The Experience of Patients, Spouses and Nurses using the Aussie Heart Guide for Home Based Cardiac Rehabilitation

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Statement of Originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any other tertiary institution and, to the best of my knowledge and belief contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University’s Digital Repository, subject to the provisions of the Copyright Act 1968.

Dawn McIvor.................................................................
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Glossary of Terms

The AHG

The Aussie Heart Guide, the model used in the study to deliver home based cardiac rehabilitation to patients.

Home based Cardiac rehabilitation

Cardiac rehabilitation (exercise and education) delivered in the patient’s home either via the telephone or face to face. For the purpose of my study when this term is used it is predominately in relation to telephone support as described below.

Telephone based/ telephone support

Nursing support given to patients via telephone with no face to face contact. Patients and spouses within my study mainly had telephone support.

Telehealth

Telehealth refers to “the use of telecommunication technology to remove time and distance barriers in the delivery of health care services” (Artinian, 2007, p. 25). In the context of my study it refers to the use of the telephone to provide nursing support to patients.
Abstract

The Aussie Heart Guide is a home based cardiac rehabilitation program. It is delivered over the telephone, to patients with coronary artery disease by an Aussie Heart Guide nurse mentor who works in partnership with the patient for lifestyle change and the management of their condition. Home based cardiac rehabilitation using programs like the Aussie Heart Guide is effective in reducing the morbidity and mortality from coronary artery disease. However little is known about the acceptability of this type of program to the Australian patient, their principle lay care giver, nurse mentors who work alongside patients in its delivery or about what impact it has on nursing roles and functions. The purpose of this study was to explore all these factors in the context of using the Aussie Heart Guide with patients experiencing coronary artery disease and their lay carers (all spouses in this instance).

The methodology used in the study was qualitative description. Four patients with requiring cardiac rehabilitation, three spouses and five nurse mentors participated in the study. Their experiences of using the Aussie Heart Guide were captured via semi structure interviews (nurses) and questionnaire (patients and spouses).

Findings from the study include that patients perceived the Aussie Heart Guide was useful for their recovery and liked the ability it provided to them to monitor their own progress. They also valued their relationship with their nurse mentor. Patient engagement with the program was influenced by their previous illness experience, transition from hospital to home and previous experience of cardiac rehabilitation. The implications of the patient findings were that an individualised program with flexibility of modality would enhance the patient experience. Therefore nurses need
additional skills and knowledge in how to deliver telephone based services to patients which enhance the patient nurse relationship. Spouses though few in number also found the Aussie Heart Guide useful to them in supporting the patient.

Nurses found the Aussie Heart Guide useful in supporting patients experiencing lifestyle change and support with disease management. However, they were uncertain about their relationships with patients when contact was predominately telephone only. The uncertainty resulted in concerns regarding their rapport and honesty in communications with patients. Nurses and patients struggled with issues such as power and control within their relationship and some nurses found working in partnership with patients challenging. Therefore nurses need additional skills and knowledge in how to deliver telephone based services to patients which enhance the patient nurse relationship.

Nevertheless, the Aussie Heart Guide appears to be an acceptable model of home based cardiac rehabilitation patients with coronary artery disease, their spouses and nurses.
Chapter 1

1.0 Introduction

My research study sought to explore the patient, spouse and nurse experience of using the Aussie Heart Guide (AHG), a home based cardiac rehabilitation program. The AHG’s emphasis is on the patient’s recovery from an acute cardiac illness such as myocardial infarction, including lifestyle change and supporting the patient and his/her spouse in understanding and managing his/her illness. When using the AHG, there is an expectation that the nurse, patient and spouse will work in partnership in the delivery of home based cardiac rehabilitation.

Little is known about the use of home based cardiac rehabilitation in Australia, as hospital based cardiac rehabilitation is the predominant model of care for patients with Coronary Artery Disease (CAD). Therefore the purpose of my study is to evaluate the use of the AHG home based cardiac rehabilitation program within a region of Australia. I anticipated that the information gained from this study might help improve participation rates and the future experience of patients and their spouses referred to home based cardiac rehabilitation. I also anticipated that information from my study might identify education and support needs for nurses implementing home based cardiac rehabilitation programs of this nature.

This chapter describes the background and significance of my study and my background and reason for undertaking this research. It also outlines my research question and the aims of my study. The chapter concludes with an outline of the structure and content of the remaining chapters within this thesis.
1.1 Background to my study

The increasingly ageing population and improved survival rates from previously fatal diseases suggests that by 2020 chronic diseases such as cardiovascular disease, diabetes and arthritis may account for 80% of the health care burden within New South Wales (NSW), Australia (NSW Department of Health, 2006a). There are several reasons for this, including the complex causes of chronic diseases from multiple risk factors, their long latency period leading to possible functional impairment and the chronic nature of these diseases (National Public Health Partnership, 2001). Currently, cardiovascular disease, which incorporates stroke and CAD, accounts for more than 18% of the chronic disease burden and 38% of all deaths in NSW (NSW Department of Health, 2006a). Coronary artery disease is the leading cause of cardiovascular disease mortality accounting for 50% of deaths in NSW (NSW Department of Health, 2006a).

Coronary artery disease is caused by atherosclerosis, which is the build up of plaque on the wall of the coronary arteries (Jowett & Thompson, 2007). Plaque is a substance made up of cholesterol, fat and calcium that develops on the inner lining of the arteries. The function of the coronary arteries is to supply the myocardium (heart muscle) with blood and oxygen; if the blood supply to the myocardium is permanently or temporarily interrupted, then the individual may experience chest discomfort and other symptoms that might lead to heart muscle damage. Acute Coronary Syndrome is the umbrella term used to describe an acute episode of chest pain resulting in unstable angina or acute myocardial infarction. Acute myocardial infarction (AMI or heart attack) occurs when the artery is completely blocked, usually by a thrombus (blood clot) caused by plaque breaking off the wall of the artery, leading to necrosis (death) of heart muscle. Unstable angina occurs when the coronary artery is partially narrowed owing to the build up of plaque, resulting in increased demand on the myocardium (Jowett & Thompson, 2007). The debilitating
condition of heart failure commonly resulting from CAD occurs when the myocardium is damaged to such an extent that it restricts its ability to effectively pump blood around the body (Jowett & Thompson, 2007). Coronary Artery Disease has a significant impact on the individual, the community and the health care system.

1.1.1 Impact of Coronary Artery Disease on the individual

Having CAD has a significant impact on the individual, their partner or spouse and their family and friends. After musculoskeletal conditions and mental illness, CAD is the third highest cause of morbidity and disability within NSW (NSW Department of Health, 2006a). Nationally, cardiovascular disease remains the largest cause of mortality in Australia, accounting for 34% and 39% of male and female deaths, respectively (National Heart Foundation of Australia 2007). Taking fatal and non-fatal disease into account, cardiovascular disease contributes 18% of the total burden in disability-adjusted life years (DALYs)¹ (National Heart Foundation of Australia 2007). These figures are similar to those of other developed countries. To put this morbidity into context, the American Heart Association suggests that if a person survives their heart attack then they have a risk of illness or death up to fifteen times higher than the general population and that over the course of their lifetime approximately two-thirds of people will fail to make a complete recovery (American Heart Association, 2003).

A multitude of risk factors for CAD exist, including gender, increasing age, family history of CAD or stroke, diabetes, smoking cigarettes, high blood pressure, high cholesterol, obesity, lack of physical activity, and dietary factors such as high fat and

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¹ Disability-adjusted years (DALYs) relates to a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death (National Heart Foundation of Australia 2007).
salt intake (National Heart Foundation of Australia, 2005). Jointly, these eight risk factors explain 81.5% of CAD deaths and 85.2% of CAD DALYs (National Heart Foundation of Australia, 2007). Within Australia it is estimated that 54% of adults do not exercise enough, 60% of those over 25 years are overweight, and 24% continue to smoke (National Heart Foundation of Australia, 2005). In addition it is estimated that 53% of the Australian population have two or more risk factors, which is of concern as the risk for CAD progressively increases according to the number of risk factors impacting on the individual (Australian Institute of Health and Welfare, 2011). A reduction in the number of risk factors may be effective in decreasing disease progression, as well as improving potential morbidity and mortality in those who have experienced a myocardial infarction or have angina (Taylor, Unal, Critchley, & Capewell, 2006).

In addition to the need to modify risk factors, the impact of CAD on an individual varies significantly according to age and gender (Dixon, Lim, Powell, & Fisher, 2000; Moser & Dracup, 2004; Svedlund & Danielson, 2004; Worrall-Carter, Jones, & Driscoll, 2005; Bowman, Watson, & Trotman-Beasty, 2006; Thombs, et al., 2006; Smith & Liles, 2007). Older patients are less able to manage the physical side of their illness such as chest pain or taking medication; while younger (under 50 years) patients describe greater difficulty with the emotional impact such as return to work and relationships with family and friends (Lavie & Milani, 2000). Women with CAD have been found to have worse outcomes, poorer emotional adjustment and more ongoing complications than men (Hanratty, et al., 2000; Vaccarino, Krumholz, Yarzebski, Gore, & Goldberg, 2001; Grady, Chaput, & Kristof, 2003; Worrall-Carter, et al., 2005).

As well as age and gender the impact of CAD on an individual varies significantly according to their psychological well-being and relationship with their spouse. Individuals with CAD who have had an acute hospital admission with acute
coronary syndrome may suffer anxiety, depression, emotional and/or psychological distress which may contribute to a higher mortality for this group of patients at six to 12 months post hospital admission (Dixon, et al., 2000; Clark, 2003; Dejong, Chung, & Roser, 2004; Bowman, et al., 2006; Thombs, et al., 2006). A positive supportive relationship with a spouse or significant other can lessen the impact of CAD on the individual (Moser & Dracup, 2004; Svedlund & Danielson, 2004). Despite this, some individuals report that CAD has a significant negative impact on their personal relationships (Svedlund & Danielson, 2004; Mahrer-Imhof, Hoffman, & Sivarajan, 2007), which causes disharmony and sadness in their daily life. Coronary artery disease also has a significant impact on the community.

1.1.2 Impact of Coronary Artery Disease on the community

Coronary artery disease can cause significant morbidity with approximately “1.5% of Australians corresponding to approximately 303,500 people” having a disabling condition such as difficulties with self care, communication, and mobility due to CAD (Australian Institute of Health and Welfare 2011, p. 70). People with CAD have lower rates of employment and those who are employed have higher rates of absenteeism than people without CAD (National Heart Foundation of Australia, 2005). People with CAD who are employed have 2.3 times the national average of days with reduced work activity due to their illness (National Heart Foundation of Australia, 2005). This has a financial impact on the community with a loss in tax revenue from direct and indirect taxation. The negative impact of CAD on the individual and community also impacts on the health care system.

1.1.3 Impact of Coronary Artery Disease on the health care system

People with CAD utilise the health system more than the average Australian. Health action rates defined as hospital or General Practice (GP) admissions, visits or
appointments for CAD in 2005 were higher than the national average, with 57% of people with CAD utilizing health resources compared to 43% of the average population, and these figures continue to rise due to advances in medical treatment (National Heart Foundation of Australia, 2005; Australian Institute of Health and Welfare, 2012). The Australian Institute of Health and Welfare (2011) identified that the costs of CAD are substantial due to direct health expenditure that includes hospital admissions, invasive and highly technical treatments and pharmacotherapy. It is estimated that in 2012 direct health care costs for CAD will be $7.9 billion or 11% of health spending with the bulk of this cost from hospital inpatient care and pharmaceuticals (Australian Institute of Health and Welfare 2011).

Coronary Artery Disease, as a chronic condition, requires ongoing management over a period of years and seriously challenges the efficiency and effectiveness of a health care system designed for acute episodic care (World Health Organisation, 2002). There is therefore, a need for a complimentary and integrated model of care delivery such as home based cardiac rehabilitation to meet this challenge and meet the needs of patients with CAD.

1.1.4 Cardiac rehabilitation

“Improving well-being and preventing further cardiac events (secondary prevention) are essential goals of healthcare provision for people with CAD” (National Heart Foundation of Australia, 2010). Contemporary secondary prevention includes strategies such as cardiac rehabilitation that can reduce the impact of CAD on the individual, the community and the health care system (Briffa, et al., 2009; National Heart Foundation of Australia, 2010). Therefore cardiac rehabilitation is essentially secondary prevention of CAD and is defined as “a coordinated system of care necessary to help people with CAD return to an active and satisfying life and helps prevent the recurrence of cardiac events or new cardiovascular conditions”
Core components of cardiac rehabilitation are assessment, individualised intervention, ongoing support/follow up and evaluation (Briffa, et al., 2009; Redfern, Maiorana, Neubeck, Clark, & Briffa, 2010). In clinical practice effective cardiac rehabilitation is a multi-faceted intervention that includes an individual physical and psychological assessment of needs, modification of risk factors, health education and counselling, behaviour modification, support for self-management and support to manage medicines. Cardiac rehabilitation includes and complements the care and support the individual receives from their spouse and family, medical specialist and general practitioner. Cardiac rehabilitation for patients with CAD has resulted in cost-effective long-term reductions in mortality and disease progression, as well as improvement in psychological welfare (Taylor, 2004; Heran Balraj, et al., 2011). "Patients who participate in programs are up to three times less likely as those who do not participate to die and have a stroke or further cardiac event" (Clark A, 2012, p. 835). Thus cardiac rehabilitation is an effective form of secondary prevention of CAD by reducing patient’s risk of further disease progression (Briffa, et al., 2009).

1.1.4.1 Hospital based outpatient cardiac rehabilitation

Hospital based cardiac rehabilitation programs in Australia are traditionally delivered within an outpatient setting and are predominately nurse led (National Heart Foundation of Australia, 2004, p. 4). This usually involves the patient attending a health care facility (hospital or community health centre) once or twice a week to receive education, support and exercise from a nurse in conjunction with a multi-disciplinary team including dieticians, physiotherapists and psychologists. The program usually runs for a fixed time period of six to eight weeks and patients
can access the program from one to two weeks post discharge from hospital following an admission with acute coronary syndrome. There are currently 169 hospital and community based programs in NSW (National Heart Foundation of Australia, 2011). Despite this number of programs patients, especially in rural areas, can have difficulty in accessing an appropriate program.

Access and availability are key factors in health care utilisation. This is compounded in rural areas by the limited number of cardiac rehabilitation programs due to low numbers of patients over a large geographical area, the distances patients have to travel to access hospital based cardiac rehabilitation or lack of skilled staff to deliver the program (Dollard, Smith, Thompson, & Stewart, 2004). Even when hospital based programs are available, rural participants are less likely to attend due to road conditions, distance and access to transport (Johnson, Weinert, & Richardson, 1998; Schulz & McBurney, 2000). In metropolitan areas similar issues in relation to access to transport can affect access to cardiac rehabilitation; however, in contrast to rural areas the increased numbers of patients needing to access cardiac rehabilitation programs can lead to an extended wait for patients to attend (Beswick, et al., 2005; NSW Department of Health, 2006b). A NSW policy directive suggests that patients should be able to access a cardiac rehabilitation program within one month of referral (NSW Department of Health, 2006b). An extended wait of longer than this recommendation reduces access to evidence based health care and can delay the patient’s recovery and increase anxiety for the patient and his/her family. Improving access to cardiac rehabilitation is a priority within NSW (NSW Department of Health, 2006a, 2007). In the Local Health District where this study was conducted, metropolitan and rural patients can wait up to eight weeks before accessing cardiac rehabilitation (Local Health District Data 2012). Even if patients can access a hospital cardiac rehabilitation program a limited number attend or complete the desired number of sessions.
Despite the evidence for benefits of hospital cardiac rehabilitation fewer than one in three people referred actually attend and even fewer people complete the full program (National Heart Foundation of Australia, 2010). In NSW, only 7% of eligible patients were referred to cardiac rehabilitation in 2007 (NSW Department of Health, 2008). If referred, less than 30% attended or completed the program (NSW Department of Health, 2008). This referral rate is lower than national and international referral and attendance rates of between 30% and 50% and similar to completion rates of between 14% and 43% (Scott, Lindsay, & Harden, 2003; Beswick, et al., 2005; NSW Department of Health, 2006a).

Reasons for non-attendance are complex. In the literature people have reported not attending because of distance, program timing, the program itself or a dislike of working in a group (Beswick, et al., 2005; Jones, et al., 2007). Even if patients do attend hospital cardiac rehabilitation programs less than a third complete their program for physical, social, psychological and personal reasons (Scott, et al., 2004; Beswick, et al., 2005; Neubeck, Briffa, Freedman, Clark, & Redfern, 2011; Clark, et al., 2012). In addition people at the highest risk of recurrent disease such as women, the elderly and indigenous Australians are less likely to be referred, attend or complete a hospital based cardiac rehabilitation program when compared to men, younger people and non-Indigenous Australians, respectively (Beswick, et al., 2005; National Heart Foundation of Australia, 2010).

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2 Referral rates relate to the number of eligible patients referred to a cardiac rehabilitation program. Attendance rates refer to the number of eligible patients who commence a program.
There is a clear need therefore for an alternative to hospital based cardiac rehabilitation in an attempt to improve patient outcomes through attendance and completion, together usually captured in the word ‘adherence’ of cardiac rehabilitation. It has therefore been suggested in the literature that cardiac rehabilitation programs should be individualised according to patients needs instead of the one size fits all approach to hospital based cardiac rehabilitation (Jones, et al., 2007; Neubeck, et al., 2012).

A policy directive from NSW Health and a call to action from the National Heart Foundation of Australia in conjunction with the Australian Cardiovascular Health and Rehabilitation Association, suggests that alternatives to hospital based cardiac rehabilitation such as home based programs should be made available as a means of giving patients choice and individualising programs to improve commencement and completion rates (NSW Department of Health, 2006b; Briffa, et al., 2009; National Heart Foundation of Australia, 2010).

1.1.4.2 Home based cardiac rehabilitation

Home based cardiac rehabilitation was first described by American researchers over twenty years ago. At this time the primary concern about this model of cardiac rehabilitation was the safety of patients immediately post myocardial infarction exercising at home with minimal support or observation and this was the focus of several early studies (Miller, Haskell, Berra, & Debusk, 1984; Debusk, et al., 1985; Heath, 1987). These early studies were similar in design in that they compared

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3 Attendance and completion of cardiac rehabilitation is usually termed adherence to programs however for the purpose of my study this will be referred to as engagement. I feel the term engagement better reflects the partnership between patients and nurses, which is integral to home based cardiac rehabilitation using the AHG.
outcomes of patients undertaking supervised exercise (hospital or gym, group or individual sessions) against patients exercising unsupervised at home and patients undertaking no exercise (Miller, et al., 1984; Debusk, et al., 1985; Heath, 1987). In two of these studies the patients exercising at home had electrocardiograph links with the local hospital (telemetry); these links assisted in monitoring heart rate and cardiac function and enabled a comparison with patients exercising in a hospital based group (Miller, et al., 1984; Debusk, et al., 1985). These two studies found that home based exercise-only programs using intensive monitoring were safe for patients and were as effective in improving functional capacity as hospital based programs (Miller, et al., 1984; Debusk, et al., 1985).

However, Debusk et al.’s (1985) study found that patients undertaking the home cardiac rehabilitation program had better engagement with exercise than the hospital program, and this was credited to the telephone support the home patients received from the nurse (Debusk, et al., 1985). Subsequent studies continued to focus on the safety and efficacy of exercise at home (Ueshima, et al., 1990; Sparks, Shaw, Eddy, Hangiosky, & Vantrese, 1993). Studies also began to emerge that focused on other aspects of cardiac rehabilitation that could be delivered at home such as psychological support (Beckie, 1989) or risk factor reduction (Imich, 1997). Several studies emerged combining exercise, psychological support and risk factor reduction (Lewin, Robertson, Cay, Irving, & Campbell, 1992; Linden, 1995; O’Rourke & Hampson, 1999). These studies used The Heart Manual which is a structured home based cardiac rehabilitation program, developed in the United Kingdom, consisting of an exercise program and education package in the form of booklets, supported by a nurse over the telephone for a period of six weeks. The improved outcomes of patients demonstrated in the studies using The Heart Manual for home based cardiac rehabilitation led to studies comparing the effectiveness of home based cardiac rehabilitation (using The Heart Manual) with hospital based cardiac rehabilitation (Dalal, et al., 2007; Jolly, et al., 2008).
Home based cardiac rehabilitation using The Heart Manual has been found to be as effective as hospital based cardiac rehabilitation in reducing patients’ risk factors such as high blood pressure, improving patients’ quality of life and improving mortality (Dalal, et al., 2007; Jolly, et al., 2008). Despite their using different measurement tools, these two studies randomised patients to either hospital or home based cardiac rehabilitation and had similar outcomes including decreased mortality rates (cardiac and all cause), reduction in risk factors (blood pressure, cholesterol, and smoking status), improved exercise capacity and improved quality of life, anxiety and depression scores. There was no statistically significant superiority between either home or hospital based cardiac rehabilitation in these studies and the authors concluded that home based cardiac rehabilitation when using The Heart Manual was as effective as hospital based cardiac rehabilitation (Dalal, et al., 2007; Jolly, et al., 2008). These were the first studies to provide robust evidence for the benefits of home based cardiac rehabilitation.

Previous studies of home based cardiac rehabilitation were challenged by the lack of a clear definition of what constitutes a home based program. For example, home based programs discussed in the literature ranged from exercise and/or education with follow-up by telephone or home visiting to a written discharge plan with no follow-up to review progress or engagement. The lack of a universally recognised or accepted definition or structure of a home based program appears to have negatively impacted attempts to measure the effectiveness of home based cardiac rehabilitation. In addition the methods used to measure the interventions in previous studies of home based cardiac rehabilitation and poor reporting of findings resulted in inconclusive evidence for the benefits of home based cardiac rehabilitation (Jolly, Taylor, Gregory, & Stevens, 2006).
Addressing this deficit, a more recent systematic review defined home based cardiac rehabilitation as “a structured program with clear objectives for the participants, including monitoring, follow up visits, letters or telephone calls from staff, or at least self-monitoring diaries” (Taylor, Dalal, Jolly, Moxham, & Zawada, 2010b, p. 1).^{4} Both Taylor, et al’s (2010) systematic review and an earlier systematic review conducted by Jolly, et al. (2006) used the same definition of home based cardiac rehabilitation and found that home based cardiac rehabilitation was as effective as hospital based cardiac rehabilitation in reducing mortality, improving risk factors, improving quality of life and reducing costs. Consequently, home based cardiac rehabilitation as an alternative option to hospital based cardiac rehabilitation for patients with CAD has been gaining momentum within Australia and elsewhere (Dalal & Evans, 2003; Dollard, et al., 2004; Brubaker, 2005; Redfern & Briffa, 2011).

Despite the research supporting the effectiveness of home based cardiac rehabilitation, little is known about the patient, spouse and nurse experience of this type of program. There are several non-published evaluations of the use of The Heart Manual, and these indicate a positive experience for patients (Heart Manual, 2007). In addition a qualitative study undertaken as part of a larger randomised controlled trial comparing home based (using The Heart Manual) and hospital based cardiac rehabilitation, explored patients’ experiences of their rehabilitation (Jones, Greenfield, & Jolly, 2009). These researchers found that patients had a positive experience regardless of the type of program they attended (Jones, et al., 2009). The experience of spouses and nurses was not explored by Jones et al. (2009). In addition Jones, et al’s (2009) study results might not be transferable to Australia because their study was undertaken in the United Kingdom where the health care system, the practice of cardiac rehabilitation and the experience of patients may differ. Therefore

^{4} The definition of home based cardiac rehabilitation by Taylor, Dalal, Jolly, Moxham & Zawada, (2010) will be used to define home based cardiac rehabilitation for the purpose of my study.
there is a need for an Australian study to explore the experiences of nurses, patients and spouses who utilise home based cardiac rehabilitation.

1.2 Significance of the study

The discussion so far indicates that hospital based rehabilitation programs are effective but have their limitations, particularly with regard to access. There is a need to understand the potential of home based cardiac rehabilitation as a viable alternative to improve health outcomes for patients with CAD and their spouses in Australia. Research evidence has demonstrated the effectiveness of home based cardiac rehabilitation on health outcomes using a structured program such as The Heart Manual; however this has not been demonstrated using the AHG (a modified and updated Australian version of The Heart Manual). The majority of research on home based cardiac rehabilitation has been conducted outside Australia therefore there is limited evidence regarding the experiences of Australian patients, spouses and nurses.

There are research findings from the UK where patients found using The Heart Manual at home to be a positive experience (Jones, et al., 2009; Clark, Kelly, & Deighan, 2011), however there is no published research into spouses’ and nurses’ experience with this type of program. Understanding the experience of patients and their spouses is essential because a positive experience is likely to increase engagement with cardiac rehabilitation programs and improve outcomes for both of these groups. However, a negative experience may result in discord, uncertainty and a lack of engagement to modify risk factors, or maintain drug regimes (Davies, 2010, p. 2). Given existing research indicating that uptake and engagement with cardiac rehabilitation is low (Beswick, 2005, p. 25; Davies, 2010 p. 182), understanding the experience of the patients, spouses and nurses may assist in developing home based cardiac rehabilitation programs that address these factors.
Home based cardiac rehabilitation within Australia is in its infancy and little is known about the acceptability of this type of program to the Australian public or health professionals. Home based cardiac rehabilitation within Australia has utilised structured telephone support at home and in most instances combined this with some face-to-face contact with a GP or nurse (Vale, et al., 2003; Redfern, Briffa, Ellis, & Freedman, 2008). These programs, generally referred to as secondary prevention programs aim to demonstrate the effectiveness of alternative models to hospital based cardiac rehabilitation, and although they fulfil the definition of a home based program they differ in structure and philosophy to the modified and updated Australian version of The Heart Manual, the AHG.

