that you are invited to participate in as part of this research program. You can agree to participate in one or both of the data collection procedures. The first data collection method is observation. If you agree to participate in this part of the research, you will be observed while providing care for a patient who has consented to take part in the study. The observation will be conducted over a 2 hour period during which activities relating to patient participation in key goals of care will be observed. The researcher/observer is a Registered Nurse, who will describe activities using a small microphone and may also make additional notes. During this period the researcher may ask you to clarify your care decisions to enhance understanding of patient participation.

The second data collection method that you are invited to participate in is a focus group. The focus group will be used to help clarify barriers and facilitators of patient participation in the acute care context and explore your understanding of patients as participants in their care.

4. Possible Benefits
While there may be no direct benefit to you from participating in this study, an improved understanding of how patients participate and their desired level of participation will potentially improve the quality and safety of health care.

5. Possible Risks
There are no anticipated risks relating to your participation in this research program.
6. **Privacy, Confidentiality and Disclosure of Information**

Any information obtained in connection with this project and that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law. If you give us your permission by signing the Consent Form, we plan to publish the results in a professional journal and submit the findings to Deakin University in the form of a thesis for examination.

In any publication, information will be provided in such a way that you cannot be identified.

7. **New Information Arising During the Project**

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs and medical condition.

8. **Results of Project**

A summary of the results will be available for you on request.

9. **Further Information or Any Problems**

If you require further information or if you have any problems concerning this project you can contact the principal researcher Professor Mari Botti on (03) 94266565.

10. **Other Issues**

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name: Ms Rowan Frew
Position: Ethics Manager, Office of Ethics and Research, Alfred Hospital

Telephone: (03) 9076 3848

or

Name: Ms Sylvia Rametta
Position: Secretary, Deakin University Human Research Ethics Committee

Telephone: (03) 9251 7123

You will need to tell the contact person the name of the researcher given in section 10 above.
12. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with the Alfred Hospital.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

13. Ethical Guidelines

This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of this institution.

14. Reimbursement for your costs

You will not be paid for your participation in this project.
Consent Form
Version 1 Dated 20th October 2007

Full Project Title: Defining patient participation in treatment in acute care contexts

I have read, or have had read to me in my first language and I understand the Participant Information version 1 dated 20th October 2007.

I freely agree to participate in the observation component and/or interview component of this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant’s Name (printed) ……………………………………………………
Signature Date

Name of Witness to Participant’s Signature (printed)
……………………………………………
Signature Date

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher’s Name (printed) …………………………………………………
Signature Date

* A senior member of the research team must provide the explanation and provision of information concerning the research project.

Note: All parties signing the Consent Form must date their own signature.
REVOCATION OF CONSENT FORM

Revocation of Consent Form

**Full Project Title:** Defining patient participation in treatment in acute care contexts

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with the Alfred Hospital.

Participant’s Name (printed) .................................................................

Signature                                      Date
Appendix C Preadmission Patient Participation Questionnaire

Patient Identification Number:____________
Date:__________
Time interview commenced:__________
Time interview completed:__________

Eligibility Criteria

Date of birth: __________  1 □ before or equal 1990   2 □ after 1990

Type of surgery: __________

Patient eligible:  1 □ Yes    2 □ No

Patient consented to interviews:  1 □ Yes    2 □ No

Patient consented to observation:  1 □ Yes    2 □ No
Preadmission Data

Age (years): ______  Sex: 1 □ Male  2 □ Female

Marital status:  1 □ Single  2 □ Married  3 □ De facto
4 □ Separated/divorced  5 □ Widowed

Number of children: ______  Number of dependents: ______

Country of birth:  1 □ Australia  2 □ UK  3 □ Italy
4 □ Greece  5 □ Germany  6 □ Russia
7 □ Israel  8 □ China  9 □ Malaysia
10 □ Other: __________

Age on arrival to Australia (years): ______

Language spoken at home:  1 □ English  2 □ Italian  3 □ Greek
4 □ German  5 □ Russian  6 □ Hebrew
7 □ Mandarin  8 □ Cantonese  9 □ Other: __________

Requires an interpreter:  1 □ Yes  2 □ No
Highest level of education completed:  1  □  < year 12  
2  □  VCE or equivalent  3  □  Tertiary  4  □  Postgraduate  
5  □  TAFE  6  □  Other:__________

Medical History: Vessel Disease  1  □  Single  2  □  Double  
3  □  Triple  Valve dysfunction  1  □  Aortic  2  □  Mitral  

Other:____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
Semi-structured questions

In the near future you are going to have cardiac surgery. I am interested in how you see your involvement in your recovery following your operation.

While you are in hospital (after your operation) you will be receiving various treatments to ensure optimal recovery.

There are four aspects of your recovery that I would like to talk to you about today: your medications, your pain management, your respiratory management and your discharge from hospital.
MEDICINE MANAGEMENT

The first one is medicines. While you are in hospital (after your operation) you will be receiving medicine for your disease, your pain and nausea and to prevent complications.

I would like you to think about how you would like to be involved in the management of your medicines while you are in hospital.

Let’s begin with what medicines you are now taking

How many medicines are you taking?_____________________

Medicine:________________________

Amount of medicine:___________

Time of day you take medicine:
________________________________________________________

Medication:__________________ Ordered Dose:____________

Frequency: 1 □ Daily 2 □ BD 3 □ TDS
4 □ QID 5 □ 4/24 6 □ Hourly
7 □ Other

Route/s: 1 □ Oral 2 □ IM 3 □ IV
4 □ SC 5 □ PR 6 □ S/L

PRN order: 1 □ Yes 2 □ No

Can you tell me why you are on this medicine?
Is there anything you need to look out for when taking this medicine (side effects)?

**PAIN MANAGEMENT**

Following your operation you may experience pain which will require pain management. While you are in hospital (after your operation) you will be receiving medicines and other treatments to manage this pain and prevent complications.

I would like you to think about how you would like to be involved in the management of your pain while you are in hospital.

Can you tell me why you think it is important to control your pain following your operation?

If you experience pain in hospital will you tell someone? How?

If so who and why?

If you are given pain relief and your pain has not subsided will you tell anyone? How?
Why?

Can you tell me if you will be offered one or several medicines to control your pain after your operation?

If several why?

Can you tell me any other things apart from medicines that may be used to control your pain after your operation?

Are you concerned about any medicines or other treatments that you may receive for pain relief? If yes why?

RESPIRATORY MANAGEMENT

While you are in hospital (after your operation) you will be expected to undertake respiratory exercises.

I would like you to think about how you would like to be involved in your respiratory exercises while you are in hospital.
Can you tell me what respiratory exercises you will be expected to do?

Can you tell me why you think it is important to do respiratory exercises following your operation?

Can you tell me if there will be anything that may prevent you from doing respiratory exercises? If so, what will you do?

If you are told how and when to do the respiratory exercises will you wait until someone instructs you to do them or will you manage them yourself?

Why/Why not?

**DISCHARGE PLANNING**

While you are in hospital (after your operation) you will discuss what is required of you after leaving hospital with your doctors and nurses.

I would like you to think about how you would like to be involved in these discussions while you are in hospital.

Can you tell me where you will go following discharge from hospital?
Have you spoken with any clinician about cardiac rehabilitation?

If yes, who?

Do you intend to participate in cardiac rehabilitation?

Why/Why not?

PATIENT PARTICIPATION

Would you like to participate in your care while recovering from surgery?

What do you think would make it difficult (barrier) to participate in your care?

What do you think would make it easier (facilitate) to participate in your care?
**Control Preference Scale – Medication Management**

Following patient decisions about preference number the boxes starting at 1 (their most preferred role) to 5 (their least preferred role).

<table>
<thead>
<tr>
<th>I prefer to leave all decisions about my medicines to my clinicians.</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>I prefer that my clinicians make the final decisions about my medicines, but seriously consider my opinion.</td>
<td>2</td>
</tr>
<tr>
<td>I prefer that my clinicians and I share responsibility for decisions about my medicines.</td>
<td>3</td>
</tr>
<tr>
<td>I prefer to make the final decisions about my medicines after seriously considering my clinicians’ opinion.</td>
<td>4</td>
</tr>
<tr>
<td>I prefer to make the final decisions about my medicines.</td>
<td>5</td>
</tr>
</tbody>
</table>

For medication management why did you rank your preference in this way?
**Control Preference Scale – Pain Management**

Following patient decisions about preference number the boxes starting at 1 (their most preferred role) to 5 (their least preferred role).