The secondary prevention studies conducted in Australia have demonstrated effectiveness in improving patient outcomes in relation to quality of life, improvement in patients risk factor profiles and their anxiety and depression levels (Redfern, Briffa, Ellis, & Freedman, 2008; Vale, et al., 2003). The AHG is currently being investigated in regard to effectiveness in improving similar patient outcomes to the secondary prevention studies (Vale, et al., 2003; Redfern, et al., 2008). However none of these studies exploring the effectiveness of telephone based programs within Australia have explored the patient, spouse and nurse experiences of these programs. Thus there appears to be no qualitative evidence regarding the experience of patients, spouses and nurses utilising home based cardiac rehabilitation within Australia. My study therefore seeks to address this gap in the research based literature and contribute to the evaluation of home based cardiac rehabilitation in Australia from a qualitative point of view by identifying and describing the patient’s, spouse’s and nurse’s experiences of using a structured program, the AHG.

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5 These studies are discussed in more detail in Chapter 2, page 29.
1.3 Background to the researcher

My current position is as a Clinical Nurse Consultant (CNC) for cardiology for a Local Health District within New South Wales. The Local Health District covers metropolitan and rural areas and includes a large tertiary hospital, which is the regional centre for cardiology. Health care is provided across the Health District through local district hospitals and community health facilities. The local district hospitals vary in size, capacity and capability with some hospitals described as rural referral hospitals incorporating intensive care/coronary care facilities and minor surgery, and some small multi-purpose sites incorporating emergency departments, community health services such as podiatry, and hospital wards for the elderly or those requiring respite. Medical care is provided by medical specialists in the larger hospitals such as cardiologists or general physicians supported by junior medical staff and by GPs in the community multi-purpose sites with limited additional support. Nursing care is delivered by specialist\(^{6}\) and non-specialist nurses across a variety of sites, from larger hospitals to small district hospitals and community centres. The differences in skills, knowledge and medical/nursing provision can result in variations of health care provision, especially in relation to effective evidence based health interventions and support for patients with CAD (Australian Institute of Health and Welfare, 2012). Part of my role as the CNC for cardiology is to address any inequity of health care provision and support medical and nursing colleagues across the district in delivering evidence based cardiology practice.

My CNC role incorporates five domains of education, clinical service and consultancy, research, clinical leadership, and clinical services planning and management. The role is very challenging, combining a clinical workload supporting

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\(^{6}\) Specialist nurses for the purpose of my study refers to nurses who have additional training and skills in cardiology to enable them to provide a specialist service to patients.
patients with cardiac illness, in hospital and following discharge, with strategic service planning for district wide cardiology services, educational support for nurses working with cardiac patients, and responsibility for standards of care including policy development. Within the role I work with state and national bodies such as the state Department of Health, the National Heart Foundation, the Australian Cardiovascular Health and Rehabilitation Association and other non-government organisations to develop local and national policy for cardiac services including cardiac rehabilitation. Membership of committees on these state and national bodies allows me to learn, be part of new initiatives and to implement and evaluate new ways of delivering cardiac services, such as heart failure specialist nurse programs and alternative models of cardiac rehabilitation.

Research, as one of my role domains, involves designing and developing nursing research within the field of cardiology and cardiac rehabilitation and this led to the development of this study using the AHG. My research experience prior to this study was limited to small audits and quality improvement projects. Therefore the opportunity to pilot the AHG using qualitative research methodology has enabled me to develop my research skills within the framework of a Masters degree. I was particularly interested in piloting the AHG because prior to being appointed to my current position I had the opportunity, when working as a community cardiac rehabilitation nurse in the United Kingdom, to work with The Heart Manual. This experience meant that I was keen to explore the experience of patients, their spouses, and nurses working in NSW and using the AHG for home based cardiac rehabilitation. The AHG, which is the focus of my study, shares similar features with, and is the modified and updated Australian version of The Heart Manual a home based cardiac rehabilitation program.
The Heart Manual is an evidence-based self-management resource for patients with a cardiac condition and the families who support them. Developed in 1992, The Heart Manual provides information to patients and spouses about Coronary Artery Disease, risk factors, medication, and recovery from an acute episode of cardiac illness (angina or myocardial infarction). Its psychological underpinning is cognitive behavioural therapy and it sets out to promote patient and spouse ownership of the rehabilitation process through the principles of adult learning and partnership between patient, spouse and the nurse facilitator. The information is provided in different formats (booklets, compact disc, and questionnaires) and the patients, each supported by their spouse, develop their own action plans for their recovery and risk factor modification using a patient diary as a monitoring tool. The Heart Manual is given to patients on discharge from hospital as a home based cardiac rehabilitation program and the patient receives support and regular follow-up by a nurse facilitator either in the home, at a clinic or by telephone (Lewin, et al., 1992).

Prior to using The Heart Manual with patients and their spouses, my clinical background in the UK was in hospital based group cardiac rehabilitation, and I was sceptical as to how useful The Heart Manual would be to patients and spouses. The reason for my scepticism was that patients used The Heart Manual at home without the support of other patients and the nurse’s only contact with the patient may be via the telephone. I was concerned that patients may not receive the benefits of hospital cardiac rehabilitation that the evidence demonstrates. Despite my initial scepticism about The Heart Manual, I found that some patients liked the program and demonstrated benefit from its psychological underpinning, evidenced by their improved scores in the screening tools used to assess their psychological welfare. Some patients also told me that they enjoyed directing and being responsible for their own recovery. I, in my role as a nurse facilitator supporting users of The Heart Manual, also found it had a lot of positive features and that although the lack of face to face contact was challenging, I found that telephone interactions with patients
could be as rewarding as face to face contact. I further discovered The Heart Manual was a useful alternative for patients who were unwilling or unable to attend the community or hospital based exercise programs.

I migrated to Australia in August 2005 and upon commencing my current CNC position I was surprised to find the only program available within my Local Health District for patients with CAD was a hospital based cardiac rehabilitation program. The hospital based programs within this local district are predominately based at local health care facilities such as the larger hospitals and small community hospitals with a varying degree of service provision and accessibility for patients and their spouses. Hospital based cardiac rehabilitation programs in larger facilities are held once or twice weekly supported by a multi-professional team of nurses, physiotherapists, dieticians, occupational therapists, pharmacists, psychologists and social workers. In contrast smaller health facilities may provide programs four times a year led by a nurse with limited access to other health disciplines, or no hospital based program where the patient with CAD receives a limited amount of community nurse support. In addition there is limited governance within the Local Health District regarding the content of the hospital cardiac rehabilitation programs, reporting of patient outcomes or the skill and knowledge of the nurses delivering the cardiac rehabilitation programs.

The variation in hospital based cardiac rehabilitation program availability, limited governance and no alternative home based program has resulted in reduced access to cardiac rehabilitation for patients. This is especially so for patients who live some distance from their nearest health facility or who live in rural areas. This, in turn has led to longer waiting times. This led me to explore the availability of alternatives to hospital based cardiac rehabilitation programs within Australia and the feasibility of implementing a home based cardiac rehabilitation program using telephone support within my Local Health District. As a result of my exploration I discovered (as
discussed on page 22) that there was a limited number of home based cardiac rehabilitation programs within Australia. A chance meeting and discussion with the creator of The Heart Manual led to my involvement, in conjunction with the Australian Cardiovascular Health and Rehabilitation Association, in the development and piloting of the AHG.

1.3.1 The Aussie Heart Guide

The AHG is an individualised, cognitive behavioural, chronic disease management program for people with CAD based on The Heart Manual and adapted for use in Australia. The AHG includes information on heart disease, risk factor reduction, relaxation and psychological adjustment to having a chronic illness, self-management through goal setting, and action planning, and review through nurse/patient collaboration and working in partnership. The AHG contains information for patients and spouses in the form of booklets and compact discs, a patient diary to assist with action planning and monitoring of the patient’s recovery and risk factor modification, and a relaxation program.

Spouse and family involvement with the AHG is encouraged through the provision of a section specifically for their use. The opportunity to be part of the AHG development team enabled me to contribute towards ensuring that the language and terms used in the guide and the program itself were appropriate to the Australian context. A training program conducted in a one day workshop was also developed to support Australian nurses to facilitate the AHG with patients. Similarly to my experience of using The Heart Manual, patients and their spouses using the AHG are supported by an AHG nurse mentor; a nurse who has completed the AHG training program and who is able to facilitate the AHG with patients.
Facilitating the AHG involves the AHG nurse mentor working in partnership with the patient and spouse in the context of the patient’s home to promote his/her self management and recovery. Prior to implementing the AHG within Australia, nurses likely to be involved in supporting patients using the AHG were invited to attend a one day workshop conducted by the author of The Heart Manual who had been integrally involved in the AHG’s development. At this workshop nurses were provided with information about the history and development of the AHG, evidence for the use of home based cardiac rehabilitation programs of this type, cognitive therapy and how to facilitate the program with patients and spouses.

The process of facilitation involves assessment and review with the AHG used as a tool to underpin the cardiac rehabilitation process. The facilitation commences with an assessment of the patient’s knowledge of CAD and his/her risk factors, and progress towards recovery. If patients have had an acute event such as a myocardial infarction, this assessment may be conducted face to face in a clinic or over the telephone according to the patient’s preference and the patient’s accessibility to health services. Following the initial assessment the patient, supported by the AHG nurse mentor develops an action plan for recovery and risk factor modification. Subsequent contacts between the patient and the AHG nurse mentor may be weekly or fortnightly and are usually telephone based, but may be face to face, and involve monitoring; reviewing and adapting the action plans until the patient and AHG nurse mentor agree the process is complete. The AHG is used as an adjunct to the contact between patients and AHG nurse mentors with the information it contains supporting patients with their action plans and recovery, reinforcing the education on risk factors or self management and providing structure to the program. The AHG nurse mentors are encouraged to involve spouses in the process by referring to

7 I am using the term spouse as a general description although the principle caregiver may not be a spouse it may be a partner, friend, or relative.
the spouse’s guide and involving them in their contact with the patient. Patients and their spouses may use the AHG as an alternative to hospital based cardiac rehabilitation or in conjunction with a hospital based program which they may choose to attend for their exercise and information sessions. To determine the effectiveness of the AHG a pilot of its use was conducted in Tasmania and in my Local Health District in NSW in 2008.

Home based cardiac rehabilitation using The Heart Manual has demonstrated improved clinical outcomes for patients in regard to their psychological state and risk factor profile (Lewin, et al., 1992; Dalal, et al., 2007; Jolly, et al., 2008) but there is limited evidence regarding its acceptability to patients, spouses and nurses. Prior to commencing this study, to determine whether or not similar clinical outcomes to those obtained when using The Heart Manual could be obtained using the AHG, the Australian Cardiovascular and Rehabilitation Association conducted a pilot study. Eighty five patients (a mixture of rural and metropolitan from Tasmania and NSW) chose the AHG as an alternative to their local hospital based program. The unpublished results suggested improvements in anxiety, depression and quality of life scores and smoking cessation rates similar to findings of the original Heart Manual study (Lewin, et al., 1992).

The results of the pilot regarding the potential for improvement in patient outcomes when using the AHG were not conclusive given the small number of patients involved, the lack of randomisation and lack of comparison of results against hospital based cardiac rehabilitation or usual care for patients. Similar to The Heart Manual studies there was no qualitative evaluation in the pilot study of the experience of the patient or his/her spouse or of nurse mentors using the AHG for home based cardiac rehabilitation. Therefore there is no evidence regarding the usefulness or acceptability of home based cardiac rehabilitation with telephone support using the AHG to the Australian public.
There is limited knowledge of the nurses’ experience of using the AHG for home based cardiac rehabilitation. As identified above the nurse mentor’s experience in the pilot study was not formally evaluated, however an informal evaluation as part of clinical supervision (during the pilot) highlighted some challenges which they faced with home based cardiac rehabilitation and the use of the AHG. The AHG nurse mentors reported they found the use of the AHG with patients time consuming, they struggled with the concept of enabling the patient to manage his/her own rehabilitation process and they had difficulty with the concept of home based cardiac rehabilitation in general, especially as their contact with patients was limited to telephone support. Given my experience with The Heart Manual I was surprised by the comments by the AHG nurse mentors, as my assumption had been that nurses would embrace a program that could be completed by patients at home, supported by nurses over the telephone, especially in rural areas. In addition, my surprise at these nurses’ comments also arose because prior to the commencement of the pilot the nurses appeared excited about using a new program, and embraced the opportunity to offer it to their patients with limited access to their hospital programs. This was evidenced by the number of nurses who applied to take part in the pilot. However, upon reflection I recalled my initial scepticism about The Heart Manual and assumed the nurses within the pilot may also have had their doubts about the AHG and its use and benefit for patients for the same reasons I had held prior to the introduction of The Heart Manual. Thus the idea for a formal qualitative evaluation of the patients’, spouses’ and nurses’ experience of using the AHG for home based cardiac rehabilitation arose.

1.3.2 My assumptions as a researcher regarding the nurse experience of home based cardiac rehabilitation using the AHG

Due to my current role as CNC cardiology, my experience with home based cardiac rehabilitation using The Heart Manual, my involvement in the development of the
AHG and the qualitative methodology used in my study, it is necessary for me to clearly identify my assumptions as a researcher regarding the nurse experience of home based cardiac rehabilitation using the AHG. Based on my contact with the AHG nurse mentors during the Australian Cardiovascular Health and Rehabilitation Association pilot study, I assumed that the nurse mentors in my study would have doubts about the benefit of home based cardiac rehabilitation using the AHG and that this might influence their experience. This assumption was based on my perception that AHG nurse mentors might harbour a real or perceived concern that home based cardiac rehabilitation using the AHG is inferior to hospital based cardiac rehabilitation. This first assumption arises from discussion with my peers (cardiac rehabilitation nurses within Australia) and the AHG nurse mentors in my Local Health District during which it appears that some believe home based cardiac rehabilitation is an inferior and ineffective program when compared to hospital based cardiac rehabilitation. This appears especially so if there is limited face to face contact with patients and where the program is conducted over the telephone. Nurses facilitating the AHG within my Local Health District are predominately hospital based, cardiac rehabilitation nurses, some of whom have had extensive experience within this field. Therefore I assumed that to change practice to incorporate home based cardiac rehabilitation using the AHG and offer it as a positive alternative option for patients might be a major challenge for some nurses.

My second assumption stemmed from my perception that many nurses involved in cardiac rehabilitation programs (as well as in many other instances of patient care) perceive themselves to be in an ‘expert’ role (Berra, Miller, & Fair, 2006), that is, holding specialist and/or more extensive knowledge required by the patient. My perception is that due consideration may not given to patients as individuals with different as well as shared experiences, needs and contexts of daily living. Consideration of patients as individuals is nevertheless fundamental within cardiac rehabilitation, yet several studies have demonstrated that some cardiac rehabilitation
nurses are unable to individualise programs according to patients needs (Lau-Walker, 2004b; Fernandez, Davidson, Griffiths, & Salamonson, 2011; Madden, Furze, & Lewin, 2011). Using the AHG supports the nurse in individualising care by its requirement that the nurse mentor works in partnership with the patient and spouse (or carer) during delivery of this rehabilitation program. I assumed therefore that this might be challenging for some nurses who are perhaps not familiar with working this way.

While I was considering this study in light of my previous experience and assumptions, NSW Health released a policy directive relating to rehabilitation for chronic disease (NSW Department of Health, 2006b) suggesting that alternative models to hospital based cardiac rehabilitation should be available for patients. The policy directive, the lack of evidence regarding the patient and spouse experience of home based cardiac rehabilitation and my experience with the nurses involved in the AHG pilot led to my assumption that implementing alternative models of home based rehabilitation may be challenging and that cardiac rehabilitation nurses were perhaps not ready for an alternative model of cardiac rehabilitation such as the AHG. Overall, therefore I was intrigued as to what patients, spouses and nurses experience of using home based cardiac rehabilitation would be. These factors and the gaps in research relating to patients’, nurses’ and spouses’ experiences when using the AHG led to the development and implementation of my study and the formation of this thesis based on the following research question and study objectives.

1.4 Research question

The research question addressed by this thesis is: “What is the experience of patients, their spouse and nurses when using the Aussie Heart Guide for home based cardiac rehabilitation?” This study seeks to explore the experience of the patients, spouses
and nurses using the AHG in order to gain a comprehensive understanding of the experience of those engaged in the AHG program. There appears to be a limited number of studies exploring the patient’s experience of home based cardiac rehabilitation or which include their spouse or nurses delivering the program as part of their evaluation. Thus a rigorous qualitative evaluation of home based cardiac rehabilitation using the AHG is not only valuable in contributing to filling the gap in what is known about home based cardiac rehabilitation in Australia, but also sheds light on issues relating to change in relationship between nurse, patients and spouses advocated in this program. In addition, an understanding of the patient, spouse and nurse experience of home based cardiac rehabilitation using the AHG may assist in the development of alternative programs for home based cardiac rehabilitation within Australia.

1.5. **Aim and objectives of the study**

1.5.1 **Aim**

The aim of my study is to understand and describe the experience of patients with CAD, their spouses and the nurses using the AHG for home based cardiac rehabilitation by asking them to describe this experience.

1.5.2 **Objectives**

1. To describe the patient’s experience of home based cardiac rehabilitation using the AHG with support from an AHG nurse mentor.

2. To describe the spouse’s experience of home based cardiac rehabilitation using the AHG with support from an AHG nurse mentor.

3. To describe nurses’ experience of home based cardiac rehabilitation using the AHG.
4. To describe the AHG in terms of usefulness for patients, spouses and nurses in assisting with and supporting lifestyle changes and disease management.

5. To describe patient and nurse engagement with home based cardiac rehabilitation when using the AHG.

6. To describe the nurse-patient relationship when using the AHG for home based cardiac rehabilitation.

1.6 Organisation and content of thesis chapters

This chapter has provided the background to the research study, information about the researcher, the research question, and the aims and objectives of the study. The following chapter (Chapter 2) provides an overview of the literature relating to this study. Chapter 3 contains a justification for the use of the literature critique as the study’s conceptual framework and a further justification for the selection of qualitative description as the methodology for the study. Chapter 3 also describes rationale for the selection of the tools used for data collection and data analysis all of which are congruent with the study’s methodology. A profile of the study participants and the ethical considerations for this study are also discussed. Subsequent chapters describe the findings (Chapter 4) and provide a discussion of the findings in relation to the literature (Chapter 5), including the implications and relevance of the study for clinical nursing practice and the wider health community, and suggestions for further research.
Chapter 2

2.0 Introduction

The impact of Coronary Artery Disease (CAD) on the individual, the community and health care system plus the benefits of cardiac rehabilitation were outlined in the introduction to this thesis. Despite the benefits of cardiac rehabilitation engagement by patients through their attendance and completion of hospital based cardiac rehabilitation programs is low (Beswick, et al., 2005; Neubeck, et al., 2012). Poor engagement with hospital based cardiac rehabilitation and the potential for home based cardiac rehabilitation to improve access to support for patients with CAD was also discussed in Chapter 1.

A critical review of contemporary literature, particularly research based literature, revealed three main themes relevant to this thesis. This literature review will therefore be presented under each of these themes: 1) the experience of Coronary Artery Disease for the patient and their spouse; 2) the influences on the patient, spouse and nurse experience of home based cardiac rehabilitation; and 3) partnership between the patient, spouse and nurse in home based cardiac rehabilitation. Each theme has associated sub-themes and these will also be discussed.

Literature from three electronic databases, MEDLINE, CINHAL and Cochrane, were searched using key words for this review. In addition, bibliographies of the literature reviewed were searched for relevant literature related to the three themes.

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8 Cardiac rehabilitation, home based cardiac rehabilitation, myocardial infarction, angina and heart attack, the patient experience, partnership between patients and nurses in cardiac rehabilitation or cardiac nursing, the nurse patient relationship in cardiac rehabilitation or cardiac nursing.
emerging key themes. Finally State and National policy documents relevant to the research topic were also explored. The search was restricted to publications written in English between years 2000 and 2011. Publications earlier than 2000 were included if they were considered seminal works and pertinent to my study.

2.1 The experience of Coronary Artery Disease for the patient and their spouse

When seeking to understand the experiences of patients using the AHG for home based cardiac rehabilitation, it is important to understand the impact of CAD on the patients and their spouses. Within the literature there were four sub-themes: (1) anxiety and depression, (2) gender differences, (3) age, and (4) impact on spouses. Before considering these sub-themes it is necessary to understand the impact of CAD as a whole on patients and spouses.

A cardiac event such as a heart attack or angina has a significant impact on patients and their spouses (Thomson, Esrsser, & Webster, 1995, p. 121). Clark (2003, p. 344) described it as “an explosion in your life”, while Thomas (2007, p.1444) suggests it is “the medical equivalent of a ride down the turbulent and dangerous white water-rapids portion of a river”. Svedlund and Danielson (2004, p. 438) propose that a heart attack “is a dramatic example of a major life crisis for all involved”. Despite this recognition of the impact of a cardiac event such as myocardial infarction, there is a scarcity of literature around the emotional and physical effect on the patient and their experience. Researchers in Australia sent a quantitative survey to 1124 patients four months after discharge from being hospitalised with heart attack or angina (Dixon, et al., 2000). Patients were asked to indicate on the survey how often during the previous two weeks they had experienced a range of problems or concerns previously identified as common to cardiac patients. Another study by Jaarsma, Kastermans, Dassen & Philipson (1995) identified that patients with CAD had
suffered from emotional problems such as feeling low, fearful or apprehensive; their physical recovery and convalescence including symptoms such as chest pain, lack of energy and resumption of activity. Patients also expressed concerns about their interpersonal relationships relating to confidence and their inability to socialise and do usual activities with family and friends (Jaarsma, Kastermans, Dassen, & Philipson, 1995).

Further exploring these problems and concerns Dixon et al. (2000) found that a large number of patients expressed problems with their physical condition (79%), their emotions (70%), convalescence (67%) and interpersonal relationships (63%). Patients also reported severity of the problem defined as “experiencing the problem most or all of the time” (Dixon, et al., 2000, p. 1370): severe problems were reported for physical recovery (43%) and convalescence (44%). Although the patient problems and concerns identified by Jaarsma et al. (1995) were used as a basis for the study by Dixon et al. (2000), it is important to recognise that the findings from both these studies are over ten years old and may not reflect the current experience of patients. This is because the medical and rehabilitative management of patients with CAD has changed to accommodate new evidence based practice. This was found to be the case in a more recent study exploring patients’ experience of hospital and home based cardiac rehabilitation. Jones, Greenfield, and Jolly (2009) conducted focus groups with 16 patients to explore their experience of hospital and home based cardiac rehabilitation. Jones et al., (2009) found that patients had concerns about their diagnosis, their illness and their ability to maintain risk factor change rather than the emotional and physical concerns identified in earlier studies. This may be explained by the fact that the Jones et al. (2009) study was predominately focused on the participants’ experience of rehabilitation rather than the impact of CAD and so these researchers did not explore in any depth the emotional or physical concerns of patients.
The incidence of problems and how significantly patients feel they impact on their well-being may also depend on the stage the patient is situated on the illness continuum. For example, patients who are in the beginning stages of their illness either in hospital or recently discharged may experience different problems when compared to later stages in their illness experience when perhaps they have been home for several months or returned to work. In the studies by Dixon et al. (2000), Jones et al. (2009) and Jaarsma et al. (1995) discussed above, patients were interviewed four to six months after admission. However, Bowman, Watson, & Trotman-Beasty (2006) in piloting a health and emotion scale with eighty first-time myocardial infarction patients, four days after their admission, suggested that, soon after admission to hospital, emotional concerns of fear, sadness and surprise may take precedence over physical problems such as convalescence or chest pain. Interestingly, surprise was the most statistically significant emotion (p<0.0001) suggesting that patients, despite in some cases a previous illness experience or risk of CAD, do not expect an acute cardiac event will happen to them. Fear was a common concern in Dixon et al.’s (2000) and Jaarsma et al.’s (1995) studies; however, Bowman et al. (2006) found that, although patients expressed fear, it was not statistically significant. This may be explained by the fact that Bowman et al. (2006) interviewed patients earlier than the previous studies, when the patients were still in hospital, whereas fear may be an emotion that occurs on a patient’s return to comparative normality or a transient threat according to individual perception. The content and staff of cardiac rehabilitation programs therefore need to be adaptable to incorporate the differing emotions and physical concerns and the significance of patient problems, as well as where on the illness continuum the patient might be situated. Patient’s perception of the severity of their illness can also impact on their experience of CAD.
Medical advances in the management and treatment of CAD and myocardial infarction through the use of thrombolysis and Percutaneous Coronary Interventions (PCI), as opposed to the highly invasive Coronary Artery Bypass Graft (CABG)⁹, have reduced patients’ length of stay in hospital and may impact on their perception of the severity of their illness. Previously a hospital stay of up to seven days was the norm followed by an extended period of rest and recuperation (Lauck, Johnson, & Ratner, 2009). In contrast a patient undergoing PCI may be discharged the same day or if following myocardial infarction after three to four days, and encouraged to resume normal activity within four weeks of discharge (Lauck, et al., 2009; Radcliffe, Harding, Rothman, & Feder, 2009). Studies focusing on patients experiencing this short time frame have demonstrated that although patients engage with discharge advice such as the need to take medication, their understanding of CAD as a chronic disease requiring monitoring and modification is limited (Lauck, et al., 2009; Radcliffe, et al., 2009). Following primary angioplasty (urgent PCI for myocardial infarction) several studies found that patients perceived themselves as “cured” or that their myocardial infarction was mild, or not significant, resulting in limited engagement with risk factor modification or cardiac rehabilitation (Astin, Closs, Mclenachan, Hunter, & Priestly, 2008; Sampson, O’Cathlin, & Goodacre, 2009). One reason for this may be that hospital cardiac rehabilitation programs appear to have not altered their format to address the changing needs or perceptions of patients in line with the advances in medical technology (Briffa, et al., 2009; Redfern, Maiorana, Neubeck, Clark, & Briffa, 2010). Therefore alternative approaches to programs for cardiac rehabilitation need to be explored to reflect the changed experiences of

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⁹ Thrombolysis is the breakdown of blood clots in the coronary artery by pharmacological means. Percutaneous coronary intervention (PCI), commonly known as coronary angioplasty or simply angioplasty, is a non-surgical procedure used to treat the stenotic (narrowed) coronary arteries of the heart found in CAD. Coronary artery bypass graft (CABG) is a procedure, arteries or veins from elsewhere in the patient’s body are grafted to the coronary arteries to bypass narrowings (Jowett & Thompson, 2007).
patients and their spouses. This is particularly important in relation to reducing patients’ anxiety and preventing clinical depression, which is a significant cause of morbidity and mortality for patients with CAD.

2.1.1. Impact of anxiety and depression on the patient experience of CAD

As discussed, patients with CAD may have a myriad of psychological concerns relating to their health and welfare. It could be argued that anxiety, and to a degree symptoms of depression, are normal reactions to the stress of CAD and the associated patient concerns. It is therefore probably not surprising that individuals who have had a hospital admission with heart attack or angina or those living with chronic CAD are at risk of developing clinically significant anxiety and depression requiring treatment. Anxiety is an intrinsic human emotion that can have positive and negative effects on the individual and can be defined as a “psycho physiological phenomenon experienced as foreboding, dread or threat to a human organism whether that is generated by internal, real or imagined dangers” (De Jong, et al., 2005, p. 130). The prevalence of anxiety in those with CAD who have not had an admission with acute coronary syndrome is around 20%-25% compared to those who have had an admission with acute coronary syndrome, where the prevalence of anxiety is 36%-54% (Dejong, et al., 2004). The prevalence of depressive symptoms for patients with CAD is similar to that for anxiety (Dobbels, et al., 2002).

Medically diagnosed depression, or depressive symptoms such as fatigue, sadness or lack of motivation, is the most commonly observed psychological illness in patients with CAD and is defined as a depressed or sad mood and/or markedly decreased interest in all activities over a two-week period (Dobbels, et al., 2002; Rees, Bennett, West, Davey Smith, & Ebrahim, 2007). Depression or depressive symptoms are present in approximately 15%-20% of patients with CAD and 13%-30% in those who have had a hospital admission with acute coronary syndrome (Thombs, et al.,
The variation in reported prevalence rates for anxiety and depression may be due to the sensitivity and specificity of the tools used to test for anxiety and depression, as well as when the tests are undertaken in the client’s period of hospitalisation. Despite the difficulty in accurately estimating the prevalence of anxiety and depression, the literature is consistent in that anxiety and depression have a significant negative impact on morbidity, mortality, recovery, and ability to change lifestyle following myocardial infarction (Ziegelstein, et al., 2000; Yousaf, Hawkin, & Ompun, 2004; Moser, et al., 2007).

Anxiety and depression have a direct impact on the individual’s adjustment to CAD, their ability to modify risk factors, and the resumption or uptake of activities such as work or exercise (Dobbels, et al., 2002; Milani & Lavie, 2007; Moser, 2007). In particular, depression is associated with an increase in unhealthy behaviours, such as smoking, and is also deemed as an independent risk factor for CAD (Milani & Lavie, 2007; Rees, et al., 2007). The effects of anxiety and depression on the individual impacts on their experience of CAD and cardiac rehabilitation because patients with anxiety or depression are less likely to attend hospital based cardiac rehabilitation (Beswick, et al., 2005). Hospital and home based cardiac rehabilitation offers psychological support for patients with CAD through education, support and stress management, resulting in a reduction in symptoms of anxiety and depression for patients (Rees, et al., 2007). Similar to anxiety and depression a patient’s gender can also impact on their experience of CAD.

2.1.2 Impact of gender on the patient experience of CAD

Women and men experience CAD differently and this has an impact on the individual and the health community developing and implementing services such as cardiac rehabilitation. The “majority of people experiencing myocardial infarction and attending cardiac rehabilitation are men” (Heran Balraj, et al., 2011; Hutton &
Men are considerably more altruistic about their illness, their recovery and their support needs than women (Gregory, Bostock, & Backett-Milburn, 2006; Hindleigh, Fridlund, & Lidell, 2006; Hutton & Perkins, 2008). Men tend to view their condition as less severe than women with the same condition and adjust better to the idea of CAD as a chronic illness than women (Hutton & Perkins, 2008). Men are more positive about their future, control over their illness and its cause, but complain of feeling “older”. In contrast women are less optimistic about their future, attribute their illness to be out of their control and report little has changed regarding their perception of themselves (Hindleigh, et al., 2006; Hutton & Perkins, 2008; King, 2002). Men are also more likely to accept, demand and expect support with their recovery and are less likely than women to put the needs of others before themselves compared to men (Gregory, et al., 2006). Married men are also more likely to recover quickly, receive hospital visits and attend cardiac rehabilitation than single men or women (Johnson, Fisher, Nagle, Inder, & Wiggers, 2004; Hutton & Perkins, 2008). However men complain about over protectiveness from their spouses, but the over protectiveness appears to give men less problematic adjustment and better clinical outcomes than women (Hindleigh, et al., 2006; Hutton & Perkins, 2008).

Women are less represented in studies investigating CAD prevention and treatment than men despite having significant problems in their physical and psychological adjustment to CAD (Lee, Alexander, Hammill, Pasqual, & Peterson, 2001). Both Dixon et al. (2000) and Bowman et al. (2006) found gender differences in the incidence and severity of problems following admission to hospital. Women described more concern with the emotional aspect of cardiac illness than the physical concerns that are more frequently identified by men (Dixon, et al., 2000; Bowman, et al., 2006). Women describe emotional concerns such as powerlessness, fear and greater levels of anxiety than their male counterparts and describe conflict and guilt and the impact of their illness on their role as caregiver or home manager (Dixon, et
al., 2000; Moser, et al., 2003; Worrall-Carter, Jones, & Driscoll, 2005). This can result in a poorer psychological adjustment to CAD for women (Worrall-Carter, et al., 2005).

In addition to more negative emotions after an acute event, women with CAD have been found to have worse outcomes than men in relation to complications and ongoing problems with their illness (Grady, Chaput, & Kristof, 2003; Hanratty, et al., 2000; Vaccarino, Krumholz, Yarzebski, Gore, & Goldberg, 2001). The worst outcomes result in increased mortality (Hanratty, et al., 2000) and more acute events such as chest pain or cardiac arrhythmias\textsuperscript{10} for up to two years after their first AMI (Vaccarino, et al., 2001). In a systematic review of literature on the diagnosis and treatment of women with heart disease, women were more likely to be under-diagnosed and under-treated in all aspects of CAD management than men (Grady, et al., 2003). There is also a difference between men and women in regard to their experience of cardiac rehabilitation.

The difference between men and women in regard to their experience of hospital cardiac rehabilitation relates to their referral, attendance and benefit from the programs. Women are also less likely to be referred for cardiac rehabilitation than men and, if referred, are less likely to attend due to multiple factors including home and family commitments and ill health (Bongard, et al., 2004; Jones, et al., 2007). However, in comparison, an Australian study found there was no difference in referral to cardiac rehabilitation between men and women (Johnson, et al., 2004). Women’s reasons for non-attendance or adherence to cardiac rehabilitation were found to be individualistic and multi-faceted (Jones, et al., 2007). In contrast men

\textsuperscript{10} A cardiac arrhythmia is a problem with the rate or rhythm of the heartbeat. During an arrhythmia the heart may beat fast, slow or irregularly. Some arrhythmias are harmless but others may cause cardiac arrest or death. (Jowett & Thompson, 2007).
who attend cardiac rehabilitation appear to benefit from the comradeship with other patients, increased confidence in exercising and the one on one support from nurses than women (Hutton & Perkins, 2008; Heran Balraj, et al., 2011). However given that less women than men attend hospital cardiac rehabilitation this finding is perhaps unsurprising. Men also complain that the hospital cardiac rehabilitation exercise programs were too easy for their level of fitness and had a low opinion of the nurses’ expertise when compared to the advice given by doctors (Hutton & Perkins, 2008). The different experiences of hospital cardiac rehabilitation of men and women would suggest that cardiac rehabilitation models need to be more flexible to meet the individual and different needs of patients according to their gender and psychosocial factors. Similar to gender, the patient’s age also has an impact on his/her experience of CAD and needs for cardiac rehabilitation.

2.1.3 Impact of age on the patient experience of CAD

An individualised cardiac rehabilitation programme should also be developed with patients to reflect the differences that age may bring to patients’ problems and their concerns following an acute cardiac event. Older patients (aged more than 65 years of age) have been found to express more concerns relating to their physical illness than younger patients (Kardis, Shermann, & Barnett, 2007; Smith & Liles, 2007). Smith and Liles (2007) identified that older patients needed more support and information relating to convalescence than younger patients. Older patients have also been found to have worse health related quality of life than younger patients (Kardis, et al., 2007; Smith & Liles, 2007). Elderly (over 70 years) and younger (less than 40 years) patients are identified as being less likely to be referred to or attend cardiac rehabilitation programs (Beswick, et al., 2005). The reasons are mixed, based on physician referral patterns, early return to work and lack of understanding about the benefit of cardiac rehabilitation (Daly, et al., 2002; Beswick, et al., 2005).
Even if older patients do attend cardiac rehabilitation, their needs may not be met (Tolmie, et al., 2009). Tolmie et al. (2009) found that older patients were embarrassed about their co-morbidities, such as arthritis, or their lack of energy that hindered their ability to complete the group exercise program and this led to a higher dropout rate for older patients. Younger patients (aged less the 50) have also been identified as less likely to be referred or to attend cardiac rehabilitation, citing reasons such as return to work or not feeling the program was relevant to their needs (Astin & Jones, 2006; Cooper, Jackson, Weinman, & Horne, 2002, 2005). This further endorses the need for cardiac rehabilitation programs to be individualised for older and younger patients.

2.1.4 Impact of CAD on the spouse experience

Spouses have a pivotal role in supporting patients with CAD (Stewart, Davidson, & Meande, 2000). They assist the patient in their management of a chronic illness and managing subsequent lifestyle change, while supporting their emotional needs. Patients and their spouses experience similar emotions such as fear, anxiety, guilt and loss of control (O’Shea, Wilcox, & Skene, 2002; Berkman, Blumenthalal, & Burg, 2003). Anecdotally, it could be argued that the spouse of a patient hospitalised with CAD experiences equivalent levels of stress and anxiety without the physical pain. However, having an intimate partner such as a spouse reduces the likelihood of the patient experiencing problems post myocardial infarction and is protective in reducing subsequent morbidity (Dixon, et al., 2000). The quality of the relationship can have an impact on the recovery of the client: a good relationship will have a positive impact on recovery and adjustment to lifestyle changes (Moser & Dracup, 2004; Svedlund & Danielson, 2004). The healthier the relationship between the patient and spouse, the easier the patient adapts emotionally and physically to their health status, leading to positive readjustment to recovery or lifestyle changes and reduced anxiety or depression (Moser & Dracup, 2004; Svedlund & Danielson, 2004).
In contrast, several studies describe how the quality of the relationship can negatively impact on the patient with CAD and their spouse (Mahrer-Imhof, Hoffman, & Sivarajan, 2007; Stewart, et al., 2000; Svedlund & Danielson, 2004).

Many couples live side-by-side, avoiding discussion about the illness or its impact on their relationship (Moser & Dracup, 2004; Svedlund & Danielson, 2004). Couples describe conflicting emotions, anger and discourse in their dealings with each other (Svedlund & Danielson, 2004; Mahrer-Imhof, et al., 2007). This has a significant negative impact on the individual’s recovery and the significant other’s coping as they struggle with the emotional impact of the illness and the emotional fallout from each other (Mahrer-Imhof, et al., 2007; Stewart, et al., 2000; Svedlund & Danielson, 2004). Couples also cope differently with the overall experience of CAD, which may impact on the patient’s recovery.

In a phenomenological study on the aftermath of myocardial infarction and subsequent living with CAD, twenty-four couples were interviewed individually and together (Mahrer-Imhof, et al., 2007). Three patterns emerged of how couples viewed their experience: some couples viewed the experience as positive and felt they were stronger as a couple than before the illness; others viewed the illness as a threat and found it a challenge to work together to bring about the changes necessary to prevent the patient’s deterioration and maintain their relationship; finally, some couples felt it was a missed opportunity to work together and became disenchanted about each other and their relationship (Mahrer-Imhof, et al., 2007). A systematic review of cardiac disease and its consequence on the partner relationship (Dalteg, Bemzein, Fridlund, & Malm, 2011, p. 140), concluded: “though couples found the cardiac event distressful they conformed and adjusted their relationship to the new situation”. These experiences are important to recognise and need to be taken into account in cardiac rehabilitation programs so these can accommodate the different dynamics between couples. Unsurprisingly, given the low number of
women included in studies into CAD, in all but one of the studies discussed, the man is the individual with CAD and the woman is the spouse or carer. Only one study explored whether or not the difficulties couples faced differed according to the gender of the spouse or carer; the carers in this study were male (Svedlund & Danielson, 2004). The researchers, using a phenomenological hermeneutic methodology interviewed nine married women and their partners and discovered that the gender of the carer or spouse had little impact on the difficulties couples face when managing CAD (Svedlund & Danielson, 2004). A common complaint from spouses in the studies reviewed was their lack of involvement in cardiac rehabilitation.

Spouses complain of being excluded from cardiac rehabilitation despite a desire to attend (Timmins & Kalisner, 2003; McLean & Timmins, 2007). Very few cardiac rehabilitation programs have specific components for spouses and few programs encourage the spouses to attend outpatient exercise programs (McLean & Timmins, 2007). The AHG includes a section for spouses based on The Heart Manual’s spouse support, which appears to have had no formal evaluation.

In summary, the literature suggests there is a lack of understanding of current patient or spouse experience of CAD. Research evidence suggests that patients with CAD experience different physical and emotional factors, depending on the stage they have reached in their illness continuum. It also indicates that women, the elderly and younger patients may have different needs in relation to rehabilitation and are often excluded from cardiac rehabilitation or research into cardiac rehabilitation. Spouses of patients with CAD describe conflicting emotions, difficulties in their spousal relationships and complain of a lack of involvement in cardiac rehabilitation. Therefore there is a need to investigate whether or not, and how home based cardiac rehabilitation using the AHG meets the individual needs of patients and their spouses.
2.2 Influences on the patient, spouse and nurse experience of home based cardiac rehabilitation

Within the literature there is a scarcity of information regarding the patient experience of home based cardiac rehabilitation. Therefore literature regarding the patients’ experience of hospital based cardiac rehabilitation was also explored. From the literature it was apparent that certain factors influenced the patient, spouse and nurse experience of home and hospital based cardiac rehabilitation. These influences formed sub-themes of the patient, spouse and nurse experience of home based cardiac rehabilitation and were seen as relevant to my study because they reflected the use of the AHG. The underpinning philosophy of the AHG is engagement between the patient, spouse and nurse in the process of home based cardiac rehabilitation. Therefore it was necessary to explore what influences patient, spouse and nurse engagement with home based cardiac rehabilitation using the AHG.

Telehealth was identified as a further sub-theme to this exploration because the AHG is predominately used over the telephone with patients. Given that contact between nurse mentors and patients using the AHG is largely via the telephone, exploring the effectiveness, as well as the patient, spouse and nurse experience of telehealth more generally is necessary for my study. The limited literature regarding the patient, spouse and nurse experience of home based cardiac rehabilitation will be discussed first.

2.2.1 Patient, spouse and nurse experience of cardiac rehabilitation

The patient experience of cardiac rehabilitation may influence its effectiveness. However, few studies have explored the patient, spouse and nurse experience of hospital and/or home based cardiac rehabilitation programs. One of these (Clark, Barbour, White, & MacIntyre, 2004), using focus groups, explored the experiences of
44 patients attending hospital based cardiac rehabilitation and described their experience of feeling initially embarrassed about exercising in a group. It also described how they became more positive about the group over time, and emphasised that the support and motivation of other group members and staff was found necessary for their recovery.

A sub study of a large randomised trial comparing hospital and home based cardiac rehabilitation included a qualitative study exploring the patients’ experience of both hospital and home based cardiac rehabilitation using The Heart Manual (Jones, et al., 2009). Sixteen patients who attended a hospital program and ten patients who attended a home program took part in focus groups to discuss their experiences (Jones, et al., 2009). The overall finding of Jones et al.’s (2009) study was that that both groups of patients benefited from this regardless of the type of program they attended. Participants in each group reported that they had no prior knowledge of the content of either home or hospital based cardiac rehabilitation programs and that they were very satisfied with the program they had attended.

All participants thought that the alternative program to the one they chose would not be as good: for example, home patients thought that the hospital program would not have been as good as the home program. The reasons for this were related to their experience of their particular type of program, for example patients in the hospital program described the benefit of the camaraderie of the group and suggested that this increased their motivation to exercise. In contrast patients in the home program felt that their individual exercise programs constituted a lifestyle change rather than a treatment and were motivated to maintain the change themselves (Jones, et al., 2009). Home based patients said they had a positive experience in regard to the program itself and support from the nurse over the telephone. Interestingly the patient experience of elements of the program such as relaxation differed; all but one of the patients in the home group felt that the
relaxation tapes were beneficial however they described mixed experiences about the relaxation tapes they were given and several participants said they did not attend the relaxation session offered in a face to face hospital based cardiac rehabilitation program. In conclusion, Jones et al.’s (2009) suggested that “patients should be encouraged to attend either a home or a hospital based cardiac rehabilitation program as both can improve a patient’s well-being”.

There are several limitations to Jones et al.’s (2009) study. Patients did not have a choice of program and were randomised to either a hospital or a home program and they were also part of a larger study exploring effectiveness of hospital and home based cardiac rehabilitation. Therefore their experience may be very different to those who actively choose a hospital or a home program as part of their usual care. In addition, patients were recruited to the study by telephone and asked if they had completed their cardiac rehabilitation, patients who confirmed they had completed the program were subsequently invited to take part in the study. Relying on self-report by patients on their engagement with the program might suggest some selection bias because those who appeared not to engage might have had a less positive experience. Despite the fact that spouses were not included in this study, several patients in the home program group mentioned the support their spouse received from The Heart Manual (the home based program used in the study) which they said improved their overall experience. No study has explored the spouse or the nurse experience of home based cardiac rehabilitation.

2.2.2 Patient, spouse and nurse engagement with home based cardiac rehabilitation

As discussed in Chapter 1 adherence to a hospital based cardiac rehabilitation is low, with approximately one-third of patients not completing the program (Daly, et al., 2002; Beswick, et al., 2005). Adherence is defined as “the extent to which patients
follow the instructions they are given for prescribed treatments” (Hayes, Yoa, Degani, Garg, & McDonald, 2005, p. 1). However, as mentioned previously, for the purpose of my study the term engagement defined as “the action of engaging or being engaged” (Oxford English Dictionary, 2012) is used in preference to adherence as I feel it reflects the notion of partnership which is congruent with the philosophy of the AHG. There is some research evidence regarding patient engagement with home based cardiac rehabilitation; however given the limited involvement of spouses in cardiac rehabilitation it is perhaps not unexpected that generally there is little research regarding spouse engagement with programs. There appears to be no literature about what may influence nurse engagement with home based cardiac rehabilitation. Interestingly despite the lack of research regarding spouse and nurse engagement, the research evidence demonstrates that patients engage well with home based cardiac rehabilitation but defining what constitutes engagement is challenging (Dalal, et al., 2007; Jolly, et al., 2008).

Defining and measuring engagement to home based cardiac rehabilitation is complex. The few studies that have reviewed engagement to home based cardiac rehabilitation have generally compared engagement between hospital and home based programs as part of the studies exploring the effectiveness of home based cardiac rehabilitation discussed in Chapter 1 (Dalal, et al., 2007; Jolly, et al., 2008). Home based programs generally appear to have better patient engagement than hospital based programs (Taylor, 2010; Beckie, 1989; Debusk, 1985; Dalal, 2007); however, the methods used to measure engagement with the home based programs within studies are varied, which may impact the strength of their effect. Two recent studies comparing the effectiveness of hospital and home programs used two very different methods of measuring engagement with a home based cardiac rehabilitation. Dalal et al. (2007, p. 2009) randomised 230 patients to hospital or home based cardiac rehabilitation and classed engagement with the program as the patient completing “four of the six week self-completion patient diaries”.
In contrast, Jolly et al. (2008) randomised 470 patients to hospital or home based cardiac rehabilitation and counted patient engagement as the number of contacts the home group received from health professionals by recording the number of times the patient was not available, as the patient not engaging with the program. Both studies reported improved engagement with the home program when compared to patients’ engagement with the hospital program (75% and 91% respectively) but these results were not statistically significantly different (Dalal, et al., 2007; Jolly, et al., 2008; Jolly, Taylor, Gregory, & Stevens, 2006). The reporting of the results in both studies was poor, as the comparison rate for engagement with the hospital based rehabilitation was not reported. It could also be argued that both methods of measuring engagement were flawed because there may be many variables that could account for the increased engagement. For example Dalal et al. (2007) used contact with a health professional as engagement with the home program but, as the health professional initiated the contact and the intensity or duration of the contact was different to that of the hospital program, it may not have been a reliable measure. Neither study explored the impact of the patient and system factors that may also influence engagement.

Engagement is complex and multi-faceted with lack of patients’ engagement resulting in poor patient outcomes and increased health care costs (Hayes, et al., 2005; Bissonnette, 2008). Patient engagement with cardiac rehabilitation, either hospital or home based, is dependent on patient and system factors (Beswick, et al., 2005; Jones, et al., 2007; Neubeck, et al., 2012). Much of the literature focuses on engagement with hospital based cardiac rehabilitation with few studies exploring patient engagement to home based cardiac rehabilitation. As part of a larger study comparing hospital and home based cardiac rehabilitation, Jones, et al., (2007) interviewed patients to determine what factors influenced their engagement with cardiac rehabilitation. Twenty-nine patients who had not engaged with a home program and 28 who had not engaged with a hospital program were interviewed.
and asked about their reasons for not engaging with their programs. There were, however, no clear criteria for what constituted engagement but rather it was based on the nurse’s opinions about a particular patient’s engagement, which may be very subjective. Bissonnette (2008) agrees and argues that clinicians are unable to accurately recognise engagement among patients in their care preferring to use the terms compliance or non-compliance suggesting the patient is at fault. Patients’ reasons for not engaging with the home program were related to demands on time, such as work or domestic life, and psychological and emotional reasons, such as fear or anxiety (Jones, et al., 2007). Patients felt they were doing enough of their own activity or exercise and did not feel they needed the intervention of cardiac rehabilitation. This suggests that patients consider cardiac rehabilitation to be about exercise only and do not fully understand its full range of benefits, which may account for the lack of engagement with cardiac rehabilitation programs.

Recent studies have demonstrated that patients who do not attend hospital based cardiac rehabilitation have multiple risk factors and are at higher risk of subsequent events than those who do attend (Redfern, Ellis, Briffa, & Freedman, 2007; Johnson, Inder, Nagle, & Wiggers, 2009). In a systematic review and meta-synthesis of qualitative data into participating in cardiac rehabilitation, Neubeck et al. (2011) found similar patient factors for lack of patient engagement as those identified by Jones et al. (2007) and concluded that many of the patient factors, which are physical, emotional and psychological, are modifiable with innovative strategies to overcome the barriers. It is worth noting, however, that the majority of studies in the review by Neubeck, (2011) were related to hospital based cardiac rehabilitation. None of the studies exploring engagement investigated the patients’, spouses’ or nurses’ experience of home based cardiac rehabilitation. Neubeck (2011) concluded that considering patients’ preferences for hospital or home based programs may increase engagement.
Offering patients a choice of hospital or home-based cardiac rehabilitation might indeed improve outcomes and increase engagement with the program. Researchers found that when patients chose their program there was improved engagement, although this had little impact on patient outcomes (Grace, McDonald, Fisman, & Caruso, 2005; Dalal, et al., 2007). Nevertheless, a further study found that patients who make an informed choice about their cardiac rehabilitation program are more likely to complete the program (Wingham, Dalal, Sweeney, & Evans, 2006). This qualitative study using semi-structured interviews and interpretive phenomenological analysis concluded that “each patient should be given the choice of cardiac rehabilitation to increase their feelings of control and thus their motivation to complete the program” (Wingham, et al., 2006, p. 294).

How choice of program is offered to patients has been found to impact patients’ uptake and engagement to a particular program (Madden, et al., 2011). Thirty-five patients and 12 staff were interviewed about the choices patients make when choosing between hospital and home-based cardiac rehabilitation. Interestingly, all of the staff interviewed in this study stated they had given patients a choice of program; however, 37% of the patients could not remember being offered a choice of hospital or home-based program. Home-based cardiac rehabilitation was often offered as a “default option for those unwilling to do the hospital-based program” (Madden, et al., 2011, p. 6), which resulted in frustration and concern for the staff running the home-based program because they perceived that the lack of engagement with their home program when compared to the hospital-based rehabilitation program was attributable to the likelihood that they would be receiving less motivated patients. In hindsight, the staff interviewed felt that all programs should be offered on an equal basis. The researchers concluded that “choices offered to patients should be real and unconstrained not predetermined by the convenience of providers, and that nurses needed to ensure that patients were able to make informed choices about the type of cardiac rehabilitation they would
prefer” (Madden, et al., 2011, p. 8). Patients also sought the support of their family in regard to choice of cardiac rehabilitation and this appeared to influence their attendance (Wingham, et al., 2006). These researchers concluded that family should be involved when patients are choosing their cardiac rehabilitation program. Exploring the patient, spouse and nurse experience of home based cardiac rehabilitation might assist in understanding how cardiac rehabilitation programs are offered to patients, what influences a patient’s choice of program and if this has any impact on patient, spouse and nurse engagement with the program.