<table>
<thead>
<tr>
<th>Preference</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>I prefer to leave all decisions about my pain to my clinicians.</td>
<td>1</td>
</tr>
<tr>
<td>I prefer that my clinicians make the final decisions about my pain, but seriously consider my opinion.</td>
<td>2</td>
</tr>
<tr>
<td>I prefer that my clinicians and I share responsibility for decisions about my pain.</td>
<td>3</td>
</tr>
<tr>
<td>I prefer to make the final decisions about my pain after seriously considering my clinicians’ opinion.</td>
<td>4</td>
</tr>
<tr>
<td>I prefer to make the final decisions about my pain.</td>
<td>5</td>
</tr>
</tbody>
</table>

For pain management why did you rank your preference in this way?
Control Preference Scale – Pulmonary Management

Following patient decisions about preference number the boxes starting at 1 (their most preferred role) to 5 (their least preferred role).

1. I prefer to leave all decisions about my respiratory exercises to my clinicians.  

2. I prefer that my clinicians make the final decisions about my respiratory exercises, but seriously consider my opinion.  

3. I prefer that my clinicians and I share responsibility for decisions about my respiratory exercises.  

4. I prefer to make the final decisions about my respiratory exercises after seriously considering my clinicians’ opinion.  

5. I prefer to make the final decisions about my respiratory exercises.  

For pulmonary management why did you rank your preference in this way?
### Control Preference Scale – Discharge Planning

Following patient decisions about preference number the boxes starting at 1 (their most preferred role) to 5 (their least preferred role).

<table>
<thead>
<tr>
<th>Preference Description</th>
<th>Box</th>
</tr>
</thead>
<tbody>
<tr>
<td>I prefer to leave all decisions about my discharge to my clinicians.</td>
<td>1</td>
</tr>
<tr>
<td>I prefer that my clinicians make the final decisions about my discharge, but seriously consider my opinion.</td>
<td>2</td>
</tr>
<tr>
<td>I prefer that my clinicians and I share responsibility for decisions about my discharge.</td>
<td>3</td>
</tr>
<tr>
<td>I prefer to make the final decisions about my discharge after seriously considering my clinicians’ opinion.</td>
<td>4</td>
</tr>
<tr>
<td>I prefer to make the final decisions about my discharge.</td>
<td>5</td>
</tr>
</tbody>
</table>

For discharge planning why did you rank your preference in this way?
Appendix D Pre-discharge Patient Participation Questionnaire

Patient Identification Number:__________

Date:__________

Time interview commenced:__________

Time interview completed:__________

Six- Item-Screener

I would like to ask you some questions that ask you to use your memory. I am going to name three objects. Please wait until I say all three words, then repeat them. Remember what they are because I am going to ask you to name them again in a few minutes. Please repeat these words for me:

APPLE – TABLE – MONEY.

(Interviewer may repeat names 3 times if necessary but repetition not scored).
<table>
<thead>
<tr>
<th>Incorrect</th>
<th>Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the day of the week?</td>
<td>0</td>
</tr>
<tr>
<td>What month is this?</td>
<td>0</td>
</tr>
<tr>
<td>What year is this?</td>
<td>0</td>
</tr>
<tr>
<td>Apple</td>
<td>0</td>
</tr>
<tr>
<td>Table</td>
<td>0</td>
</tr>
<tr>
<td>Money</td>
<td>0</td>
</tr>
</tbody>
</table>

Did patient correctly repeat all three words?  1 [ ] Yes  2 [ ] No

Total score = _______

**Semi-structured questions**

In the near future you are going home. I am interested in how you were involved in your recovery following your operation. While in hospital (after your operation) you have received various treatments to ensure optimal recovery.

There are four aspects of your recovery that I would like to talk to you about today your medications, your pain management. Your respiratory management and your discharge from hospital.
**MEDICINE MANAGEMENT**

The first one is medicines. While in hospital (after your operation) you have received medicine for your disease, your pain and nausea and to prevent complications.

I would like you to think about how you were involved in the management of your medicines while in hospital.

Let’s begin with what medicines you are now taking.