2.2.3 Use of telehealth for home based cardiac rehabilitation

Telehealth refers to “the use of telecommunication technology to remove time and distance barriers in the delivery of health care services” (Artinian, 2007, p. 25). Nurses have emerged as key providers of telehealth resulting in the term telenursing defined as “the use of telemedicine technology to deliver nursing care and conduct nursing practice” (Peck, 2005a). Telemedicine technology or telecommunication technology refers to the use of the telephone, internet or other technology such as computers to enable nurses to support patients at home (Peck, 2005a). Home based cardiac rehabilitation may utilise telehealth to support patients with CAD. Telenursing may include nurses supporting patients through a structured program such as the AHG, or it may be nurses providing indirect patient care and advice through a helpline such as Healthdirect\(^\text{11}\) or it may be responding to data from telemonitoring through a smart phone.

\(^{11}\) Health direct is a telephone support program. Nurses are based within a call centre responding to calls from the general public, subsequently interpreting the patient symptoms, and advising the patient on the need for further care such as GP, home management or hospital admission as needed.
Telehealth for patients with CAD has demonstrated an improvement in clinical outcomes such as anxiety and depression levels, blood cholesterol levels and a reduction in risk factors (Inglis, et al., 2010; Neubeck, et al., 2009). Utilising telehealth for patients with CAD leads to a reduction in patient risk factors but this may not lead to a reduction in mortality (Neubeck, et al., 2009; Inglis, et al., 2010; Stolic, Mitchell, & Wollin, 2010). A review of telehealth interventions for patients with CAD by Neubeck et al. (2009) included 11 trials (two of which were Australian) and 3145 patients, and found that telehealth interventions were effective in reducing risk factors including blood pressure, cholesterol and smoking but did not significantly reduce all-cause mortality. Neubeck et al. (2009) concluded that telehealth interventions, especially telephone based interventions, could increase the uptake of secondary prevention to those who do not attend cardiac rehabilitation.

A review focusing on nurse led telephone interventions for patients with cardiac disease included 24 studies with 8330 participants and found slightly different results (Stolic, et al., 2010). Studies were included in the review if they were nurse led and involved the use of the telephone or telephone interventions for people with CAD and related to the post hospital discharge period. In contrast to Neubeck, et al., (2009) the authors concluded that people with CAD showed some benefits from nurse led telephone interventions; however, there was no clear definition within the study of what the difference was between telephone use and telephone interventions by nurses which may affect the interpretation of the results (Stolic, et al., 2010).

The difference in results may also be related to the different way in which the reviews were undertaken. Neubeck, et al., (2009) give detailed descriptions of data synthesis and analysis, in contrast to Stolic et al. (2010) who did not describe these. A Cochrane review of structured telehealth and or telemonitoring for patients with chronic heart failure versus usual care found that telehealth and/or telemonitoring was effective in reducing death by all causes and resulted in less hospital admissions.
for patients with heart failure (Inglis, et al., 2010). An updated review compared telemonitoring and structured telephone support defined as “the monitoring and/or self-care management of patients with heart failure delivered using simple telephone technology (telephone calls)” found that structured telephone support was as effective as telemonitoring in improving patient outcomes and reducing costs to the health services (Inglis, et al., 2010, p. 1). Similar to Neubeck et al. (2009), within the review by Inglis et al. (2010) there was a clear definition of the intervention of telehealth or telemonitoring. Included in Neubeck et al.’s (2009) review were two Australian studies which utilised telehealth for patients with CAD.

The first of these was The Choice of Health Options in preventing Cardiovascular Events (CHOICE) study and the second was the Coaching Outcomes to Achieve Cardiovascular Health (COACH) study; both are secondary prevention programs which utilise telehealth to support patients with CAD (Vale, et al., 2003; Redfern, et al., 2008). Secondary prevention is defined as:

Healthcare designed to prevent recurrence of cardiovascular events (heart attack or stroke) or complications of cardiovascular disease in patients with cardiovascular disease. It involves medical care, modification of behavioural risk factors, psychological care, education and support for self management (including adherence to prescribed medications), which can be delivered in various settings. Examples of evidence-based secondary prevention strategies for cardiovascular disease include cardiac rehabilitation services and chronic heart failure management services (National Heart Foundation of Australia, 2010).

Home based cardiac rehabilitation is part of the secondary prevention of CAD thus programs such as CHOICE and COACH, although not described as home based cardiac rehabilitation are included within this literature review because they fulfil the definition of home based cardiac rehabilitation as described in Chapter 1.
CHOICE is an innovative modular program\textsuperscript{12} in which the patient receives support over the telephone from a nurse regarding their progress with their chosen module in addition to regular contact with the general practitioner or face-to-face contact with nurses or other patients (Redfern, et al., 2008). The COACH program used health coaching which is defined as “a method of engaging and guiding others to “discover” and address their own ambivalence about health behavior change” (Huffman, 2010, p. 245). Patients with CAD were coached in a didactic way by a nurse or dietician using a continuous loop of coaching, a general practitioner visit and coaching. The CHOICE and COACH programs were evaluated in randomised controlled trials to determine their effectiveness in the secondary prevention of CAD (Vale, et al., 2003; Redfern, et al., 2008).

The CHOICE and COACH studies demonstrated improved outcomes for patients with CAD when compared to usual care (Redfern, et al., 2008; Vale, et al., 2003). Both studies were similar in design in that they randomised patients to an intervention group or a usual care group (information on discharge from hospitals regarding CAD). Patients included in the COACH study were not excluded from attending hospital based cardiac rehabilitation, if that was part of the usual care offered by their treating cardiologist or the hospital they were admitted to, whereas patients recruited to CHOICE were those patients who did not attend hospital cardiac rehabilitation. Both studies demonstrated that patients accessing CHOICE and COACH programs had significantly lower cholesterol levels, lower blood pressure levels, improved exercise tolerance and less anxiety or depression and improved quality of life than those patients accessing usual care (Vale, et al., 2003; Redfern, et al., 2008).

\textsuperscript{12} CHOICE is a modular program in that each risk factor (smoking, cholesterol, lack of exercise, diet) are separate modules, patients choose the modules they wish to complete and the process in which the education is delivered (telephone, group session or clinic appointment).
In CHOICE however, they compared results to a third group accessing hospital cardiac rehabilitation and found they had significantly lower cholesterol results, improved exercise capacity and less symptoms of depression than those accessing CHOICE alone or usual care (Redfern, et al., 2008). This suggested a greater benefit of attending outpatient CR compared to CHOICE however the patients attending CR were not randomised. The COACH study reported that there was no significant difference between the intervention and usual care group in the attendance at a hospital cardiac rehabilitation program (53% versus 57%), suggesting a benefit to patients in COACH over and above that of outpatient cardiac rehabilitation (Vale, et al., 2003).

Neither study into the effectiveness of CHOICE or COACH explored the patient, spouse or nurse experience of the program itself or the acceptability of home based programs to Australian patients, spouses and nurses. This qualitative evaluation may have been useful in understanding which aspects of the programs the patients, spouses and nurses found of most or of least benefit. Therefore it can be concluded that there are clinical benefits of telehealth for CAD patients (Vale, et al., 2003; Redfern, et al., 2008; Neubeck, et al., 2009; Stolic, et al., 2010) however there is need to also explore how acceptable telehealth is as a means of health care for patients, spouses and nurses.

### 2.2.4 Patient, spouse and nurse experience of telehealth

There is little evidence of the acceptability of telehealth for home based cardiac rehabilitation to patients, spouses and nurses. Rather, much of the evidence for the acceptability of telehealth is focused on telehealth being used as a means of reducing attendance at emergency departments or reducing general practitioner contact through telephone help lines, or the use of home monitoring equipment such as in telemonitoring.
Telemonitoring is the use of “information technology to monitor patient status at a distance” (Artinian, 2007, p. 25). Telemonitoring using a smart phone was used in an Australian pilot study of patients unable or unwilling to attend hospital based cardiac rehabilitation but willing to have a home program. The aim of the pilot study was to explore whether or not patients found this model of home support after a cardiac event acceptable. The smart phone was used to record and monitor the patient’s progress with physical activity and measure blood pressure, followed up with text messages and phone calls from nurses to discuss patients’ progress (Varnfield, et al., 2011). Early results indicated that patients found the phones easy and acceptable as a method of home based cardiac rehabilitation; however, further research into the effectiveness of this type of program is needed (Varnfield, et al., 2011). However, to date no studies appear to have been undertaken to evaluate the nurse experience of home based cardiac rehabilitation delivered this way.

Researchers have, however, studied the impact of telehealth and telenursing on nurses and nursing and concluded that nurses found that using telehealth was acceptable, easy to use and created new types of relationships with their patients (Mass, et al., 2001; Wahlberg, Cedersund, & Wredling, 2003; Wakefield, et al., 2008). Nurses embraced the technology of telehealth and felt that it saved time and money (Wakefield, et al., 2008). The relationship between the patient and nurse was altered because the nurses found patients were more motivated and comfortable in managing their own illness (Mass, et al., 2001). Peck (2005, p. 339) suggests this might be because telenursing focuses on the “individual’s long term wellness, self management and health”. This, Peck (2009) argues, may retain experienced nurses who are disillusioned with hospital care as telehealth provides a new means of nursing. However, Stolic et al. (2010) argue telenursing may have a detrimental effect, with experienced nurses leaving clinical practice to deliver telehealth, resulting in a less skilled nursing workforce (Reischmann & Yarrandi, 2002). Several studies have also identified some other challenges faced by nurses using only
telehealth for clinical practice (Demiris, Parker Oliver, & Courtney, 2006; Hollmstrom & Hoglund, 2006; Peck, 2005; Snooks, et al., 2008).

The skills required for telenursing have been identified as different to those of face-to-face nursing because there is no therapeutic touching or face to face interaction with the patient (Hughes, 2003; Peck, 2005a). Several studies have described how nurses are concerned and challenged in assessing patients health needs when contact is only over the telephone (Snooks, et al., 2008; Wahlberg, et al., 2003). Nurses also doubt the credibility of the information they received from patients over the telephone, without the ability to assess for accuracy with a face to face assessment (Demiris, Parker Oliver, & Courtney, 2006; Hollmstrom & Hoglund, 2006).

In a review of the ethical considerations for utilisation of telehealth in home and hospice care for cancer patients, the lack of human touch was seen as a disadvantage of telehealth and the authors recommended a combined approach (telehealth and in-person) to nursing care (Demiris, et al., 2006). In a qualitative study 12 nurses were interviewed about their experience of telehealth, they described telenursing as “the faceless encounter” and the nurses felt uncertain or anxious about their relationships with patients without face-to-face contact (Hollmstrom & Hoglund, 2006, p. 1865). The majority of these studies were conducted with nurses working in a call centre setting such as Healthdirect which may limit the application of the findings to telenursing in other settings. Nurses using the AHG for home based cardiac rehabilitation that predominately practice telenursing may have similar experiences to those identified in the studies discussed above, however, there appears to be no study that has explored the nurse’s experience of telehealth in home based cardiac rehabilitation. Generally however, in contrast to the challenges faced by nurses with telehealth patients appear to embrace its use and find it not only beneficial but in some cases superior to face to face contact with nurses.
Patients with CAD especially those who are older have found telehealth and telemonitoring an acceptable mode of health care delivery (Chumbler, Mann, Wu, Schmid, & Kobb, 2004; Clark, et al., 2007; Dimmmick, Mustarleski, Burgiss, & Welsh, 2000). Yet a study by Bowles & Baugh (2007) found that nurses and other health professionals suggested that older people may be unwilling to embrace telehealth because they lack auditory or visual acuity and preferred traditional face-to-face contact. In contrast, several studies have demonstrated the opposite that older patients embrace telehealth (Chumbler, et al., 2004; Clark, et al., 2007; Inglis, et al., 2010). Two of the studies exploring the older patients experience of telehealth were similar in design in that the researchers interviewed patients about their experience of telemonitoring (downloaded physical health information from a computer) and telenursing (support from the nurse to manage their illness over the telephone) (Chumbler, Mann, Wu, Schmid, & Kobb, 2004; Clark, et al., 2007). The studies found that elderly patients were able to cope with technological monitoring, the lack of face-to-face contact and telehealth, finding it easy to use and helpful in managing their illness (Chumbler, et al., 2004; Clark, et al., 2007). Other studies have found that older patients reported less anxiety and a preference for telehealth when compared to usual face-to-face clinic contact (Dimmmick, Mustarleski, Burgiss, & Welsh, 2000; Mass, et al., 2001).

Given the geographical size of Australia where access to specialist services such as cardiac rehabilitation is limited for some rural populations, telehealth has been found to be a beneficial alternative to face to face contact for rural Australians (Moffatt & Eley, 2010). Nevertheless the patient experience of telehealth and telenursing in home based cardiac rehabilitation is unknown and therefore it is important to explore this experience further.
In summary, there appears to be a dearth of information about the patient, their spouse or the nurse experience of home based cardiac rehabilitation and the factors that influence the experience. Patients have reported that they found home based cardiac rehabilitation beneficial, but there appears to be no research evidence regarding the spouse or nurse experience of home based cardiac rehabilitation. Measuring engagement with home based cardiac rehabilitation is difficult and there is a need to understand what factors help patients, spouses and nurses engage with home based cardiac rehabilitation. Offering patients a choice of program does not appear to impact on outcomes but may improve patient engagement with the program, however how the program is offered to the patient and what influences their choice of program may also improve their overall experience and subsequent engagement (Dalal, et al., 2007; Madden, et al., 2011). Few studies have explored patient experience of home based cardiac rehabilitation and the impact of a positive or negative experience on patient engagement.

Telehealth for patients with CAD has demonstrated an improvement in patient outcomes and is an acceptable model of care for patients and nurses (Peck, 2005a; Bowles & Baugh, 2007; Clark, et al., 2007; Neubeck, et al., 2009; Inglis, et al., 2010). However there is little research regarding the acceptability of telehealth to CAD patients, spouses and nurses. Much of the research regarding the influence of the patient, spouse and nurse experience, engagement and telehealth has been conducted outside Australia, so there is a need for research of this nature within the Australian context. As well from a patient/nurse relationship building perspective there is therefore a particular need to explore nurses’ experience of home based cardiac rehabilitation to understand how that experience might impact on their relationship with patients as well as the delivery of care.
2.3 Partnership between the patient, spouse and nurse in home based cardiac rehabilitation

Despite medical and nursing advances resulting in better outcomes and shorter length of hospital stays for patients, complaints, patient adverse events from medical or nursing error and health care costs have increased (National Heart Foundation of Australia, 2005; Wiggins, 2008; Clinical Excellence Commission, 2011). Wiggins. (2008b) suggests that the reason for this is fragmented care during the patient’s acute hospital phase, discharge and follow-up and the accelerated pace of modern health care. Fragmented care is due to multiple factors including multiple health care professionals providing care to a single patient without coordination or continuity of care, the complexity of modern nursing, and the demands of an ageing population. In the current fragmented system of care Wiggins, (2008, p. 631) argues that “no one knows the patient’s case from beginning to end. The only constant person in a patient’s care is the patient”. Therefore a new model of care needs to evolve within healthcare that puts the patient and their family at the centre of their own care.

As discussed in Chapter 1, CAD is a chronic condition that requires ongoing management over a period of years and seriously challenges the efficiency and effectiveness of a health care system designed for acute episodic care (World Health Organisation, 2002). Wagner, Austin & Von Koff (1996b) argue that for a health care system to be effective and efficient in the management of chronic diseases such as CAD there needs to be interaction between informed activated patients and prepared proactive healthcare teams. The nature of the interaction also needs to be considered with the patient and their family leading the process supported by the health care system to self-manage their condition (Wagner, et al., 2001). Research in the United Kingdom has demonstrated that patients are actively seeking to control their own health conditions with support from health professionals (Beasley, 2010).
Within nursing, promoting a relationship of partnership between nurses and patients has emerged as a way of supporting patients with self-management/monitoring of their chronic illness, increasing patient self-esteem and reducing fragmentation of care by improving patient satisfaction, improving patient outcomes, reducing adverse events, reducing costs and subsequently reducing the demands on acute health care (Wagner, et al., 2001; Gallant, Beaulieu, & Carnevale, 2002; Bidmead & Cowley, 2005; Hook, 2006; Jordan, et al., 2008; Wiggins, 2008; Beasley, 2010).

Partnership fosters new relationships between patients and nurses that incorporate mutual cooperation, respect and responsibility. Partnership in nursing is defined as “a relationship between individuals or groups that is characterised by mutual cooperation and responsibility, as for the achievement of a specified goal” (Hook, 2006, p. 133). A partnership relationship involves shared values, open communication, support, trust, and shared responsibility for decision-making (Gallant, et al., 2002; Wiggins, 2008). In nursing, partnership is doing with the patient rather than doing for the patient (Bidmead, Davis, & Day, 2002). It involves the nurse and patient recognising and acknowledging each other’s knowledge, skills and life experience through the development of an open and trusting relationship by working together, negotiating and discussing goals and actions (Bidmead, et al., 2002; Bidmead & Cowley, 2005). Hook (2006) suggests that it is a relationship where there is communication and patient participation resulting in an autonomous patient able to negotiate goals and plans supported by a nurse with professional competence and empathy and who is the patient’s advocate and able to share the responsibility for care (Bidmead, et al., 2002; Gallant, et al., 2002; Hook, 2006). The sharing of responsibility may be challenging for nurses who are more used to working in an ‘expert’ role.
In a partnership, each participant must respect what the other brings into the relationship for the partnership to be successful. For the nurse, this suggests “the need to be positive for the patient, believing in their capability and relinquishing the status and privilege of being a nurse” (Gallant, et al., 2002, p. 152). Wiggins (2008) states it simply as “we know better has to be replaced by no decision about you without you” (p. 633). Nevertheless, the call to be cared for by the patient to the nurse and the satisfaction in meeting that need, combined with technological or specialist care necessary for modern nursing, is a powerful driver for the nurse to maintain the traditional expert nurse/patient relationship (Joel, 2002; Henderson, 2003; Summer, 2008). Nurses may or may not acknowledge that need within them and might sabotage the partnership process to maintain the status quo (Henderson, 2003). Wiggins (2008) agrees and suggests that within a partnership model “nursing’s approach to patient care requires a new mental model that acknowledges the patient’s expertise and ability to be a full participant in care” (p.635). Public participation and partnership between health professionals and patients is the professed basis for current health policy and best practice for cardiac rehabilitation nurses (Briffa, et al., 2009; NSW Department of Health, 2007, 2006).

2.3.1 Partnership in cardiac rehabilitation nursing

Nurse led interventions for CAD such as cardiac rehabilitation have demonstrated improved patient outcomes in regard to reduction of risk factors and improved quality of life, but little is known about the relationship between nurses and patients during these interventions. In the studies exploring the effectiveness of hospital and home based cardiac rehabilitation or in a meta-analysis of nurse led interventions for secondary prevention for CAD the effectiveness of the intervention was explored but not the relationship between the nurse and patient (Jolly, et al., 2003; Dalal, et al., 2007; Stolic, et al., 2010; Taylor, Dalal, Jolly, Moxham, & Zawada, 2010). In exploring the literature further there appears to be limited studies on the nature of the nurse
patient relationship within home or hospital based cardiac rehabilitation. This is surprising given that NSW Department of Health policy (2008) suggests cardiac rehabilitation nurses should work in partnership with patients and their families and a position statement by the Australian Cardiovascular Health Rehabilitation Association advocates partnership as part of its integrated approach to secondary prevention of CAD (Briffa, et al., 2009).

The AHG home based cardiac rehabilitation program as discussed in Chapter 1 also advocates a partnership approach between the nurse and patient and spouse/family. The role of the nurse using the AHG with patients is one of care facilitator rather than care giver yet the desire or ability of cardiac rehabilitation nurses to work in this way has not been explored. Given the limited literature regarding partnership in cardiac rehabilitation nursing (hospital and home based), I reviewed and included relevant literature on the nurse patient relationship/partnership between nurses caring for patients with CAD from other settings such as primary care clinics, outpatients and hospital units. Several sub-themes emerged from the literature that influenced the nurse patient relationship and partnership. These sub-themes were 1) power and control, 2) identification of patient needs, 3) communication of information, and 4) changing the role of the nurse as ‘expert’ to the nurse as facilitator.

### 2.3.2 Power and control

Power and control influence the relationship between nurses and patients and can hinder partnership (Henderson, 2003; Summer, 2008). Power in this context is defined as having influence over another and achieving an intended effect (Du Plat-Jones, 1999). Control is defined as “being in command of” (Oxford English Dictionary). Within nursing, the concept of power and control in the nurse/patient relationship is sometimes controversial, often hidden or, as Rundqvist & Lindstram
(2005) suggest, dressed up as empowerment, which these authors define as “getting you to come round to a way of behaving that I, the expert, knew in advance was good for you, whilst encouraging you to think that changing your behaviour was your idea in the first place” (Rundqvist & Lindstram, 2005, p. 25). In contrast, Doss, DePascal and Hadley (2011) argue that empowerment is “a process of helping people to assert control over factors that affects their lives” (p.116). Power within a nursing partnership is acknowledged as the nurse recognising that his or her role is not to share or give power but to help patients realise the power sits with them (Doss, DePascal, & Hadley, 2011). Within the literature, there appears to be little reference to power and control in the nurse/patient relationship in the context of home based cardiac rehabilitation. Understanding how power and control may impact on the nurse, patient and spouse experience of home based cardiac rehabilitation using the AHG may give some insight into patient and nurse engagement in this type of program.

Power and control on the nurse’s part impacts on the nurse/patient relationship (McCormack, 2003a). Moving the patient from dependence to independence on this continuum requires nurses to develop relationships with patients during their interactions. Several studies have demonstrated that nurses have little or no insight into how power and control influence their interactions with patients (McCabe, 2004; Berg & Danielson, 2007; Summer, 2008), and several more have explored power and control in relation to the care of patients with CAD or other cardiac illnesses in a hospital ward rather than patients attending an outpatient cardiac rehabilitation program (Henderson, 2003; Wellard, Liibridge, Beanland, & Lewis, 2003; Summer, 2008). All of the studies reviewed are similar in design in that they used interviews to ask nurses about their perceptions of power and control in nursing (Summer, 2008), and several of these studies subsequently observed the interactions between patients and nurses (Henderson, 2003; McCabe, 2004). The researchers found that the nurses interviewed had little or no insight into how power and control influenced
their interactions with patients (McCabe, 2004; Summer, 2008). They discussed power and control in relation to nursing management and organisational hierarchy and its impact on them and their work practices rather than their interactions with patients.

In contrast, an Australian study by Henderson (2003) found that nurses were aware of the power imbalance and used it as part of their care. Henderson (2003) observed episodes of nurse/patient interaction and found that “the patient had little input beyond deciding on activities of daily living” (Henderson, 2003, p. 504). Rather, Henderson (2003) suggested the prevailing belief among the nurses was that they knew best, based on their medical knowledge and experience.

In some of the studies referred to above, the nurses interviewed were asked about their understanding of public participation and partnership (Henderson, 2003; Wellard 2007a). When questioned, the nurses revealed their understanding of partnership to be that it involved working with informed patients who knew their condition and required information about their health. The nurses described their experience of “involved” patients who assisted with their health care delivery and actively participated in the health care process. There was an awareness of health policy relating to increased public participation and a drive for nurses to work in partnership with patients. The overwhelming feeling by the nurses was that this was a good thing (Henderson, 2003; Wellard, et al., 2003).

However, Henderson (2003) and McCabe (2004) found there was little recognition from nurses that partnership with patients implies shared control of interactions and nursing care. Despite their positive comments about partnership, when nurses’ clinical practice was observed their articulated viewpoint appeared to be rhetoric rather than reality. Nurses wanted to make decisions for patients, instead of assisting them in decision-making, and they withheld information from patients and did not
involve them in their care (Henderson, 2003; McCabe, 2004). Sadly, Henderson (2003, p. 505) found that patients reported that the nurses would not listen or let them make up their own mind, so they “wore them [patients] down and as they were unwell they resorted to giving in and doing what the nurse wanted”. When these findings were discussed with the nurses, they admitted that they actively maintained control over their interactions with patients due to the demands of their workload. Whether the findings from the studies by Henderson (2003) and McCabe (2004) are applicable to nurses working within home based cardiac rehabilitation is unknown. Nevertheless there appears to be no evidence to suggest that nurses engaged in cardiac rehabilitation programs in the home are any different to their hospital colleagues. There is also little evidence about how the cardiac rehabilitation nurse interacts with the patient’s spouse and if power and control is apparent in that relationship. Power and control also may have an impact on how patients’ needs are identified and interpreted.

### 2.3.3 Identification of patient needs

The experiences, values, expectations and preferences of patients are important considerations within the partnership process (Bidmead & Cowley, 2005; Hook, 2006). Within nursing, this is commonly referred to as the patients’ needs. Nurses and patients have been found to have different opinions about the presence of patients’ needs (McCormack, 2003b; Hendry & Walker, 2004). Three studies explored patients and nurses in regard to patients’ needs and/or nursing/patient expectations (Lau-Walker, 2004a; Florin, Ehrenberg, & Ehnfors, 2005; Godfrey, Parten, & Buckner, 2006). All of these studies involved cardiac patients with one specific to cardiac rehabilitation.
Lau-Walker et al. (2004b) explored the cardiac rehabilitation practitioner’s perceptions of the importance of the patient’s expectations or needs of cardiac rehabilitation, the aim being to assess if the practitioner had the capacity and understanding to plan individualised care around individual patient expectations. In their study, Lau-Walker et al. (2004b) found that, although practitioners rated the role of patient expectations and needs highly within cardiac rehabilitation, a third of these practitioners were unsure if they were meeting the individualised expectations or needs of the patients. Rather, the practitioners identified they were delivering cardiac rehabilitation based on their own expectations and needs to provide a service. In the opinion of the researchers the practitioners also underestimated the impact of the patients’ psychological perspective on the ability to cope with the illness or make necessary lifestyle changes. The study concluded that, although practitioners recognised the impact of a patient’s expectations, they relied on their own interpretation of the importance of a patient’s expectations and this was influenced by their own beliefs of what the patient’s needs were (Lau-Walker, 2004b).

Lau-Walker’s (2004b) findings were similar to other’s finding from qualitative studies conducted in hospitals with patients in cardio thoracic intensive care, which compared patients’ and nurses’ views of care needs (Florin, et al., 2005; Godfrey, et al., 2006). These studies found that nurses overestimated some needs of patients such as pain relief or the need for assistance with hygiene and underestimated other needs such as the psychological support or management of nausea. These studies concluded that nurses need to obtain and use patient preferences in care delivery and have an understanding that nurses and patients have different views on nursing care needs.
In the instance of nursing care a partnership between nurse and patient is one where both parties discuss and negotiate the patient’s needs and develop a mutually agreeable plan to meet those needs (Bidmead & Cowley, 2005). Nurses using the AHG for home based cardiac rehabilitation are encouraged to work in partnership and facilitate patients’ identification of their own needs. Exploring the nurse, patient and spouse experience will assist in understanding whether or not partnership is apparent in the communication of needs in home based cardiac rehabilitation using the AHG. Knowledge about their illness and a general context of mutual information sharing between nurse and patient is likely to better enable the patient to be more confident in taking an active role in its management and being willing to communicate his/her needs. This context is created when the nurse is willing to work in partnership with the patient.

2.3.4 Communication of information

Patients and spouses complain of a lack of information about CAD and their recovery (Scott & Thompson, 2003; Hanssen, Nordrehaug, & Hanestad, 2005; McLean & Timmins, 2007). In order to understand their condition patients and spouses need information about it. Henderson (2003) and Summer (2008) found that nurses withheld information as part of retaining power and control. Hanssen, Nordrehaug & Hanstead (2005) conducted focus groups to explore if patients felt their information needs were met following myocardial infarction. They found that, despite lengths of stay of up to seven days, patients still were dissatisfied with the information they received. Also using focus groups, McLean & Timmins (2007) explored information needs of spouses of patients experiencing myocardial infarction. The researchers found that the spouses described “a tick box” approach, whereby the nurse appeared to give information based not on what information the patient and spouse wanted to know but on the information the nurse wanted to provide (McLean & Timmins, 2007). This result is similar to that of a systematic
review of the information needs of patients and spouses post myocardial infarction, which concluded that patients and nurses differed in their opinions on what information was necessary for their recovery (Scott & Thompson, 2003). Patients and spouses rated “risk factors, cardiac anatomy/physiology, medications and physical activity” as priority information needs and preferred the information to be delivered by a physician. Nurses rated diet, activity, and resumption of sexual activity as high information needs. There was correlation between nurses and patients in regard to symptom management and medication (Scott & Thompson, 2003). More recent studies have found similar results regarding the discourse between patients, spouses and nurses relating to information requirements, suggesting a more individualised partnership approach to information delivery is needed (Timmins, 2005; McLean & Timmins, 2007). The AHG provides a lot of information for patients and spouses, although there has been no evaluation regarding the relevance of the information for patients and spouses, or whether or not the nurses provide information based on individual needs or more generally. Researchers have identified that one of the obstacles for good patient education was the lack of partnership between patients and nurses during health education/information sharing (Scott & Thompson, 2003). Patients’ length of hospital stay for myocardial infarction can be as little as three days and therefore the role of the cardiac rehabilitation nurse in meeting the information needs of patients and building their knowledge about their illness within a very short time frame is crucial.

Building knowledge and providing information about patients’ illnesses in a partnership approach requires the nurse to listen to, assess and acknowledge the patient’s existing knowledge and experience (Jordan, et al., 2008). This is challenging because nurses are often more comfortable using closed communication, which elicits yes or no answers from the patient, enabling them to give the information they think the patient needs to know, which often results in dissatisfied or uninformed patients (McCabe, 2004). However, it has been suggested that closed communication
is used by nurses because it saves time (McCabe, 2004); yet Henderson (2003) observed that, even when the nurse had time, closed communication was used.

An example of closed communication is evident in a study where nurses (four) supporting patients (20) with chronic heart failure and patients were interviewed about their experiences of giving and receiving information (Lloyd-Williams, Beaton, Goldstein, Mair, & Capewell, 2005). In this study, nurses in a clinic for patients with heart failure provided information focused on the patient’s illness and medication requirements because the nurses felt that this was important. In the nurses’ opinion, this empowered the patients to manage their condition and increase compliance with medication. The patients, however, reported that they couldn’t remember talking about medication, remained confused about their condition, and couldn’t remember being given the opportunity to discuss their own individual concerns (Lloyd-Williams, et al., 2005). There may be reasons why the patient did not recall the information given to them such as cognitive impairment or illness, but closed communication framed around the nurse’s judgement of the patients’ information needs may have compounded this.

In contrast, in a similar study involving 18 patients and six nurses who were interviewed about their experience of communication in a stress management clinic and community heart failure program demonstrated the benefits of open communication (Lowenberg, 2003). The underpinning philosophy of care in this clinic was openly stated as holistic and framed around the patient (Lowenberg, 2003). Patients and nurses in this second study unanimously agreed that, although the patients were in the clinic for stress management or the nurse was in the patient’s home to review her/his heart failure, the relationship and communication between nurse and patient was open and framed around the patient. Patients were found to have a high level of knowledge and there was evidence of a trusting relationship between patients and nurses. This indicates a partnership approach may have
existed between nurse and patient facilitated by willingness by both parties to communicate openly and resulting in informed patients and nurses and a positive trusting relationship between both.

In another study ten nurses were interviewed regarding the preconditions needed for a trusting relationship when counselling patients with high blood pressure. These preconditions were based on the competency of the nurse relating to awareness of expression, pedagogical competence and professional credibility (Eriksson & Nilsson, 2008). Despite the nurses in the study having recognised these conditions, they acknowledged it was easy to fall into a routine non partnership or non trusting way of working (Eriksson & Nilsson, 2008). Little is known about communication and trust between nurses, patients and their families engaged in home based cardiac rehabilitation, and therefore exploring the relationship between patients, spouses and nurses in this study may inform this discussion.

2.3.5 Changing the role of nurse as ‘expert’ to ‘facilitator’

As previously identified the central focus of the AHG is a partnership approach between nurse, spouse and patient. This requires a change for nurses who may be more used to working in an expert role. This change, however, is consistent with a broader emphasis on consumer participation in their own health care provision (Glasgow, et al., 2008). Anderson’s (1991) Intervention: Nursing Roles and Functions Model, through its identification of nurses’ roles and functions when in the role of health care giver as well as those relating to the nurse as health care facilitator, serves to describe what this change in emphasis between these two roles might mean in terms of changes in nursing practice.
The Intervention: Nursing Roles and Functions model was developed in the early 1990s by Betty Anderson, a nurse educator and researcher and was situated against a background of seeking to achieve curriculum development based on a conceptual framework of the discipline of nursing that was inclusive of the nature, structure and knowledge of nursing (Anderson, 1991). Her work sought to conceptualise the discipline of nursing from a holistic perspective. To arrive at this Anderson and colleagues endeavoured to map “the terrain of nursing” (Anderson, 1991, p. 95) and subsequently arrived at two interrelated frameworks, termed the Intervention: Nursing Roles and Functions Model and the Nursing Activity Model, which have:

not only incorporated concepts previously identified in relation to intervention and nurse/patient relationships but have extended the conceptual analysis. They have done this by undertaking an exploration in some depth and detail of significant concepts, opening up understanding of their meaning in nursing and thereby adding to the process of explicating the structure of the body of knowledge basic to nursing… (Anderson, 1991, p. 119)

The development of these models was based on “the belief that practice should drive theory which in turn should inform practice” (Anderson, 1991, p. 121); a process that Anderson (1991) emphasised is cyclical. More recent models of nursing including patient centred care (McCormack, 2003a) and health care more generally have had to respond to a growing emphasis on consumer participation in health care, largely underpinned by the increasing amounts of and accessibility of health information for patients and their families through multimedia. These models urge a change in emphasis in nursing, a change which is identified in Anderson’s (1991) model as being from health care giver, that is the nurse in the direct care giving role to that of health care facilitator in which the nurse takes on a “more indirect” role aimed at facilitating the patient/carer “to develop self-care skills or initiatives” (Anderson, 1991, p. 99). Anderson (1991) points out that encompassed in these role descriptions
is the relationship of the nurse to the patient. Given that the AHG requires the nurse to work in partnership with the patient and spouse in a more facilitative way, based inherently in the notion of partnership, Anderson’s (1991) model assisted in better understanding the nurse participants’ experience of using this home based cardiac rehabilitation program with patients.

In summary, health care organisations and health care providers such as nurses need to respond to the changing nature of health care (Wagner, et al., 2001). Patients are older, sicker, have complex illnesses, are better informed and demand to be more involved in their care (World Health Organisation, 2002; Beasley, 2010). Patients with CAD and their spouses complain of a lack of information regarding their condition (Scott & Thompson, 2003; Timmins & Kalisner, 2003; Timmins, 2005). Partnership between patients and nurses leads to improved outcomes, which include increased patient self-esteem and confidence, reduced health care costs and less complaints or adverse events (Wagner, et al., 2001; Gallant, et al., 2002; Bidmead & Cowley, 2005; Hook, 2006; Wiggins, 2008; Beasley, 2010).

Partnership between nurses and patients is not without its challenges. Nurses struggle to relinquish the status that comes from being the expert through the maintenance of power and control in their interactions with patients (Henderson, 2003; Summer, 2008). Patients are struggling to communicate their needs to nurses and complain of limited involvement in their own care planning or delivery (Lau-Walker, 2004b; McCabe, 2004; Florin, et al., 2005). Partnership with patients challenges the traditional role and function of the nurse, therefore new models supporting the transition of the nurse from care giver to care facilitator may be useful (Anderson, 1991; Gallant, et al., 2002; Hook, 2006). The AHG is used in partnership with patients but there is a distinct lack of literature regarding partnership and the nurse patient relationship within home based cardiac rehabilitation. Therefore a study exploring the nurse experience of home based cardiac rehabilitation using the AHG is needed.
2.4 Conclusion

This chapter has explored the contemporary literature relevant to this study on the patient, spouse and nurse experience of using the AHG for home based cardiac rehabilitation. While exploring the literature three themes emerged: the patient and spouse experience of CAD; influences on the patient, spouse and nurse experience of home based cardiac rehabilitation; and partnership between patients, spouses and nurses in home based cardiac rehabilitation. The literature revealed that the patient’s age and gender impacted on their experience of CAD; however, patients also reported concerns regarding their physical and psychological well-being (Dixon, et al., 2000; Jaarsma, et al., 1995; Moser, et al., 2003; Worrall-Carter, et al., 2005). The impact of CAD also affected the patient’s relationship with their spouse, and spouses reported a lack of involvement in cardiac rehabilitation (Moser & Dracup, 2004; Scott & Thompson, 2003; Svedlund & Danielson, 2004; Timmins, 2005). The significant impact of CAD on patients and their spouses called for individual and flexible approaches to cardiac rehabilitation to meet patient needs.

Home based cardiac rehabilitation using the AHG offers patients and their spouses an individually structured program with the flexibility to meet differing patient needs; however, there is limited evidence regarding this type of program within Australia. In literature relating to home based cardiac rehabilitation three sub-themes emerged as influencing the patient, spouse and nurse experience of home based cardiac rehabilitation: 1) the patient, spouse and nurse experience, 2) patient, spouse and nurse engagement and 3) the influence of telehealth. Patients describe positive experiences of home based cardiac rehabilitation however much of this data is from outside Australia therefore there is a need to explore the patient, spouse and nurse experience of home based cardiac rehabilitation using the AHG.
The literature suggests that patient engagement with home based cardiac rehabilitation is satisfactory, however little is known regarding what influences patient engagement. Spouses complain of a lack of involvement in cardiac rehabilitation however it is not known how this influences their engagement or the patient’s engagement. There is also little evidence regarding what influences nurse engagement with home based cardiac rehabilitation. Home based cardiac rehabilitation programs using telehealth have demonstrated effectiveness in improving patient outcomes (Neubeck, et al., 2009; Inglis, et al., 2010; Stolic, et al., 2010). However, there is little evidence regarding the patient, spouse and nurse experience of telehealth within home based cardiac rehabilitation. This is necessary as telehealth is rapidly becoming regarded as a low cost option to improving patient access to health care, without an understanding of how this impacts on nurses, patients and spouses.

The AHG for home based cardiac rehabilitation encourages nurses to work in partnership with the patient and spouse, instead of in an ‘expert’ and ‘information giving’ role, and there is a need to better understand this changed role for nurses within cardiac rehabilitation. Partnership within nursing requires the nurse to facilitate patient care based on the expressed needs of the patient and to develop interventions in conjunction with the patient to meet those needs (Gallant, et al., 2002; Hook, 2006). Nurses may relish this opportunity to work in partnership with patients but, alternatively, some nurses may find this change in role and function challenging. Subsequently four themes emerged in the literature: influencing partnership between patients, spouses and nurses; power and control; identification of patient needs; communication of information towards partnership and changing emphasis in the role of nurse as ‘expert’ to nurse as ‘facilitator’. The influence of these sub-themes on partnership between patients, spouses and nurses in home based cardiac rehabilitation does not seem to have been explored. Anderson’s Intervention: Nursing Roles and Function Model (Anderson, 1991) describes the
elements in the role of nurse as health care giver and nurse as health care facilitator, and provides an appreciation of what this change involves in terms of nursing practice. Given that facilitation is a key element of the formation of partnership between nurses and patient, and that partnership is advocated in the AHG, Anderson’s (1991) model may promote an understanding of the nurse’s experience of changes in nursing practice when using the AHG for home based cardiac rehabilitation.

Following this review of the literature the justification for my study is that there is a gap in knowledge regarding the patient, spouse and nurse experience of home based cardiac rehabilitation. My study attempts to fill this gap by providing a greater understanding of the nurse, patient and spouse experience of using the AHG as a home based cardiac rehabilitation program. This information is important because describing the experience of these three key stakeholders using the AHG may enhance the body of knowledge about the acceptability of home based cardiac rehabilitation Australian public and health care professional. Further, the information obtained from my study may assist in the development of home based cardiac rehabilitation programs within Australia, and in the development of education or support programs for nurses to work in partnership with patients and their spouses. My study therefore aims to add to the body of nursing knowledge and to seek to inform nursing practice about the patient, spouse and nurse experience of home based cardiac rehabilitation using the AHG.

The following chapter outlines the methodology and methods used for my study, including the use of the literature outlined in this chapter as its conceptual framework. This is followed by a description of my study’s design, participant recruitment and, finally, the ethical considerations of undertaking this study.
Chapter 3

3.0 Introduction

The focus of my study is to understand the experience of patients, their spouses and nurses using the Australian Heart Guide (AHG) for home based cardiac rehabilitation. This chapter describes my study’s conceptual framework and the rationale for its selection, the study’s methodology and its design, including participant recruitment, and a detailed account of the methods used for data collection and data analysis. The chapter also includes a description of the patients, spouses and nurses who agreed to participate in my study and it concludes with a discussion of the ethical considerations relevant to it.

3.1 Conceptual framework

The conceptual framework for my study is the three themes of the literature review discussed in chapter 2. “A conceptual framework is described as a set of broad ideas and principles taken from relevant fields of enquiry and used to structure a subsequent presentation” (Smyth, 2004, p. 167). Polit and Hungler (1997, p. 109) suggest that the “framework is the underpinning of a study”. This suggests that the framework is the structure used to assist the researcher in critiquing, understanding and presenting the findings of his/her research and should complement the research question (Minichiello, Sullivan, Greenwood, & Axford, 2004). My research question asks “What is the experience of patients, their spouse and nurses when using the Australian Heart Guide for home based cardiac rehabilitation?” Therefore, the study’s conceptual framework needs to enable me to critically consider, and situate the experience of those who participated in my study.
The literature review discussed in Chapter 2 is presented under three main themes emerging from this literature: the experience of CAD on individuals and their spouses, influences on the patient, spouse and nurse experience of home based cardiac rehabilitation, and partnership between patients, their spouses and nurses. This literature review forms the conceptual framework for my study because the literature discussed within it provides a critical perspective of contemporary research and review of topics congruent with the research question. In this way the themes identified are useful when reflecting on and discussing the experience of participants in my study.

I acknowledge that the findings from my study are not on their own generalisable. However, as Denzin & Lincoln (1998) suggest, using the literature review as a conceptual basis for research facilitates empirical generalisation. That is, this process enables me to contrast the results from my related literature review with new data from my study to develop new generalisations that support or add to already existing findings on the topic of my research (Denzin & Lincoln, 1998). The literature review as my study’s conceptual framework also complemented the qualitative descriptive research methodology used in my study because this methodology focuses on the clear, everyday facts of the situation without using complex theories to describe the data (Sandelowski, 2000). This methodology resulted in a description of the “real” experience of the participants, which could then be compared with the empirical description captured in the literature review. Using the literature review as the conceptual framework ensured I was able to demonstrate the ideas and experiences of the individual participants as they reflected on their experience without the constraints of a structure or philosophy, which may not be entirely helpful in furthering understanding of that experience.
3.2 Methodology

Qualitative research aims to capture and understand the human experience as it is lived by interpreting people’s feelings and thoughts about a situation to understand why they acted in a certain way (Polit & Hungler, 1997; Minichiello, et al., 2004). Qualitative research focuses on human interaction, language and behaviour with a view to a better understanding of the world, the individual and/or society. In contrast the focus of quantitative research is to compare quantities or amounts through measurement and is usually used in nursing to measure effectiveness (Gerrish & Lacey, 2006). Capturing and describing the subjective experience of patients, their spouses and nurses using the AHG for home based cardiac rehabilitation to gain a better understanding of their experience requires a qualitative approach. To enhance the description of the subjective experience of patients, spouses and nurses a quantitative research method (numerical frequency rating scales) is also used. The methodology selected for my study is qualitative description and was selected because this methodology focuses on the “who, where and what of the phenomena by obtaining the insider’s view” (Sandelowski, 2000, p. 336). And, also enables the use of quantitative methods to illustrate my study participants’ experiences.

3.2.1 Qualitative description

Qualitative description methodology is appropriate where a straightforward description of a phenomenon is sought (Sandelowski, 2000). This is in keeping with the aims of my study, namely the collection of subjective, descriptive data from participants to provide an insider’s view of the experience of using the AHG.

The term qualitative description is sometimes used in relation to processes integral to other qualitative methodologies, including ethnography or phenomenology, but it
may be used as a research methodology in its own right. Sandelowski (2000) suggests “it is particularly useful in obtaining information on people’s concerns, thoughts and feelings about an event or service” (p. 337). An example of this comes from Sullivan-Bolyai, Knaf, Tamborlane, & Grey (2004) who used qualitative description as the methodology for their examination of parents’ reflections on managing their children’s diabetes with an insulin pump. The advantage of using this methodology was that it enabled the researchers to stay true to the parents’ reflections because, unlike other qualitative methodologies, qualitative description does not have any pre-existing philosophical or theoretical obligations to present the data in any way other than the facts (Sandelowski, 2000). Rather, it is a naturalistic enquiry in that it studies a phenomenon in its natural state (Denzin & Lincoln, 1998) with no obligation to any philosophical viewpoint (Sandelowski, 2000). Sandelowski, (2000) argues that qualitative description may also use a “quasi-statistical analysis where by data is summarised numerically but with descriptive statistics” (p. 338) thus incorporating both qualitative and quantitative methods for data analysis. Using qualitative description as the methodology for this study enabled me to present the experiences of the patients, their spouses and nurse participants using the AHG for home based cardiac rehabilitation as they articulated and described this. However, it is important to note that I took account of Sandelowski’s (2010) concern that her earlier paper (Sandelowski, 2000) had failed to “adequately communicate that qualitative descriptive research is still interpretive” (Sandelowski, 2000, p. 79) and this is evident in the process I used for data analysis and verification of my study’s findings.

3.2.2 Rationale for methodology selection

In any research study, the research question determines the selection of the most appropriate research methodology (Polit & Hungler, 1997). This section justifies the selection of qualitative description as my studies methodology by reviewing other
methodologies that may have answered the research question and thus were considered as options for use in this study.

3.2.2.1 Phenomenology

Phenomenology has become a popular methodology for nursing research as a means of understanding the world from the patient’s point of view. As this study wished to explore experience, it might be considered to be the logical methodology of choice; however, it was rejected because of its in-depth interpretive nature that allows the researcher to arrive at a description of the essence of the phenomenon under study rather than a description of participants’ experience of the research topic albeit with some interpretation of this (Sandelowski, 2010).

Based on the philosophical works of Husserl (1962) and Heidegger (1962), phenomenology was developed to assist researchers from social sciences such as psychology or sociology to answer questions relevant to their objectives rather than relying on methodologies described by other sciences such as medicine, which may not answer the questions appropriately (Sadala & Adorno, 2001). Phenomenology explores people’s lived experience and phenomenological studies aim to convey the meanings people attach to those experiences (Gerrish & Lacey, 2006). The approach is to find something new, unique or similar within the lived experience of each case so as to arrive at a description of the essence (or meaning) of the phenomenon (Earle, 2010). The essence is subsequently described in a descriptive narrative rich in information and knowledge about the phenomenon.

Phenomenological research is similar to other research methodologies in that a research question needs to be formed. However, in contrast to other research methodologies, the extent of knowledge about the relevant literature needed by the researcher is open to debate. Husserl (1962) suggests that no knowledge is beneficial; however, others argue that knowledge is beneficial and needs to be looked at
through fresh eyes questioning assumptions made in the literature (Heidegger, 1962; Gerrish & Lacey, 2006). The literature for my study forms a conceptual framework for data analysis and is necessary because part of the study requires some reflection on differences between the AHG as a model of cardiac rehabilitation and models previously used for this experience. The AHG as a new model of care for cardiac rehabilitation needs to be considered within these previous experiences so that new or shared insights can be gained reflecting the experience of the participants.

In phenomenological research, once the lived experiences of study participants have been gathered, a narrative structure is formed highlighting common themes and using quotes from participants to abstract and illustrate those themes. This narrative is described by the researcher using a process of phenomenological reduction, involving bracketing of the researchers assumptions so these may be suspended and enable them to focus on and consider the lived world of the participants (Husserl, 1962). Alternatively, the researcher may use existing preconceptions as a way of reflecting on what is missing or different in their findings of their study (Heidegger, 1962). The criticism surrounding this systematic review of the text is that the data is manipulated, not empirically but solely on the researcher’s interpretation (Paley, 1997; Sandelowski, 2000). This may impact on the neutrality and objectivity in the presentation of the data. In contrast, qualitative description has no obligation to present the data in any way other than the facts that are articulated because there is no need to follow any particular philosophical underpinning (Sandelowski, 2000). There is however still a need for the data to be presented interpretively, that is with some meaning attached to it by the researcher (Sandelowski, 2000).

The strength of phenomenological research for this study might appear to be that it relates directly to the experience of the participant, and its philosophical underpinnings aid the methodological approach to understanding experience as a phenomenon. However, there are many different philosophical underpinnings to
phenomenology and much of nursing research is bewildered about which underpinning should be used, mixing and matching according to the study (Sadala & Adorno, 2001; Thomas, 2005; Earle, 2010). Phenomenology might also give richness in describing the experience of the participants in this study that qualitative description might not because the narrative in phenomenology is carried out through interpretive reflecting and an artistic process of writing and rewriting the themes to give them internal and external meaning (Earle, 2010; Flood, 2010). However, Sandelowski (2000) argues that data presented with minimal manipulation in a description that reflects the facts as articulated by patient participants may result in a truer insight than that of a researcher’s interpretive phenomenological narrative.

3.2.2.2 Case study

As my study is focusing on individual “cases” within participant groups, case study design was also considered for the methodology. The term “case study” is often used in nursing as part of education with the nurse selecting “a case”, which is usually a patient with a specific illness, and the nurse subsequently investigating and describing the patient, their illness and treatment. Case study as a research methodology on a basic level follows a similar process, which has led to criticism of it as a research methodology (McGloin, 2008). Case study design is a flexible approach “providing an intensive, in depth method of enquiry focusing on a real life single case using a variety of sources of evidence” (McGloin, 2008, p. 46). Case study investigates the effect of a phenomenon in its real life context with variables and key factors being explored as they occur (Glaser & Straus, 1967; McGloin, 2008). The philosophical underpinning of case study is based on a holistic approach to exploring the case within its natural format. Defining the case is crucial to the research process and the pre-understanding of the researcher about the research and its question informs the definition of the case. One of the difficulties with pre-
understanding, however, is the ability of the researcher to balance their own experiences against the research, which can affect the reliability of the study (Gerrish & Lacey, 2006).