How many medicines are you taking? ________________

Medicine: ____________________________

Amount of medicine: ___________

Time of day you take medicine: __________________________________________

<table>
<thead>
<tr>
<th>Medication: __________________</th>
<th>Ordered Dose: __________</th>
</tr>
</thead>
</table>

- Frequency: 1 □ Daily  2 □ BD  3 □ TDS  4 □ QID  5 □ 4/24  6 □ Hourly  7 □ Other
- Route/s: 1 □ Oral  2 □ IM  3 □ IV  4 □ SC  5 □ PR  6 □ S/L
- PRN order: 1 □ Yes  2 □ No

Can you tell me why you are on this medicine?
Is there anything you need to look out for when taking this medicine (side effects)?

Have any new medicines been introduced following your operation?

Are there any medicines that you have been taken off while you have been in hospital?

How many medicines have been stopped?

Can you tell me why this medicine has been stopped?

Tell me about the medicines you were taking before admission and are to continue taking after you leave hospital.

Have any of the medicines you were taking before admission been changed in relation to number of tablets, time of day etc?
PAIN MANAGEMENT

While you have been in hospital (after your operation) you received medicines and other treatments to manage your pain and prevent complications.

I would like you to think about how you have been involved in the management of your pain while in hospital.

Can you tell me why you think it has been important to control your pain following your operation?

Did you tell someone when you experienced pain in hospital? How?

If so who and why?

Were you given pain relief and your pain did not subside?

If yes, what did you do and why?
Can you tell me if you were offered one or several medicines to control your pain after your operation?

If several why?

Can you tell me any other things apart from medicines that were used to control your pain after your operation?

Are you concerned about any medicines or other treatments that you received for your pain relief while in hospital? If yes why?

**RESPIRATORY MANAGEMENT**

While in hospital (after your operation) you have been expected to undertake respiratory exercises.

I would like you to think about how you have been involved in your respiratory exercises while in hospital.

Can you tell me what respiratory exercises you have been expected to do?
Can you tell me why you think it is important to have undertaken your respiratory exercises following your operation?

Can you tell me if there has been anything that has prevented you from doing respiratory exercises? If so, what did you do?

Did you do the respiratory exercises yourself or did you wait until someone told you to do them? Why/Why not?

**DISCHARGE PLANNING**

While in hospital (after your operation) you have discussed your discharge with your doctors and nurses.

I would like you to think about how you have been involved in these discussions while in hospital.

Can you tell me where you will go following your discharge from hospital?
Have you spoken with any clinician about cardiac rehabilitation?

If yes, who?

Do you intend to participate in cardiac rehabilitation?

Why/Why not?

**PATIENT PARTICIPATION**

Did you participate in your care while recovering from surgery?

Were you happy with your level of participation or would you have liked more involvement?

What made it difficult (barrier) to participate in your care?

What made it easier (facilitate) to participate in your care?
### Reported Control Scale – Medication Management

Following patient decision reflecting their reported participation cross the box that reflects patients’ reported participation.

- My clinicians made all decisions about my medicines. 1
- My clinicians made the final decisions about my medicines, but seriously considered my opinion. 2
- My clinicians and I shared responsibility for decisions about my medicines. 3
- I made the final decisions about my medicines after seriously considering my clinicians’ opinion. 4
- I made the final decisions about my medicines. 5

For medication management why do you think this happened?
### Reported Control Scale – Pain Management

Following patient decision reflecting their reported participation cross the box that reflects patients’ reported participation.

<table>
<thead>
<tr>
<th>Description</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>My clinicians made all decisions about my pain.</td>
<td>1</td>
</tr>
<tr>
<td>My clinicians made the final decisions about my pain, but seriously considered my opinion.</td>
<td>2</td>
</tr>
<tr>
<td>My clinicians and I shared responsibility for decisions about my pain.</td>
<td>3</td>
</tr>
<tr>
<td>I made the final decisions about my pain after seriously considering my clinicians’ opinion.</td>
<td>4</td>
</tr>
<tr>
<td>I made the final decisions about my pain.</td>
<td>5</td>
</tr>
</tbody>
</table>

For pain management why do you think this happened?
**Reported Control Scale – Pulmonary Management**

Following patient decision reflecting their reported participation cross the box that reflects patients’ reported participation.

| My clinicians made all decisions about my respiratory exercises. | 1 |
| My clinicians made the final decisions about my respiratory exercises, but seriously considered my opinion. | 2 |
| My clinicians and I shared responsibility for decisions about my respiratory exercises. | 3 |
| I made the final decisions about my respiratory exercises after seriously considering my clinicians’ opinion. | 4 |
| I made the final decisions about my respiratory exercises. | 5 |

For respiratory exercises why do you think this happened?
### Reported Control Scale – Discharge Planning

Following patient decision reflecting their reported participation cross the box that reflects patients’ reported participation.