Case study design can be rigid in that sometimes multiple cases are explored using the same queries, exploring their similarities and differences. Alternatively, a single case study can be used to identify key themes and subsequent cases are explored to examine those themes. This flexibility has led to criticism because it can lead to inconsistencies in data and a lack of rigour in the research process (Glaser & Straus, 1967; Gerrish & Lacey, 2006; Anthony & Jack, 2009). This is because the “case” may generate a large amount of irrelevant data, which is then subsequently explored because it might be deemed interesting; however, it might distract from the aim of the research and might not answer the research question. As my study was set in a large health district of NSW, I was concerned that there might be multiple cases from a variety of locations (rural and metropolitan), which may have resulted in a large amount of complex data that may not be relevant to my study objectives. Therefore case study was rejected as a methodology for my study.

3.2.2.3 Action research

A further methodology considered for my study was Action Research. Action research “integrates research and action” (Spalding, 2009, p. 130). It is defined as “a form of self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own practices, their understanding of these practices, and the situations in which these practices are carried out” (Kemmis, 2006, p. 230). The purpose of action research in nursing is for the researcher to work with the participants who are co-researchers, together reflecting on an issue or practice, planning ways to address or implement a plan and then evaluating the process in a continuous motion. Evaluation is not the end but the
beginning of a cyclical process. This process can be simply described as a continuous interaction between inquiry, intervention and evaluation (Kemmis, 2006; Spalding, 2009). The cyclical process is one of the strengths of action research because it aids the mutual learning of the researcher and the participants, as well as developing individual and group knowledge and skills that other forms of research methodology such as phenomenology might not. The involvement of the researcher as a participant is essential to action research because this embeds the research process with the research participants. However, because the AHG study is about the individual’s experience of utilising a home based cardiac rehabilitation program, the researcher and participants were unlikely to be able to work together in cyclical process. Changing practice or raising awareness of issues or policies through collaboration is a goal of action research. However, my study sought to evaluate participants’ experiences of using an existing home based rehabilitation program without intent to work with participants to plan or implement change within the study. Therefore action research was not a suitable methodology for this study.

3.3 Method

3.3.1 Setting

The setting for this study was a Local Health District in NSW. The Local Health District has a population of 840,000 people and covers a geographical area of 130,000 square kilometres equivalent to the size of England (Hunter New England Local Health District, 2008). There is a mixture of metropolitan, rural and remote areas and a number of large hospitals, smaller local referral hospitals and multi-purpose health centres. Hospital based group cardiac rehabilitation programs constitute the main model of care, with individual home visiting for patients with CAD in some

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13 As classified by the Australian Standard Geographic Classification from the Australian Bureau of Statistics.
rural areas and limited cardiac rehabilitation provision in other areas. The AHG was introduced as an alternative to hospital based cardiac rehabilitation within the Local Health District in an attempt to address the inequality of access to cardiac rehabilitation and to offer an alternative to patients who were unable or unwilling to attend a hospital group program.

3.3.2 Participant selection

The aim of participant selection (sampling) in qualitative research is to select an information rich sample (Gerrish & Lacey, 2006); therefore a defined group of participants was selected to ensure the sample was purposeful and could assist in answering the research question. Three groups of participants were sought for this study: patients, their principle caregiver (relative, partner or friend) and nurses. These participant groups were selected because there is only a small group of patients, their principle caregiver and nurses who have used the AHG within my Local Health District from whom to obtain meaningful data. Therefore the participants were patients and their spouses (the principle caregivers for all my patient participants) who, following a hospital admission with acute coronary syndrome had used the AHG for home based cardiac rehabilitation in conjunction with an AHG nurse mentor. AHG nurse mentors who have facilitated the AHG with patients were also participants in this study.

3.3.2.1 Inclusion criteria

The inclusion criteria for patients in this study were that they must:

1. have had an admission to hospital and been discharged alive with a diagnosis of acute coronary syndrome (heart attack or unstable angina); and
2. be able to provide informed consent (cognitively able to understand the information statement and study);

3. have used the AHG as their sole cardiac rehabilitation program commencing within two years of discharge from hospital with acute coronary syndrome;

4. completed a minimum of six weeks of the AHG; and

5. be able to read and speak English or agree to the use of an interpreter.

The inclusion criteria for principle caregiver in this study were that they must:

1. be the partner, relative or friend nominated by a patient who has had an admission to hospital with a diagnosis of acute coronary syndrome and who has used the AHG for home based cardiac rehabilitation;

2. be able to provide informed consent (cognitively able to understand the information statement and study);

3. have used the AHG with the patient within two years of the patient’s discharge from hospital;

4. completed with the patient a minimum of six weeks of the AHG; and

5. be able to read or speak English or agree to the use of an interpreter.

In my initial study design submitted and approved by the Local Health District human research ethics committee, patients and principle caregivers were only eligible for the study if they had used the AHG within six months of discharge from hospital. However, due to recruitment difficulties discussed later in this chapter and
following a human research ethics variation submission, this was changed to two years from discharge from hospital. In addition the term significant other was recommended for the principle care giver (partner, relative or friend) of the patient following ethical review and is used on all recruitment documents. However following data collection all the principle care givers identified themselves as spouses therefore, in an attempt to simplify this issue, this term is now used throughout the entire thesis.

The inclusion criteria for AHG nurse mentors who wished to participate in this study were that they must:

1. be registered nurses;
2. have completed the one-day training in AHG facilitation and be an accredited AHG nurse mentor; and
3. have facilitated the use of the AHG to completion (six weeks minimum) with at least one patient who may or may not be included in the patient sample for the study.

At the time the study was planned there were 10 trained AHG nurse mentors in the Local Health District where my study took place that had collectively mentored 35 patients.

3.3.2.2 Recruitment

“The relationship between the researcher and the potential participant is one of unequal power” (Minichiello, et al., 2004, p. 101). In order to minimize this power inequality all potential participants were approached by a third party not involved in the study process.
1 Patients were recruited to the study by AHG nurse mentors.

2 Spouses were recruited to the study by AHG nurse mentors.

3 AHG nurse mentors received a letter from the president of the Australian Cardiovascular Health and Rehabilitation Association inviting them to take part in my study.\(^\text{14}\)

The recruitment process for each participant group will now be discussed. It is necessary to note here that nurses have a dual role within my study. AHG nurse mentors were invited to recruit patients and spouses and were also invited to take part in the study themselves as nurse participants. Therefore for clarity, when I am describing the process of recruitment for patients and spouses I will refer to nurses as AHG nurse mentors. When describing the recruitment and participation of nurses as participants in my study, and in subsequent presentation and discussion of findings, I will refer to the nurses as nurse participants.

\subsection{3.3.2.2.1 Recruitment of patients and their spouses}

Recruitment of patients and their spouses was originally planned to be undertaken by AHG nurse mentors as part of their clinical contact with patients. However, following ethical review this was deemed potentially unethical because AHG nurse mentors could be seen to be in a position of power by patients or their spouses. Therefore an alternative recruitment strategy was devised and this involved the AHG nurse mentors posting information about the study to all patients and their spouses using the AHG within their caseload.\(^\text{15}\)

\(^{14}\) The Australian Cardiovascular Health and Rehabilitation Association had previously conducted a quantitative pilot study on the effectiveness of the AHG within the Local Health District and were responsible for the training of the AHG nurse mentors, production of the AHG itself and evaluation of the AHG. Therefore it was felt they were an appropriate body to approach the AHG nurse mentors to take part in a qualitative evaluation of the AHG.

\(^{15}\) Caseload refers to the number of patients each cardiac rehabilitation nurse has had referred to him/her for
In order to provide information about the study and their role in recruitment of patients and their spouse, all AHG nurse mentors were invited to attend an information session held as part of a cardiac rehabilitation education day. However, due to the pressure of workloads and distance to attend the study day, only four AHG nurse mentors out of ten were able to attend the information session. Therefore I approached the remaining six AHG nurse mentors by asking them via email whether or not they would be happy to be part of the recruitment process and attaching a recruitment information sheet, which detailed the role of the nurse mentor in recruitment (Appendix 1). I followed this approach with an individual phone call to each AHG nurse mentor to address any concerns or recruitment issues.

Ultimately, a total of nine AHG nurse mentors agreed to recruit participants and one declined. The nine AHG nurse mentors who agreed to recruit were sent information packages to post to their patients and spouses who had or were using the AHG. The information packages included a copy of the recruitment information statements for patients and their spouses (Appendix 2a and 2b), consent forms (Appendix 3a and 3b) and a stamped addressed envelope. The information statement explained the purpose of the study and invited patients and spouses to participate in a face-to-face interview and focus group. The information statements also described the rights of the patient and their spouse in relation to the study process, confidentiality and data storage. It also contained contact details of the chief investigator and I to enable patients and their spouses to seek further information about the study if they wished. Patients and their spouses were invited to use the replied paid envelope to return their signed consent forms to me. This resulted in 35 information packs being sent to AHG nurse mentors to post onto patients and spouses.
After approximately two weeks, one information package was returned from a patient declining to take part but no other responses were received from patients or spouses to whom information packs had apparently been posted. A reminder letter encouraging the patient and spouse to take part in the study was sent after one month via the AHG nurse mentors to patients and spouses. There was no response from patients and their spouses to the reminder letter. Therefore an alternative strategy for the recruitment of patients and their spouses was sought because it was essential to obtain the views of patients and their spouses in order to ensure comprehensive evaluation of the AHG by these stakeholders.

An ethics variation was submitted and approval was given for an alternative patient and spouse recruitment strategy via the use of a questionnaires. This meant that instead of inviting patients and spouses to consent to attend an interview and focus group, a questionnaire constructed on the basis of the literature review and prompts for interview, would be forwarded to patients and spouses. The completion of this questionnaire would be taken as consent for participation in the study. A revised study information package containing study information leaflets (Appendix 4a and 4b), and a patient and a spouse questionnaire (Appendix 5a and 5b) was sent in the same package to all patients on the AHG nurse mentors caseload who had used or were using the AHG. Thirty five patient and 35 spouse questionnaires were sent to AGH nurse mentors to foreword too potential participants. One month after the questionnaires were sent out I had not received any returned questionnaires. Assuming that AHG nurse mentors had sent out all 35 information packages with questionnaires to patients and spouses on their caseload, this was very disappointing.

16 Recruitment of patients and spouses was conducted by the AHG nurse mentor; I posted information packs to the AHG mentors to post onto patients and spouses. However there was no method of confirming if the packs had actually been posted to the patients and spouses, therefore I had to assume that all packs were posted on to potential participants.
Following consultation with the Chairperson of the human research ethics committee, I emailed the AHG nurse mentors requesting clarification on the number of questionnaires they had posted to patients and spouses in the hope I could obtain an accurate assessment of what response rate I could anticipate. Six nurse mentors responded to me and their responses revealed that a total of ten spouse and ten patient questionnaires between them had been sent out to patients and their spouses. Therefore it is unknown if the remaining 25 patient and 25 spouse questionnaires were posted to patients.

3.3.2.2 Recruitment of nurse participants

I sent all potential nurse participants using the AHG with patients an information package containing a letter from the President of Australian Cardiovascular Health and Rehabilitation Association inviting them to take part in the study and explaining its purpose (Appendix 6). The information package also included a participant information sheet that invited the nurse participant to take part in an interview and a focus group and explained the rights of the potential nurse participant in relation to the study process, confidentiality and data storage (Appendix 7). The information package also contained a consent form (Appendix 8), a reply paid envelope and provided contact details for the Chief Investigator and myself to enable the potential nurse participant to seek further information about the study if they wished. Nurse participants were invited to return the completed consent form in the stamped addressed envelope provided. Ten information packs were sent out to AHG nurse mentors: this reflected the number of potential nurse participants qualified at the time of recruitment to facilitate the AHG. Six nurse participants responded and agreed to take part in the study, one declined as she had recently changed employment, one declined but did not give a reason, and there was no response from two nurse participants.
3.3.3 Data collection

Sandelowski (2000, p. 338) states that “Data collection in qualitative descriptive studies is typically directed toward discovering the who, what and where of events or experiences”. In my study the initial planned data collection methods were interviews followed by focus groups to verify the data with patients, spouses and nurses. Lambert and Loiselle (2008) suggest that combining individual interviews and focus groups improves the rigour of the data and subsequent analysis. However, given the initial poor response from patients and their spouses to participation in an interview and focus group, a third data collection method, a questionnaire, was designed to take the place of patient and spouse interviews and focus groups.

Nurse participants took part in individual interviews. Although follow up focus groups for nurse participants had been planned and consented for, the organisation of a follow up focus group proved challenging due to geography and nursing workloads. The purpose of the focus groups for nurses was to enable the themes and their explanations that I had identified in the data emerging from the nurses’ interviews, to be fed back to the nurses for discussion and confirmation of these findings. When it proved impossible to convene the nurses’ focus groups because of time and distance constraints, these were replaced by the development and circulation to them of a verification document (Appendix 9) outlining the themes emerging from the interview data and their explanation (and seeking written feedback on these from nurse participants). A videoconference for nurse participants and I to discuss these themes was also convened. The outcome of circulating the verification document and conducting the video conference are discussed as part of data analysis because they relate to the confirmation processes of the outcome of this analysis. The combination of methods of data collection (questionnaire and interview) for patients, spouses and nurses and the confirmation process of the nurse
interview data provided an opportunity to gain a deep and rich insight into individual experiences of the use of the AHG and the opportunity for triangulation\textsuperscript{17} (Gerrish & Lacey, 2006) of the method as well as increased rigour.

### 3.3.3.1 Patient and spouse questionnaire

Questionnaires as tools for data collection are used “to collect information in a standardised manner from a representative sample” (Rattray & Jones, 2007, p. 237). Questionnaires are used in nursing to measure a variety of issues including emotions, cognition and attitudes but are commonly used to measure patient perceptions of healthcare (Rattray & Jones, 2007; Sorenson, 2009). The aim of the patient and spouse questionnaires (Appendix 5a and 5b) was to explore the patient and their spouse’s experience of using the AHG. As indicated previously the initial data collection strategy for patients and their spouses had been interviews, and interview prompts (Appendix 10) had been developed based on the objectives of the study to guide the interviews. The draft patient and spouse interview prompts were piloted, and subsequently used as the basis for the patient and spouse questionnaires when it became apparent interviews appeared not to encourage participation in the study from patients and spouses.

The patient and spouse interview prompts were piloted by interviewing a patient and spouse attending hospital based cardiac rehabilitation. The patient and spouse were given a copy of the AHG and asked to review it as if they were using the AHG for their rehabilitation. I subsequently interviewed the patient and spouse engaged in the pilot separately using the interview prompts. The interview prompts were related to their experience of heart disease; home based cardiac rehabilitation using

\textsuperscript{17} Triangulation provides an opportunity for verification of data from two or more sources (Gerrish & Lacey, 2006).
the AHG, the usefulness or the AHG, advantages and disadvantages of using the AHG, and the relationship with the cardiac rehabilitation nurse. During the interview, prompts relating to an individual’s experience of heart disease and the working relationship with the cardiac rehabilitation nurse were found to be relevant and easily understood by the patient and spouse participating in the pilot. However, during this interview it became apparent that the patient and spouse struggled, when prompted, regarding their experience of the AHG as a model of care because they had only reviewed the guide, not used it in practice. Because of this I adjusted the prompts relating to the AHG and home based cardiac rehabilitation to relate to hospital rehabilitation more generally so that they became more relevant, readily understood and comprehensively answered by the patient and spouse in the pilot. The two pilot interviews were digitally recorded and reviewed by the research supervisors and myself.

Analysing the pilot interview data demonstrated some benefits in piloting the interview prompts. Prompts relating to the patient’s and spouse’s experience of heart disease and their relationship with the hospital cardiac rehabilitation nurse appeared useful in describing their experience. Prompts about the model of rehabilitation (hospital based rehabilitation) were also relevant, understood by the patient and spouse involved in the pilot, and provided an insight into their experience of hospital based rehabilitation. Whether or not the same (prompts) could elicit a similar response to participants’ experience of home based cardiac rehabilitation using the AHG was unknown. Despite this, given the level of understanding by the participants in the pilot of the prompts, the sense of these was retained in questions posed in the patients and spouses questionnaires. The only exception to this was that, instead of the words “hospital based rehabilitation”, the words “home based rehabilitation using the AHG” were used in my study.
The patient and spouse questionnaires comprised some questions seeking demographic data, some questions requiring respondents to use a five point Likert® Scale and some open-ended questions. Patients’ and spouses’ demographics were included in the questionnaire (Appendix 3.5a and 3.5b, questions 1-4) because the literature demonstrates that age and gender, education and employment experience impact on a patient’s and spouse’s experience of rehabilitation as described in Chapter 2 (Lee, et al., 2001; Beswick, et al., 2005; Budnick, et al., 2009). Patient participants were asked to tick a box to identify the reason for their recent hospitalisation for heart problems which were described without medical terminology to assist patients’ understanding. Patients were also asked why they chose the AHG for home based cardiac rehabilitation and if they used it. These questions were asked because offering patients a choice of program has demonstrated improved engagement as discussed in Chapter 2 (Grace, et al., 2005; Dalal, et al., 2007). Spouse participants were asked to tick a box to identify their relationship with the person using the AHG.

A Likert scale designed to enable a frequency rating of the usefulness of the AHG was included in one question on the patient questionnaires (Appendix 5a/question 8 and question 9) and two questions on the spouse questionnaires (Appendix 5b question 9 and question 10). An additional question for spouses was to ascertain how useful the AHG itself was in assisting them to understand the patient’s illness, given that spouses have complained of a lack of information as discussed in Chapter 2 (Scott & Thompson, 2003). Both questionnaires used the Likert scale to ascertain usefulness of the contact with the AHG nurse mentor although contact was not clearly defined as the nature and type of contact between patients, spouses and

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18 A Likert scale measures strength and intensity of experience on a linear scale, usually with five response options; for example a person may agree with something very strongly at one end of the scale to not very strongly at the other end of the scale (strongly agree, agree, neither agree or disagree, disagree, strongly disagree).
Frequency rating scales such as Likert scales are used to measure attitude and opinions by asking participants to respond to declarative statements that express a viewpoint about a topic stating on a continuum the degree to which they agree or disagree with the statement (De Vaus, 2004; Gerrish & Lacey, 2006). A numeric value is attached to each viewpoint and once the scale is administered the responses are scored and combined in an attempt to quantitatively identify different attitudes and opinions (Polit & Hungler, 1997). The Likert scale used in the patients and spouses questionnaires was not piloted prior to its use in the patient and spouse questionnaires due to the lack of available participants on whom to pilot the questions (Appendix 5a questions 8 and 9, Appendix 5b questions 9, 10 and 11).

Open-ended questions were also used to seek information about what the patients and spouses liked most and least about the AHG. Open-ended questions in the questionnaires enable the respondent to reply freely on the basis that they might be difficult to analyse but they give a richness of data (Polit & Hungler, 1997; Rattray & Jones, 2007). In previous research, spouses have complained of a lack of involvement in cardiac rehabilitation (McLean & Timmins, 2007; Timmins & Kalisner, 2003) and the aim of the following two questions was to ascertain if there was a difference in responses between patients and spouses. Spouses were asked a closed question regarding how much contact they or the patient had with the AHG nurse mentor; the contact was defined as sessions (Appendix 5b question 8). In contrast patients were asked to specify the number of contacts with the AHG nurse mentor from a selection of choices (Appendix 5a question ten). The final question asked for additional comments to enable the respondent to add anything in their experience of using the AHG that they felt the questionnaires had not addressed. In total there were 13 questions on the patient questionnaire (Appendix 5a) and 12 on the spouse questionnaire (Appendix 5b). The benefits of using patient and spouse participant questionnaires for this study were that they provided anonymity to respondents and it was economical to develop and administer. Four completed questionnaires were
received from patients; three completed questionnaires and one uncompleted were received from spouses. Upon receipt of the questionnaires, in order to match patients with spouses I allocated a code to each couple: for example, patient 1 matched with spouse 1 and so on.

### 3.3.3.2 Individual semi-structured interviews with nurse participants

Nurse participants’ individual semi-structured interviews were conducted either face-to-face or by telephone, depending on the nurse participant’s preference. This method of data collection was chosen because semi-structured interviews collect “detailed accounts of participants’, thoughts, attitudes, and beliefs and knowledge pertaining to a given phenomena” (Lambert & Loiselle, 2008, p. 229).

A semi-structured interview may have a combination of closed and open questions around an experience and this should be centred on a flexible or fixed order of questions or topics (Gerrish & Lacey, 2006). A list of questions were developed to prompt the conversation, the interview prompts contained a number of open and closed questions for use in the nurse participants’ interviews (Appendix 11). The aim of the interview prompts was to ensure consistency in the topics being explored in the nurse participant’s interviews, while still allowing for flexibility to discuss or clarify topics which the nurse participants may raise. The purpose of some closed questions was to ascertain information about the number of patients using the AHG the nurse had facilitated. Demographic information regarding the nurse participants’ experience in nursing and in cardiac rehabilitation, were asked through a mixture of open and closed questions. I did not specifically ask about the nurse participants working location (rural or metropolitan) as I felt this would naturally be discussed during the interview when the nurse participant was describing her background or experience. This was because I wanted the nurse participant’s personal view regarding their work setting (rural or metropolitan) in order to gain an
understanding of their individual experience of this. Some open ended questions were used to prompt responses about their experience of using the AHG for home based cardiac rehabilitation focusing on its usefulness for patients in regard to lifestyle change, the advantages and disadvantages of the AHG, and their relationship with patients and spouses. The nurse participants’ interview prompts (Appendix 11) were piloted by interviewing a hospital based cardiac rehabilitation nurse who had reviewed the AHG over a two-week period. The aim of piloting the interview prompts (Appendix 11) was to ascertain if these questions were useful prompts for the conversation, were meaningful to the nurse and adequately captured her experiences.

My supervisors and I listened to the interview and reviewed the outcome and analysed the data. This analysis demonstrated that the questions used in the interview prompt enabled the hospital cardiac rehabilitation nurse to describe her experience. Prompts relating to the usefulness of the AHG for patients with lifestyle change and the advantages and disadvantages of the AHG were appropriate and gave a good insight into the nurse’s experience. Prompts relating to the nurses’ experience of home based cardiac rehabilitation proved to be difficult for the hospital cardiac rehabilitation nurse to answer given she had only reviewed the AHG and not actually facilitated it with patients. Therefore I changed the wording of home based cardiac rehabilitation to hospital based cardiac rehabilitation in the hope this may assist her to describe her experience. This subsequently demonstrated that the nurse participants’ interview prompts (Appendix 11) were a useful tool to guide the interview process.

Six nurse participants consented to participate in my study and six nurse participants were interviewed: two face-to-face in the nurse participant’s office and four over the telephone. I anticipated that the interviews would last about 60 minutes; however, the longest was 45 minutes and the shortest was 35 minutes. The
nurse participants’ interview prompts were used as the basis for the interviews with supplementary prompts such as “can you tell me more?” or queries seeking clarifying prompts when I was unsure about the meaning of a response. The interviews were digitally recorded with the consent of each participant and then transcribed by a transcribing service. In order to verify that the transcript was an accurate representation of the interview, a copy of the transcription was sent to all the nurse participants to edit or delete content as they wished. All nurse participants returned their transcript without any alterations. To aid my understanding of the context of the interviews I noted on the transcripts comments regarding the context of the interview including the surroundings, demeanour of the nurse participant and any concerns with the interview process.

3.3.4 Data analysis

3.3.4.1 Analysis of the patient and spouse questionnaire

Questionnaires from four patients and from their four spouses were returned. As previously stated the questionnaires were coded based on the order they were received, matched to their spouse’s questionnaire (patient 1 matched with spouse 1 and so on) and each participant given a pseudonym. I first analysed the patient questionnaires, followed by the spouse questionnaires using the following process: patient and spouse demographic data was initially reviewed individually, and then reviewed together (patient 1 with spouse 1) to assist in developing a demographic description of the participants (patients, spouses and couples).

Quantitative data from the patient and spouse questions on the Likert rating scale were analysed by counting the number of responses in each viewpoint on the scale for a particular question. For example, patients were asked to rate the usefulness of their contact with the nurse mentor: two patients rated their contact as very useful as
compared to two patients who rated their contact as moderately useful. The number of responses for each viewpoint was next compared between patient and spouse questionnaires, for example one patient rated their contact with the AHG nurse mentor as very useful and their spouse rated their contact as moderately useful.

Qualitative content analysis (Sandelowski, 2000; Satu & Kyngäs, 2008) was used to analyse patient and spouse responses to open-ended questions in their questionnaires so as to arrive at a clear description of the participants’ experience. The responses were read several times looking for common themes between individual participant groups (patients, spouses and couples). From this analysis of the questionnaires a general description of the data was produced by combining the demographic description of the participants, quantitative data and the qualitative data from the open-ended questions. The aim of the general description of the data was to articulate the experience of the patient and spouse participants as they described it which is in keeping with the research methodology of qualitative description (Sandelowski, 2000).

3.3.4.2 Analysis of nurse participants’ interviews

Analysis of nurse participants’ interview data was in two stages; analysis of nurse participants’ interviews and confirmation of the categories and sub-categories and their explanation emerging from data relating to the description of their experience. This confirmation was conducted via a verification document (Appendix 9) and video conference. Initial analysis of the nurse participant’s interviews involved reviewing the digital recording and interview transcript. Once the transcripts for the interviews with the nurse participants’ were received from the transcription service I used to undertake this process, I reviewed each one while listening to the digital recording of the related interview so as to ensure it was an accurate representation. This allowed me to fill in any words, sentences, exclamations or pauses that the
transcribers had not been able to hear or had not understood. It also helped me to reflect on the context of the interview and what was going on around this and to make notes about this. The data analysis process used for the nurse participants’ interviews is described below.

The interview transcripts were analysed using qualitative content analysis, which is a means of analysing written or verbal communication (Satu & Kyngäs, 2008). The aim was to summarise the informational content of the data and determine not only the obvious content but also the hidden content (Sandelowski, 2000; Satu & Kyngäs, 2008). In the first stage of data analysis I immersed myself in the data by reading and re-reading the transcripts. The aim of this was to enable me as the researcher to become completely familiar with all of the data (Polit & Hungler, 1997). The second stage involved the identification and development of common themes, which were grouped together and given preliminary names depending on the content. From these themes, categories and sub-categories were formed and the interview data was further filtered in an attempt to reduce the number of categories and sub-categories by asking questions such as “what is the participant experience in this category or sub-category?” or “how does this category or sub-category differ to another?” This formation of the categories and sub-categories and their subsequent overall general description of the nurse participants’ experience is the final step of content analysis and is called abstraction (Satu & Kyngäs, 2008). Figure 3.4.5.2.1 describes the data analysis process.

The categories and sub-categories constitute the results of my study and data in the form of quotes from participants’ transcripts are used to illustrate and shed light on each category and sub-category. Appendix 12 comprises a detailed audit trail of the data analysis process of the interview data. In order to ensure the rigour of my study and confirm my findings regarding the nurses’ experiences, nurse participants were asked to confirm the categories and sub-categories through their review of a verification document (Appendix 9) and participation in a videoconference.
Stage 1

Review transcripts for common themes for example power and control and group together accordingly.

Stage 2

Explore the themes for similarities and differences, for example control in the relationship between the participants, power with the nurse as a health professional and control for the patient in regard to their lifestyle change. Similar themes merged and grouped together to form categories. Within each categories themes further explored for similarities and differences to form sub-categories.

Stage 3

Abstraction: Categories and sub-categories reviewed to ascertain relevance to the research question and description of the research topic formed.

Figure 1 Process for data analysis

3.3.4.3 Confirmation of my findings from nurse interviews

The aim of using a verification document (Appendix 9) and video conference was to improve the study’s rigour by taking my findings from the data analysis of the nurse participants’ interviews back to each nurse participant and asking her\(^{19}\) to review...

\(^{19}\) All nurse participants included within my study were female.
and assess whether or not these reflected her experience of using the AHG for home based cardiac rehabilitation. This process of verification combined with my triangulation of data collection methods fulfils Creswell’s (1988) recommendation that two methods are used to verify qualitative findings. My initial strategy for confirmation of my findings captured in the form of categories and sub-categories from the nurse participant’s interviews was to hold focus groups. The proposed focus group was designed to provide a forum at which to share with participants the categories and sub-categories that had emerged from my analysis of their interviews, so as to allow them to consider these in terms of their accuracy in capturing their experience. It was also thought possible that the focus group might generate additional or expanded data as a result of group discussion (Plummer-D’Amato, 2008). In reality, however, due to workload, time commitments and geographical distance between each of the nurse participants, a face-to-face focus group proved impossible to convene and, after careful consideration, an alternative format for the focus group via recorded video conferencing was decided upon. To better facilitate discussion during the video conferencing, each nurse participant was forwarded prior to it a document (the verification document; Appendix 9) to review, that outlined the categories and sub-categories emerging from data analysis of their interview content. A rating scale was included within the verification document with the aim of rating in the nurse’s opinion the most important and least important category. However this was not analysed as the ratings given by the nurse participants were inconclusive.

The verification document was provided to nurse participants prior to the videoconference with the aim of giving them time to consider and comment on whether or not these categories and sub-categories that I had derived from the data reflected their experience of the research topic. The verification document itself contained an outline of each category, a description of each as it emerged from the interview, and illustrations of each using quotations from the interviews.
Participants were requested to keep the verification document discussed above close to hand during the videoconference so that they could raise any issues relating to these categories and, or sub-categories as well as their experience more generally for discussion. They were also requested not to change or add to any pre videoconference comments they had entered onto the verification document and to return it to me following completion of the videoconference. This process was adopted because it was important to have a clear record of the individual nurse’s responses to the categories and sub-categories emerging from the data without them being contaminated by further group discussion. All five of the nurse participants returned the verification document; however, due to workload, rosters and videoconferencing room availability in the various hospitals where the nurse participants were situated only three nurse participants were able to attend the videoconference, the process of which is described below.

For the video conference, one of my supervisors (who was there to monitor proceedings and support me but did not join in the discussion), one nurse participant who worked locally to the venue and I were situated together in one room while the other nurse participants were seated in the videoconference room of their various hospital. The agenda for the teleconference followed a pre-set format, which included an introduction including a discussion of the ethical considerations for the group discussion, participant introductions, explanation of the study including the agenda for the videoconference and establishment of ground rules, followed by the discussion of the categories and sub-categories identified from the analysis of the nurses’ interviews. When explaining the ethical considerations for the group discussion I emphasised that although I was asking those attending to keep the discussion confidential, confidentiality of the discussion was dependent on each nurse maintaining this. Ground rules such as respect for each participant, minimal interruptions by allowing each participant to talk without being talked over, time keeping, and the need to be focused on the data to be discussed were agreed. I also
acknowledged that videoconferencing, because of its sometimes poor sound and visual quality, was not the ideal mechanism for a focus group; however, at least it made it possible for the group to get together to discuss my study’s findings and enabled participants to also discuss these and make comment as they wished. The video conference was recorded and the participant’s permission to record the proceedings was obtained prior to commencement of the conference.

A similar pattern of discussion for each category and sub-category was used: I initially read the category or sub-category title as outlined in the verification document, followed by my description of the meaning of these categories and sub-categories as this emerged from the interviews. I then invited each participant to comment. I ensured that all participants had an opportunity to discuss each category by asking each of them in turn to respond. I sought clarification and, if applicable, consensus by asking again for each nurse’s response to individual points or comments. At the conclusion of discussion of each category or sub-category I summarised what appeared to me to be the participants’ responses and again sought clarification from each of the participants that this was accurate or alternatively listened to their suggestion for editing.

During the videoconference the nurse participants appeared relaxed and content to discuss the findings and comfortable to disagree with findings that did not reflect their experiences. Despite my acknowledged reservations about the quality of the videoconference process, the visual and sound quality of this process was satisfactory. All three of the nurse participants wore uniforms, while the research supervisor and I wore casual dress.

Once the videoconference was completed, I reminded participants about the need for confidentiality and then requested them to return their completed verification document to me without altering any comments they may have written on the
document prior to the videoconference and/or adding any further comments. The videoconference lasted one hour, and before closing the conference I thanked the participants for their time in attending and for their participation in the study. Subsequent to the videoconference, with human research ethics approval, a $20 bookshop gift voucher was given or sent to all nurse participants as a thank-you for taking part in the study.

3.3.4.4 Review of additional nurse participant data emerging from nurses’ comments documented in the verification document and/or recorded during the videoconference

There were two sources of additional data resulting from nurses’ comments documented in the verification document (Appendix 9) and or recorded during the video conference. The verification document returned by the nurse participants contained comments relating to the categories and sub-categories identified in their interview data. I reviewed these comments and compared them against other nurse participants’ comments and expanded or updated the description of each category or sub-category where necessary.

The recording from the videoconference was transcribed by a transcribing service and reviewed by me to ensure its accuracy. In addition I added to the transcription notes regarding the context of the video conference the surroundings, participant’s demeanour and other observations accordingly. Similar to the review of the interview data, I replayed the videoconference and reviewed the transcript checking that nothing had been missed or inaccurately recorded. This also enabled me to reflect on the videoconference content noting the participants’ body language, tone of voice or facial expressions, not apparent in a written transcript. I reviewed the comments made during the videoconference seeking to ensure or adjust my description of a category on the verification document where necessary. When
viewed together there was only a minimal amount of adjustment needed to the
description captured in the verification document or to findings from the nurse
participants interviews overall.

3.4.4.5 Trustworthiness of my study

Lincon and Guba (1985) suggest that qualitative studies should be trustworthy, in
that they accurately reflect the study participants’ experiences. To establish
trustworthiness Cresswell, (1998) argues a number of techniques should be
undertaken to ensure the research is verified and therefore credible. Within my
study there were four procedures undertaken with the aim of establishing the
studies credibility; the triangulation of the data collection methods, returning the
transcripts of the nurse participant’s interviews to the nurses, the use of the
verification document and the video conference used to verify my findings. None of
the nurse participants altered the transcripts of their interviews therefore it can be
assumed they were verified as an accurate reflection of their interviews. Lincon and
Guba (1985) suggest that a critical component of establishing credibility of
qualitative research is asking the research participants to review the researcher’s
findings. The verification process of my findings involved nurse participants
reviewing and commenting on the verification document describing my findings, in
conjunction with a video conference where the participants were again given the
opportunity to consider and discuss these findings.

In establishing trustworthiness Lincon and Guba (1985) suggest that qualitative
studies should also have elements of dependability and transferability.
Dependability relies on the researcher identifying a clear audit trail that illustrates
the process of data analysis (Appendix 12) and identification of any changes which
may affect the study outcome. Within my study, modification was made in regard to
the recruitment of participants, use of patient and spouse questionnaires instead of
interviews for participants in both groups and the use of a verification document and a focus group. My initial strategy for recruitment of patients was that I would recruit them for the study, however following ethical review this was modified to ensure a third party recruited participants. The patient and spouse questionnaires may not have given the richness of data that a patient or spouse interview may have therefore this strategy may have affected the outcome of my study. The use of the verification document and the video conference however, did not appear to impact negatively on the verification of my findings because both of these, it could be argued, reflected processes engaged in at a focus group designed for this purpose.

Transferability is about how well the results of the study can be generalised (transferred to another site) within the broader health community. I acknowledge that my study’s transferability is constrained by the limited amount of findings from patients and spouses who participated in it; nevertheless the findings from the experience of the nurse participants may be more generally transferable to the wider community.

### 3.4 Ethical considerations

Although participants in my study may not directly benefit from it, it is anticipated that their contribution to my study will influence future provision of cardiac rehabilitation services and benefit future participants of these services. It is important, however, to protect participants from harm by addressing ethical concerns and obtaining a thorough review of the research from an ethical standpoint through a recognised process. There were specific ethical issues for the individual participants and groups within this study: these issues and how they were addressed will now be discussed.
3.4.1 Ethical considerations specific to patients and spouses in my study

Specific ethical considerations for patients and spouses related to distress that completing the questionnaire might have caused them, given that patients and spouses were reflecting on an illness that might have been traumatic for them or their family. To minimise this, patient and spouse participants were informed through the information letter sent with the questionnaire that if completing the questionnaire raised questions or issues regarding their health status, the use of the AHG or provision of care for a partner with CAD, then support and assistance was available to them from either or both their nurse mentor or general practitioner. Patients and their spouses also had the opportunity to withdraw themselves or their data at anytime during the study. To my knowledge, none of the patients or spouses participants experienced distress from taking part in this study.

3.4.2 Ethical considerations specific to nurse participants in my study

There were several specific ethical considerations for nurse participants including the professional role of the researcher, confidentiality and disclosure of safety or conduct issues, recording of interviews and the video conference and withdrawal of data. My professional role as a CNC for cardiology/cardiac rehabilitation in the Local Health District in which this study is situated involves supporting patients in hospital based cardiac rehabilitation, clinical supervision of cardiac rehabilitation nurses across the district and strategic planning for cardiac rehabilitation. All of the nurse participants in this study were known to me in my professional role and therefore there was the potential for conflict of roles during the interviews and videoconference.

In order to prevent confusion, minimize conflict and reduce risk to participants and myself, I clarified with each participating nurse at every instance of contact with
them during this study that my role in all aspects of it was as researcher not CNC cardiology. Prior to their interview I informed nurse participants that the purpose of the interview was related to research I was conducting into their experience of using the AHG for cardiac rehabilitation and not for other clinical or management issues. I explained that if the nurse participants had any clinical or workplace issues arising from participating in the study that these should be discussed with their manager or the employee assist program and any issues with the study or its conduct should be discussed with its Chief Investigator. During the interviews and videoconference, none of the nurse participants raised issues unrelated to my study or difficulties participating in it.

Although participant confidentiality could be assured in relation to the interviews and their analysis, this was not the case for the video conference. This was drawn to the attention of participants in the video conference so that they were aware that confidentiality of the discussion that took place during it was to a large extent their responsibility. All participants were assured that their confidentiality would be maintained in any presentation or publication resulting from the study.

The interviews with nurse participants were recorded using a digital recorder and the video conference was also recorded, nurse participants were informed that they could refuse to be recorded or stop the digital recorder or videoconference at any time. Nurse participants were also sent a copy of the transcript of their interviews and were asked to edit this if they wished and return it to me. The nurse participants could also withdraw from the study and withdraw the data they had contributed however any request for the latter needed to be made prior to data analysis.

There was also a potential risk to my personal safety in conducting the study as it was necessary to travel and conduct interviews at venues chosen by the participants. However, only two interviews were conducted face-to-face, both within the
relatively safe environment of health care facilities in normal working hours, and only one interview involved travel by car for two hours each way, which posed a limited risk to me.

3.4.3 Ethical considerations for all participant groups

There were also ethical considerations common to nurses, patients and spouses participating in the study in terms of actions I was obliged to take should any information related to an illegal, unprofessional or unsafe practice, or adverse conduct be divulged. My study information letter advised participants that if information of this kind was divulged I was required to report it to the appropriate authorities and that the study participants’ permission need not be obtained to disclose the information. None of the participants disclosed any issues that were illegal, unsafe or that impacted on professional practice or conduct.

Despite these considerations, there was minimal ethical risk to the participants within the study or to myself as researcher. Local Health District guidelines relating to the duty of care that nurse participants and I owed to each other and to patient and spouse participants, including honesty, integrity and not to do harm to others were observed throughout the study. Finally, the requirement to submit my study to the appropriate ethics review committee prior to its commencement was followed with ethical clearance being obtained from the Human Research Ethics Committee of the Local Health District where the study was situated, and the University of Newcastle Human Research Ethics Committees on January 20th 2010. All variations to the study’s design were forwarded to these committees and ethical approval obtained prior to implementation in the study.
3.5 Data storage

In order to maintain anonymity of participants in the study in all of the data emerging from it I have assigned and used pseudonyms in place of participants’ real names. During the study, all data emerging from it was stored on a password protected hard drive with backup on a data stick and stored separately from the hard drive. Written documents were stored in a locked cabinet in my office in a large hospital in NSW. Upon completion of the research study, all data and information collected will be securely stored at the School of Nursing and Midwifery at the University of Newcastle, NSW. They will be kept for a period of five years to comply with ethical requirements. One nurse participant was excluded following the interview when it emerged at a late stage of the interview that he had not facilitated the AHG with a patient. Data relating to this interview was destroyed with the nurse participant’s permission.

3.6 Conclusion

This chapter provided a rationale for the selection of the literature review as the conceptual framework for this study and for the selection of qualitative description as the methodology for it. The design of the study including participant recruitment and the process of data collection using a postal questionnaire, telephone and face-to-face interviews has been described. Following this, data analysis methods used to analyse the qualitative and quantitative data from the patient and spouse questionnaires, and nurse participants’ interviews were discussed. In addition, the confirmation process of my initial findings from the study was outlined. The chapter concluded with a discussion about ethical considerations in the study and how they were addressed within it.
In the following chapter, the findings of the study are presented. Firstly a description of my studies participants will be summarised, this will be followed by a discussion of my findings from the patient and spouse questionnaires. Finally a detailed description of the categories and sub-categories incorporating the information from the nurse participants’ interviews including the subsequent confirmation processes of my initial findings from the study will be discussed. The findings are presented as a descriptive narrative rather than in tables, which is in keeping with the methodology used for the study.
Chapter 4

4.0 Introduction

This study sets out to explore the experience of patients, their spouses and AHG nurse mentors using the AHG for home based cardiac rehabilitation. A description of the study’s design, the participants in the study and the process used for data analysis is described in Chapter 3. This chapter describes the subsequent findings of my study. A description of my study participants will be presented first followed by the patient and spouse findings and finally the findings from the nurse interviews including the confirmation of my findings from the verification document and video conference. The majority of my findings are presented as a descriptive narrative rather than in tables, which is in keeping with the methodology used for the study.

4.1 Demographic description patient, spouse and nurse participants

This section describes the patient, spouse and nurse participants in my study.

4.1.1 Patient participants

A profile of the patients who participated in my study was obtained from participants’ responses to demographic questions posed on their questionnaire (Appendix 5a). Patients are identified by a pseudonym in order to maintain anonymity. Demographic information was necessary because a patient’s age, gender, education or employment status can have a significant impact on their experience of CAD or cardiac rehabilitation. Participants were asked to categorise their age (30-45, 45-55, 56-65, 66-75, 76-85 years), the highest educational level obtained (primary school only, secondary school not completed, secondary school
completed, trade qualification or TAFE, university or other tertiary study, other) and their current employment status (full time, part time, self employed, retired, unemployed). Patients were also asked to state the reason for their recent hospitalisation for heart problems for example heart attack, angina, post stent implementation, heart failure, acute coronary syndrome or other. Patient diagnosis was based on patient self-reporting and was not checked against medical records as the questionnaires were returned anonymously and I did not have access to clinical information for patients using the AHG. Although my inclusion criteria identified that patients discharged from hospital with acute coronary syndrome were eligible to participate in my study, this terminology was not used in the patient questionnaire as it may not have been a familiar term to patients. Patient participants were also asked why they chose the AHG for their cardiac rehabilitation; because how and why patients choose a program may impact on their engagement with the program and subsequent lifestyle change. Table 4.1 below summarises the age, educational level, employment status and reason for hospitalisation of the four patient respondents and includes their stated reason for choosing the AHG.
Table 4.1: Summary of characteristics of patient participants who have used the Aussie Heart Guide for home based cardiac rehabilitation.

<table>
<thead>
<tr>
<th>Patient</th>
<th>Age category (in years)</th>
<th>Highest educational level obtained</th>
<th>Employme nt status</th>
<th>Reason for their recent hospitalisation for heart problems</th>
<th>Reason the patient chose the AHG for their cardiac rehabilitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fred</td>
<td>30-45</td>
<td>University or other tertiary Tertiary education or other on the patient questionnaire relates to university or education resulting in a qualification. One of the patient participants commented that she had completed nurse training. study</td>
<td>Self Employed</td>
<td>Angina, post stent implantation</td>
<td>Recommended by local cardiac rehabilitation coordinator</td>
</tr>
<tr>
<td>Mary</td>
<td>66-75</td>
<td>Nursing General This refers to general adult nursing as opposed to mental health or children’s, this was exactly as written by the participant. Midwifery (Adult Nursing and Midwifery)</td>
<td>Retired</td>
<td>Blackouts several times, mild chest pain</td>
<td>Provided by sister. Sister is a term used to describe registered nurses, it stems from the early years of nursing whereby nurses were not known by names and had a strict hierarchal structure. in charge at local hospital</td>
</tr>
</tbody>
</table>
4.1.2 Spouse participants

A profile of the spouses who participated in my study was obtained from spouses’ responses to demographic questions posed on their questionnaire (Appendix 5b). Spouses are identified by a pseudonym in order to maintain anonymity. Demographic information was necessary because a spouse’s age, gender, education or employment status may have an impact on their ability to support their spouse with CAD and their experience of home based cardiac rehabilitation using the AHG. Participants were asked to categorise their age (30-45, 45-55, 56-65, 66-75, or 76-85 years), highest educational level obtained (primary school only, secondary school not completed, secondary school completed, trade qualification or TAFE, university or other tertiary study, other) and their gender and current employments status (full time, part time, self employed, retired, unemployed). Spouses were also asked to specify their relationship to the patient participant (spouse, partner, relative, and friend); all of the respondents stated they were spouses. Of the four spouses who returned the questionnaire, three questionnaires were complete and one incomplete with the comment “unavailable” written on the questionnaire. Table 4.2 below summarises the demographic characteristics of the spouses who participated in my study.
Table 4.2: Summary of characteristics of spouse participants who have used the Aussie Heart Guide for home based cardiac rehabilitation

<table>
<thead>
<tr>
<th>Spouse and relationship to patient participant</th>
<th>Age category (in years)</th>
<th>Highest educational level obtained</th>
<th>Employment status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lucy, spouse of Fred</td>
<td>30-45</td>
<td>University or other tertiary study University or other tertiary education or other on the patient questionnaire relates to university or education resulting in a qualification.</td>
<td>Full time employed</td>
</tr>
<tr>
<td>Jane, spouse of John</td>
<td>56-65</td>
<td>Secondary schooling completed</td>
<td>Retired</td>
</tr>
<tr>
<td>Anne, spouse of Jimmy</td>
<td>56-65</td>
<td>Secondary schooling completed</td>
<td>Unemployed</td>
</tr>
</tbody>
</table>

4.1.3 Nurse participants

The profile of the nurse participants in this study is obtained through the demographic information obtained from the nurse participants’ interviews (Appendix 11). The nurse participants are identified by a pseudonym to protect their anonymity. Demographic information was necessary to understand past and present influences on the nurse’s experience of using the AHG for home based cardiac rehabilitation. The nurse participants were asked as part of their interview (Appendix 11) to describe their nursing/cardiac rehabilitation experience and the number of patients with whom they had used the AHG for home based cardiac rehabilitation. The nurse participants were not specifically asked about the location in which they worked (rural or metropolitan); however during the interview they all stated their location therefore this was included in the demographic profile. Six nurses agreed to take part in the study.
One nurse, Gary, was interviewed but excluded from the study because it became apparent at the end of the interview that, although trained in the use of the AHG, he had not facilitated the guide with a patient and therefore he did not meet my study’s inclusion criteria. The data relating to this interview was destroyed with Gary’s permission. Table 4.3 summarises this information and is followed by a description of each of the five nurse participants, the setting and process of their individual interviews.

Table 4.3 Summary of number of years nursing, previous experience with cardiac rehabilitation and the use of the AHG by nurse participants.

<table>
<thead>
<tr>
<th>Nurse</th>
<th>Years in nursing</th>
<th>Rural/metropolitan based*</th>
<th>Years and type of experience in cardiac rehabilitation</th>
<th>Number of patients with whom the nurse used the AHG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrea</td>
<td>20; 10 years in cardiology nursing,</td>
<td>Metropolitan &amp; Rural</td>
<td>3 years experience in cardiac rehabilitation</td>
<td>8</td>
</tr>
<tr>
<td>Barbara</td>
<td>Did not specify</td>
<td>Rural</td>
<td>6 years hospital based cardiac rehabilitation</td>
<td>3</td>
</tr>
<tr>
<td>Claire</td>
<td>Did not specify</td>
<td>Rural</td>
<td>2.5 years community cardiac rehabilitation</td>
<td>4</td>
</tr>
</tbody>
</table>

* Based on the nurses description of their working context.
Andrea

At the time of the study Andrea had worked as a nurse in cardiology for over ten years, working with patients in an acute cardiology ward undergoing cardiac procedures as well as patients with chronic cardiac conditions. Andrea had three years of experience in cardiac rehabilitation with a small amount of experience in group-work and hospital based cardiac rehabilitation. She predominately works in a telehealth program providing home based cardiac rehabilitation over the telephone. Andrea had facilitated the AHG with eight patients.

Andrea’s office is in a busy hospital ward, and when I went to interview her she welcomed me and we shared a cup of tea together and chatted in a casual, friendly way about general cardiac rehabilitation issues and everyday pleasantries such as the weather on the day of the interview and so on. The office was very noisy (even with the door closed) and this sometimes impacted on my ability to hear Andrea’s discussion during the interview. During the interview Andrea appeared very relaxed and confident when discussing her use of the AHG. The interview was recorded using a digital recorder. At the end of the interview Andrea stated that she hoped that I had got what I wanted from the interview and if any further help was needed not to hesitate to contact her.

Barbara

Barbara has worked in cardiac rehabilitation for six years, running a rural hospital based cardiac rehabilitation program. The hospital program runs one day a week for six weeks and involves a one-hour exercise session and a one-hour education session and is delivered by a range of health professionals including physiotherapists, dieticians, social workers and pharmacists, as well as Barbara. Barbara had
facilitated the AHG with three patients and the interview was conducted in her office in a small rural hospital. On arrival at the hospital Barbara had provided some lunch for us to enjoy prior to the interview. During lunch, Barbara appeared calm and relaxed about the interview and her use of the AHG. This was in contrast to during the interview, when she appeared nervous during her discussion about her use of the AHG. There was a lot of background noise (from the air conditioner) in the office during the interview. The air conditioner could not be switched off because it was a very hot day. The noise was distracting for Barbara and to some extent distracted me. Barbara apologised several times and we discussed the challenges of obtaining office space. The interview was recorded using a digital recorder. Once the interview ended Barbara shook my hand, appeared more relaxed and offered me a cup of tea prior to my return journey. I declined and Barbara smiled and wished me luck for the rest of the study.

Claire

Claire considers herself to be new to cardiac rehabilitation, having worked with only 25 to 30 patients over two-and-a-half years. As well as cardiac rehabilitation, Claire also works as a general community nurse in a small rural hospital site. Prior to taking up her current role, Claire worked in intensive care, cardiothoracic theatres and cardiology in a large metropolitan hospital. Claire’s experience is in running hospital based cardiac rehabilitation and she also does home visits to patients post discharge following acute cardiac events. Claire had facilitated the AHG with four patients. The interview with Claire was conducted over the telephone due to the distance I would have to travel (over 400 kilometres each way), using a digital recorder to record the conversation. During the interview Claire sounded relaxed and confident and pleased to be answering questions about her use of the AHG.
Emma

Emma came to nursing as a second career and mostly cared for patients with neurological conditions. More recently, however, her work has been in a rural community gaining experience in aged care, continence and chronic care. Chronic care involves working with the cardiac and pulmonary rehabilitation teams and this led to Emma working as a hospital liaison nurse for cardiac and pulmonary rehabilitation. This included educating and supporting patients in hospital about their cardiac or pulmonary condition and referring them on to outpatient cardiac rehabilitation. As the community based program reached capacity, Emma became involved with the AHG and had facilitated the guide with two patients. I offered Emma a telephone or face to face interview but Emma preferred a telephone interview as she was concerned about my driving for four hours (approximately 170 kilometres each way). The telephone interview was recorded on a digital recorder. During the interview, Emma sounded thoughtful and appeared to be thinking hard about her answers to the questions.