- My clinicians made all decisions about my discharge planning.
  - 1
- My clinicians made the final decisions about my discharge planning, but seriously considered my opinion.
  - 2
- My clinicians and I shared responsibility for decisions about my discharge planning.
  - 3
- I made the final decisions about my discharge planning after seriously considering my clinicians’ opinion.
  - 4
- I made the final decisions about my discharge planning.
  - 5

For discharge planning why do you think this happened?
Appendix E University Ethics Approval

Research Services
Office of the Deputy Vice-Chancellor (Research) (Melbourne Campus)

MEMORANDUM

TO: Prof. Mari Botti
   School of Nursing, Burwood

FROM: Deakin University Human Research Ethics Committee (DU-HREC)

DATE: 13 May 2008

SUBJECT: Project EC 47-2008  
*Please quote this project number in future communication.*

Defining patient participation in treatment in acute care contexts

Interim approval for this project was ratified at the DU-HREC meeting held on 12 May 2008.

Approval has been given for Lauren McTier, under the supervision of Prof. Mari Botti, School of Nursing, to undertake this project for a period of three years from 10 April 2008.

The approval given by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the approval. It is your responsibility to contact the Executive Officer immediately should any of the following occur:

• Serious or unexpected adverse effects on the participants
• Any proposed changes in the protocol, including extensions of time.
• Any events which might affect the continuing ethical acceptability of the project.
• The project is discontinued before the expected date of completion.
• Modifications are requested by other HREC's.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

DU-HREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Research Involving Humans (1999)

Signature Redacted by Library

Vicky Bates, Secretary
On behalf of DU-HREC
03 9251 7012
Appendix F Hospital Ethics Approval

ETHICS COMMITTEE CERTIFICATE OF APPROVAL

This is to certify that

Project No: 273/07
Project Title: Defining patient participation in treatment in acute care contexts
Principal Researcher: Professor Mari Botti

Protocol No: 273/07

Participant Information and Consent Form (Patient Interview & Observation) version 2 dated: 11-Dec-2007
Participant Information and Consent Form (Patient Interview), version 2 dated: 11-Dec-2007
Participant Information and Consent Form (Nurse Focus Group & Observation), version 2 dated: 11-Dec-2007

was considered by the Ethics Committee on 20-Dec-2007 and APPROVED on 21-Dec-2007

It is the Principal Researcher’s responsibility to ensure that all researchers associated with this project are aware of the conditions of approval and which documents have been approved.

The Principal Researcher is required to notify the Secretary of the Ethics Committee, via amendment or progress report, of:

- Any significant change to the project and the reason for that change, including an indication of ethical implications (if any);
- Serious adverse effects on participants and the action taken to address those effects;
- Any other unforeseen events or unexpected developments that merit notification;
- The inability of the Principal Researcher to continue in that role, or any other change in research personnel involved in the project;
- Any expiry of the insurance coverage provided with respect to sponsored clinical trials and proof of re-insurance;
- A delay of more than 12 months in the commencement of the project; and,
- Termination or closure of the project.

Additionally, the Principal Researcher is required to submit:

- A Progress Report on the anniversary of approval and on completion of the project (forms to be provided);

The Ethics Committee may conduct an audit at any time.

All research subject to the Alfred Hospital Ethics Committee review must be conducted in accordance with the National Statement on Ethical Conduct in Human Research (2007).

The Alfred Hospital Ethics Committee is a properly constituted Human Research Ethics Committee in accordance with the National Statement on Ethical Conduct in Human Research (2007).

SPECIAL CONDITIONS

None

SIGNATURE: [Signature Redacted by Library]

K Dunscombe
Acting Secretary, Ethics Committee

Please quote Project No and Title in all correspondence.