Glenda

Glenda has worked in a rural acute hospital prior to moving into community health. Glenda has limited experience of acute cardiac nursing or working with cardiac patients but, she has worked within community health for nine years, during which time she has became involved with cardiac rehabilitation. This has included home visiting patients post discharge from hospital after cardiac illness and offering support and information on medication and risk factors. Glenda had facilitated the AHG with two patients and her interview was conducted over the telephone due to the distance I would have to travel (approximately 460 kilometres each way) and recorded using a digital recorder. Glenda’s interview was the most difficult to organise because Glenda’s and my workdays clashed.
However, once the interview took place, Glenda sounded confident and happy to be answering questions about her experience of using the AHG.

4.2 Findings from the patients and spouse participants in this study

Findings from the patient, spouse and nurse participants will be presented the following ways; a description of findings according to each of the questions in the patient and spouse questionnaires will be presented. This is followed by a description of the categories and sub-categories emerging from the analysis of the nurse participants’ interviews, and the outcome of the verification process, including consideration of the verification document and discussion at the video conference.

The experience of patients and spouses using the AHG for home based cardiac rehabilitation, as this emerged from the findings of my study, is presented according to the questions in the patient’s and spouse’s questionnaires (Appendix 5a and 5b). Patient findings are presented first followed by the spouse findings. The questions from the patient and spouse questionnaires are used as headings for each section, followed by a summary of the findings. Given the minimal amount of data from patients and spouses, where relevant, questions and their subsequent findings are merged to add to the quality of the findings.

4.2.1 Patient findings

The first five questions in the patient’s questionnaire related to their demographic information, the results of which are discussed in Chapter 3 (page 37).
Question 6: Why did you choose the Aussie Heart Guide for your Cardiac Rehabilitation? and Question 7: Did you use it?

Offering patients a choice of cardiac rehabilitation program may improve patient engagement with that program. Therefore patient participants were asked why they chose the AHG for their cardiac rehabilitation and if they used the AHG (Appendix 5a, question 6 and 7). Three of the patients were offered the AHG by nurses and one by a doctor. It appears that Fred, John and Jimmy were not offered a choice of program as Fred said his “local cardiac rehab nurse suggested to use it (the AHG)”, John said “I was referred (to cardiac rehabilitation) by my doctor” and Jimmy said the AHG was “recommended by (name) hospital, whilst (I was) a patient, (and I was given the AHG) on discharge”. In contrast Mary said she chose the AHG as she was “guided by (the) sister in charge at (name) hospital”. Question 7 in the patient questionnaire asked if patients used the AHG, and all four patients responded yes.

Question 8: How useful was the Aussie Heart Guide in assisting in your recovery?

Patients were asked this question in an attempt to understand whether or not the AHG and its tools (patient information booklets, patient diary, relaxation and additional information Compact Discs (CDs)) were useful to them. Patients were asked to identify their response to question 8 on a five point Likert (rating) scale (Appendix 5a, question 8). The possible Likert scale responses ranged from extremely useful, very useful, moderately useful, not very useful or not at all useful. Mary, John and Jimmy rated the AHG as “very useful” in assisting them with their recovery, with Fred rating the AHG as “moderately useful” in assisting in his recovery. It appears therefore that patients found the AHG useful to a varying degree in assisting in their recovery.
Question 9: How useful was your contact with your nurse mentor? and Question 10: How often did you have contact with your nurse mentor?

The patient relationship with the AHG nurse mentor is based on partnership with each (patient and nurse) being equal partners in the relationship. Little is known about partnership in telephone home based cardiac rehabilitation and therefore I asked the patients and spouses about their contact with the AHG nurse mentor. Contact between patient participants and their AHG mentor may have been predominately via the telephone or supplemented with some face to face contact in a clinic setting, according to the patient’s preference and accessibility to services for an unspecified amount of time. However, the balance of context (i.e. via the telephone or clinical based) in which the AHG was used with each patient participant is unknown as they were not asked this information in the questionnaire. Patients were again asked to respond via a five point Likert rating scale, identical to the one outlined in the previous question, to identify how useful their contact was with the nurse mentor and the number of contacts they had with this mentor from a series of options (Appendix 5a, question 9 and question 10). All of the patient participants, except Jimmy rated their contact with the AHG nurse mentor as very useful. Jimmy rated his contact with the AHG mentor as extremely useful. In regard to the number of contacts with the AHG nurse mentor, Fred and Mary responded that they had six or more contacts with their AHG nurse mentor compared to John and Jimmy who said they had three to five contacts with their AHG nurse mentor. The findings from this question indicate that patients found their contact with the AHG nurse mentor useful regardless of the number of contacts.

Question 11: What did you like most about the contact with your nurse mentor? and Question 12: What did you like least about the contact with your nurse mentor?

In order to explore why the patients found the contact with the AHG nurse mentor
useful, patients were asked, using open ended questions, to comment on what they liked and disliked about that contact (Appendix 5a, question 11 and question 12). All patients liked their relationship with the AHG nurse mentor and the amount of support or information they received from her. Fred commented that his AHG nurse mentor was “very friendly and helpful”; Mary commented that the AHG nurse mentor gave her “confidence in (her) general well-being and (helped her) progress”. John and Jimmy found the information and support from the AHG nurse mentor beneficial in regard to their recovery. John commented that what he liked most about the contact with his AHG nurse mentor was that she “Helped me to understand what I was experiencing in my recovery process post operation from five bypasses (sic) and a new aortic valve replacement”. Jimmy had a similar comment saying “my mentor was very nice, very understanding and took a lot of time explaining things to me, how important it was to comply with the information to my recovery, (I) could not wish for better, (our) contact was weekly”. In contrast when asked what patients liked least about their contact with the AHG nurse mentor Fred and John wrote “nothing”, Mary and Jimmy crossed out this section with no comment added. These findings suggest that patients liked their contact with the AHG nurse mentor.

**Question 13: What did you like most about the AHG? and Question 14: What did you like least about the AHG?**

To assist in the development of future home based cardiac rehabilitation programs within Australia, I explored what aspects of the AHG patients liked or disliked (Appendix 5a question 13 and question 14). Patients liked the ability to monitor their progress and the amount and type of information contained in the AHG itself. John, a patient participant, commented that what he liked most about the AHG was that it enabled him to “Learn correct exercise and diet guidelines and how to look after myself and my heart, taking (his) possible reduced energy levels and (his) rate of recovery into account”. Mary, another patient, liked that the AHG helped her in
“gauging how well I was going”. Fred commented that the AHG was “full of useful information”. Jimmy another patient agreed commenting:

All the information was forwarded in forms of books, video and diet requirements to me during the course. (I liked) keeping and recording my progress so I could continue (with my) treatment and (my) activity, (increasing my) motivation towards (sic) the future. It also put me in a better frame of mind.

Patient’s responses to what they liked least about the AHG were minimal. However, Jimmy commented that he “found it difficult to stick to targets (too lazy) (or to) change (his) - diet and drinking”.

**Question 13:** Please provide any other comments about using the Aussie Heart Guide

Overall, the patients provided positive additional comments about their experience with the AHG. Jimmy commented, “I found the ACRA Heart Guide very helpful (in explaining) the importance of understanding why this happened and what I should do to prevent this happening again”. In contrast, Mary commented about the staff at her local hospital and their impact on her recovery saying, “I feel very lucky that we have such dedicated staff at (name of local hospital) that take real interest in our well-being and gave us encouragement with such guides as this”. Fred offered a suggestion for improvement to the AHG saying it “could do with a summary (on) page 10 (in the AHG) - the important points”. Overall the patient participants appear to have had a positive experience of using the AHG for home based cardiac rehabilitation.

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20 There was an error in the numbering of the questions on the questionnaire sent to spouses so there was two questions numbered ‘13’.
4.2.2 Spouse findings

The first five questions in the spouses questionnaire related to their demographic information, the results of which are discussed in Chapter 3 page 38. So as to differentiate between patients and spouses patient’s pseudonyms are in plain text while spouses are italicized.

Question 6: What did you like most about the AHG? and Question 7: What did you like least about the AHG?

Spouses were asked what they liked most/least about the AHG (Appendix 5b question 6 and question 7). Similar to patient participants, spouses found that AHG enabled them to monitor the patient participant’s progress and the information contained in the AHG. Ann a spouse participant liked the amount of information she and her husband received, and Ann commented that:

Information sent to us (about) what to do during the session and the future (was) very helpful. His (Jimmy’s) diet had to change, (I had to change) cooking (methods). (Jimmy had to) change his mood and (be made) aware of what he can or cannot do. Helped me to help him make a quick and good recovery.

Lucy commented in her questionnaire that what she liked most about the AHG was that “it helped (Fred) know what he could/couldn’t do”. In contrast Jane wrote she “didn’t know” what she liked most about the AHG.

In regard to what the spouses liked least about the AHG, Lucy did not respond to this question, Jane wrote “don’t know” and Anne reflected on her spouse’s (Jimmy’s) difficulty with lifestyle change, saying the thing she liked least about the AHG was “Trying (to) get him (Jimmy) to change – e.g. eat better, have fun and relax, don’t worry”.

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**Question 8: How much contact (number of sessions) did you have with your spouse, partner, significant other's nurse mentor?**

Spouses were asked an open question regarding their contact (number of sessions) with the AHG nurse mentor (Appendix 5b, question 8). Similar to patient participants contact between spouses and AHG nurse mentors could be predominately by telephone or face to face in a clinic for an unspecified duration, and the number of sessions refers to the number of contacts between the spouse and the AHG mentor. Contact between the spouse and AHG nurse mentor ranged between very little to six contacts but it was not clear if this was the spouses own contact or with the patient participant. Lucy responded that “John had 3-4 sessions with (the) cardiac rehab nurse”, Ann responded “about 6 times, weekly”, however it was not clear if this was on her own or with Jimmy. In contrast Jane responded “very little” to the amount of she had with the AHG nurse mentor.

**Question 9: How useful was the AHG in assisting you in assisting your spouse, partner, significant other in their recovery?**

Spouses who responded found the AHG very useful in assisting them to support their patient participant in their recovery, but differed in opinion about how useful the AHG was in assisting them to understand their patient participant’s illness and need for lifestyle change or recovery (Appendix 5b question 9 and question 11). Spouses used the same five point Likert scale as used in the patient questionnaire, with response options of: extremely useful, very useful, moderately useful, not very useful, or not at all useful. Lucy and Ann rated the AHG as very useful in helping them to help Fred and Jimmy respectively in their recovery; in contrast Jane did not respond to this question.
**Question 10: How useful was your contact with your nurse mentor?**

Using the same Likert rating scale as the patient questionnaire regarding usefulness, spouses were asked to rate how useful their own contact was with the AHG nurse mentor (Appendix 5b question 10). Jane did not respond to this question. Lucy rated her contact with the AHG nurse mentor as moderately useful and Ann rated her contact as very useful. Interestingly Lucy’s and Ann’s rating differed to their respective spouses, in that Lucy rated her contact as moderately useful but her spouse Fred, rated his contact as very useful; similarly Ann rated her contact as very useful and Jimmy, her spouse, rated his contact as extremely useful.

**Question 11: How useful was the AHG in helping you understand your spouse, partner, significant other’s illness and their lifestyle change or recovery?**

In the questionnaire spouses were also asked about the usefulness of the AHG in helping them understand the patient participant’s illness, need for lifestyle change or recovery. Jane did not provide a response to Question 11. Lucy found the AHG moderately useful in assisting her understanding of Fred’s angina, whereas Ann found the AHG very useful in assisting her understand Jimmy’s heart attack and the need for lifestyle change and recovery.

**Question 12: Other comments: please provide any other comments about using the AHG**

There was only one additional comment from spouses, Ann commented “we got through the program and found the result we were looking for very pleasing. Thank you”.

The findings from the nurse participants’ interviews will now be discussed.
4.3 Findings from the interviews with nurse participants in this study

The experience of nurse participants using the AHG for home based cardiac rehabilitation is presented according to the five categories and sub-categories which emerged from their interview data. Following the identification of each Category a summary description of its meaning drawn from the interview data is presented. Quotations from these interviews are provided to illustrate nurse participant’s expression of each Category or Sub-Category. Table 4.4 shows the categories and subcategories identified.

Confirmation of my findings from the verification document (Appendix 9) and video conference, also a component of the verification process, will be discussed at the end of each Category and Sub-Category. Quotations may be used more than once if they illustrate more than one Category or Sub-Category. Table The first Category in the nurse participant findings is the usefulness of the Aussie Heart Guide (AHG).
Table 4.4 Summary of the categories and sub-categories identified from the nurse participants’ interviews. (sorry, I have reformatted the table)

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category 1</td>
<td>Sub-category 1.1</td>
</tr>
<tr>
<td>Usefulness of the Aussie Heart Guide</td>
<td>Usefulness of the Aussie Heart Guide in supporting nurses</td>
</tr>
<tr>
<td></td>
<td>Sub-category 1.2</td>
</tr>
<tr>
<td></td>
<td>Usefulness of the Aussie Heart Guide in supporting patients.</td>
</tr>
<tr>
<td>Category 2</td>
<td>Sub-category 2.1</td>
</tr>
<tr>
<td>Challenges on the nurse/patient relationship when using the Aussie Heart Guide</td>
<td>Challenges of telephone only contact in nurse/patient communication</td>
</tr>
<tr>
<td>Category 3</td>
<td></td>
</tr>
<tr>
<td>Advantages and Disadvantages of home based cardiac rehabilitation when using the AHG for home based cardiac rehabilitation</td>
<td></td>
</tr>
<tr>
<td>Category 4</td>
<td></td>
</tr>
<tr>
<td>Partnership and control</td>
<td></td>
</tr>
</tbody>
</table>
### Category 5
Patient and nurse engagement with the AHG

<table>
<thead>
<tr>
<th>Sub-category 5.1</th>
<th>Nurses’ perceptions of influences on patients with the AHG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-category 5.2</td>
<td>Nurses’ perceptions of what influenced their engagement with the AHG</td>
</tr>
</tbody>
</table>

#### 4.3.1 Category 1: Usefulness of the Aussie Heart Guide

The nurse participants discussed the usefulness of the AHG as a program for patients to utilise for home based cardiac rehabilitation. Nurse participants identified that the various tools of the AHG (educational booklets, patient-led consultation, and opportunity for goal setting) assisted in providing support to both patients and nurses. They discussed how the various components of the AHG were useful in providing support to both patients and nurses, however they did not mention whether or not the AHG was useful to spouses. Glenda, one nurse participant, suggested “it’s a good program really, it’s user friendly as well as worker friendly”.

Despite the nurse participants suggesting that the AHG was useful to patients they expressed concern in their interviews about the amount of information given to patients. Reflecting on this perception, Claire, one of the nurse participants, said that “it seems like you’re handing a lot of information over (to the patients)”. Barbara agreed with Claire about the amount of information given to patients, saying: “it’s too much information to give”; although she felt that the quality of the information
was good, saying, “I think there was good information. Yes, the information was good in the books. And I think if they (the patient) read the information they would have got some good knowledge”. Andrea felt that there was nothing unhelpful about the AHG. Commenting that it was “compact” and, agreeing with Barbara about the quality of the information, she added: “it (the AHG) does have all of the information in there and it does have (pause), if people want more information, it does have links to go to for more information as well”. Glenda, found that one gentleman and his wife thought “the information was great: it looked and was good information in fairly simple language that people could understand”. When Glenda, who was supporting the patient in his recovery after a heart attack, contacted the patient and spouse to review the patients progress a week after they were given the AHG and asked if they had any questions, they replied: “no it’s all very self-explanatory” and they “thought it was great”.

When this Category and its description were presented to the nurses in the verification document (Appendix 9) and later discussed during the video conference all nurses confirmed both captured their experience about the usefulness of the AHG. In their interviews, in addition to agreeing that the AHG was useful in providing support to patients, they also suggested the AHG provided support to them. Therefore two sub-categories emerged from the interview data in relation to Category 1, both of which were confirmed as an accurate reflection of the nurse participants’ experience in their verification document and during discussion at the video conference.

4.3.1.1 Sub-Category 1.1: Usefulness of the AHG in supporting nurses

During their interviews all of the nurse participants described elements of the AHG that were useful (as well as not so useful) in supporting them to support patients in their use of the AHG. This support was identified as one of the advantages of the
AHG and included the training the nurses received prior to using the AHG and the structure of the AHG itself. Commenting on this Glenda said in her interview: “I think the AHG is excellent, and it certainly gave me the background and the support and the information that I could then make available to the patient”.

To use the AHG with patients, participating nurses undertook a single day of training (see Chapter 1, p. 24). The training included the use of the AHG, its tools (diary, information CD, and relaxation tape), motivational interviewing and behaviour change theory. Overall, Emma commented that she found “the training to have been adequate, interesting, (and) it was clear, the guides were easy to use”. The nurses perceived the most useful elements of the training were behaviour change theory, motivational interviewing and the rest-activity cycle (a guide for patients to understand the gradual resumption of activity). These topics were new to four of the five nurses, one of these being Barbara who commented: “I like the rest-activity cycle; that was new to me”. Glenda agreed with Barbara about the rest-activity cycle being new and useful; she also liked the behaviour change theory and motivational interviewing, commenting: “well, the behaviour of things (theory of behaviour change) was good, and as I said (previously in the interview) the rest-activity cycle. I like those sorts of things and it did give you an idea of the brief interviewing”.

During their interviews none of the nurses specifically identified any elements of the training as not being useful to them. Although, while it was apparent that the majority of them felt that elements of the training were useful, one nurse questioned the necessity of the training. During her interview, I asked Glenda if there were any weaknesses in the AHG. Glenda hesitated, then said, “weakness, well probably it’s not really a weakness of it” and proceeded to discuss how one of her colleagues wished to use the AHG but was unable to as she hadn’t completed the AHG training. Glenda commented that she thought “the AHG looked quite simple for any health person (health professional) to pick it (sic) up and use (it) with patients”. Seeking clarification of what Glenda was saying I asked:
So you think the actual weakness of the AHG is the actual training process you go through, whereas you think if you’re already sort of doing this sort of thing (cardiac rehabilitation) you think it’s probably easy enough to just pick it up (the AHG) and go with it?

Glenda replied “yeah”. Glenda’s original concern about the need for training was because of the lack of nurses in rural areas trained to use the AHG and this she felt impacted on service provision. Glenda perceived that this lack of trained people in the use of the AHG, especially in rural areas, was a threat to the AHG being used and limited patients opportunity for cardiac rehabilitation. She said “if I left the health care and there isn’t anyone else that’s done the training in how to use it, it would leave a reduced service”.

The nurse participants confirmed my findings outlined in the verification document (Appendix 9) and discussed at the video conference that training to use the AHG was useful, but it was unclear whether or not they confirmed that the need to be trained in the use of the AHG limited access to cardiac rehabilitation provision in rural areas. An example of the confirmation of my finding that training to use the AHG was useful came from Emma in her verification document who commented that the training was part of the support mechanism for nurses:

The need to provide “trained” providers of the AHG program, I think requires the training day prior to using the tools with patients. It might look “easy” and I think it is user friendly but education for nurses providing rehab is essential and it is the education on the program plus the program itself that defines the level of support afforded to nurses

Glenda’s comment at the videoconference demonstrates the uncertainty the nurses had regarding access to AHG training, impacting on access to cardiac rehabilitation, she said ”...I’ve been on leave and another nurse was filling in for me, they’ve
(patients have) still been seen (by the nurse for cardiac rehabilitation) but not necessarily using the AHG”. This indicated that patients in her area still had access to cardiac rehabilitation when she was unavailable, but patients were not able to use the AHG.

In addition to the support offered by the training as described above by Emma the nurse participants suggested during their interviews that the structure of the AHG was particularly useful as a support mechanism for themselves to provide evidence based cardiac rehabilitation to patients, especially for nurse participants who had little previous cardiac rehabilitation experience. The structure and format of the AHG gave the nurse participants more confidence to work with patients as Emma pointed out:

I think it provides a structured intervention. It certainly provides an evidence based framework in which to work and it’s not just, I mean I’m not taking away from people’s experience, but given that I don’t have recent acute coronary care experience nor do I have specialist training with the exception of the heart guide training in cardiac rehab, I certainly found the structure very useful.

Even though some nurse participants were experienced in cardiac rehabilitation, a number of them suggested that, a further aspect of the AHG beneficial to them as nurses was that the structure of the AHG assisted them to keep track of their patient’s progress or gave direction to the patient consultation. An example of this came from Andrea, who said that “the good thing about the AHG is that if I am getting lost and the client is maybe confusing me, the AHG has got a format where I guess there is a fall-back position”. The structured approach to home based cardiac rehabilitation provided by the AHG was also identified as assisting to individualise the process of delivery of home based cardiac rehabilitation. Glenda suggested that before the AHG it was up to the individual worker how they structured their
program, especially in rural areas where there might be limited numbers of patients and the nurse might be unsure what information to give the patient. She explained:

I’ve probably only seen two or three people a year with the heart (sic), with cardiac rehab (patients with CAD). I think the Aussie Heart Guide gives you a more structured approach to it (working with patients with CAD); whereas before (the use of the AHG) you sort of, you’d think, well, what do they (patients) need, at least it (the AHG) just gives you a guide as to everything that you should cover.

Another rural nurse participant, Claire, expressed similar experiences to Glenda’s regarding how she structured cardiac rehabilitation prior to her use of the AHG saying:

Well, not using the AHG, I’m setting up the program (with the patient) and I go ok well I’ll be discussing this (e.g. CAD) with you and in the next (session) we’ll be looking at your medications and we’re looking at this (e.g. diet, lifestyle) we’re looking at that (e.g. anxiety depression). And I tell them the plan of the program and then work out a suitable time (for the session).

All of the nurses confirmed within the verification document (Appendix 9.) and at the videoconference my findings that, in their experience, the AHG was a useful support mechanism for themselves if they were new to cardiac rehabilitation and that the structure gave them guidance in supporting patients. Emma commented in her verification document that “the AHG was very effective in supporting nurses”. Andrea agreed commenting at the video conference that the AHG as a support mechanism “was actually a bit of a revelation” for her as she had not thought of that aspect (support for nurses) of its use. Andrea subsequently described in her verification document the support nurses received from the AHG as “a hidden extra (of the AHG)”. The nurses suggested that how the AHG was used as a support mechanism for nurses differed from how it was used to support patients. The latter
is now discussed in Sub-Category 1.2 (below) within Category 1 the usefulness of the AHG.

4.3.1.2 Sub-Category 1.2: Usefulness of the AHG in supporting patients with their lifestyle change and recovery

Nurse participants identified during the interviews that the AHG was useful in supporting patients with their lifestyle change (risk factor modification) and recovery (from an acute episode of illness such as myocardial infarction). Support for patients was provided by the educational resources of the AHG and all of the nurse participants thought it was beneficial that patients could access all the information in the resources at home. An example of this is from Glenda, who described how the AHG had helped one patient understand his risk factors:

The man I saw (he wasn’t aware of a lot of the risk factors) ... it’s all set out simply (the format of the AHG in explaining the patient risk factors) for them (sic) and he was keen to try (and change his lifestyle). There wasn’t anything he could do about (changing his) family history but, as for his diet and other risk factors, he was keen to find out what he could do.

Claire felt that if patients had a “good level of commitment to lifestyle changes” then the AHG was beneficial. In contrast, Barbara was sceptical whether patients actually used the AHG, commenting: “I gave them (patients) the information; whether they read it or not, it’s up to them”. Barbara also suggested that rehabilitation and risk factor change was “just a process you (nurse and patient) go through” and she “didn’t know whether the heart guide helped or not”, Support for patients, according to the nurse participants, came from the individual resources (diary, booklets, CDs, relaxation tape) used in the AHG program, although the nurses differed in opinion as to which resource patients found most supportive or useful.
Nurse participants identified that patients preferred the information booklets and
the rest activity cycle\textsuperscript{21} as opposed to the diary and relaxation tape because the
information booklets and rest-activity cycle were more helpful to them. Interestingly,
only Glenda in her interview mentioned how the carer booklet was a means of
support for spouses, commenting: “I like the carer booklet, that’s useful for
families”. In discussing patient preference for the rest activity cycle, Glenda
explained how a patient told her that she had benefited from the rest-activity cycle:
“I don’t have to get my floors done in one day and I don’t have to get the dusting
done as well on the same day and I don’t have to change the sheets on the same
day”. Claire found that she used the rest activity cycle to support patients to increase
activity, saying “I do use the rest activity cycle as I think that this crowd (her
patients) all seem to take it (exercise) gently”. However Claire in her interview also
commented that she found the rest activity cycle difficult to explain to patients,
saying “I find (it) the part that I can’t explain well and I tend to (struggle) with; the
crap bit that he (the AHG trainer) talks on and on about, is that cycle of doing too
much (rest activity cycle)”’. She suggested that the rest activity cycle needed to be
clearer in the AHG for patients and nurses to use.

The AHG resource that nurses perceived provided the least support for patients, was
the patient diary used to assist patients to set individual goals for their recovery, risk
factor modification and to monitor their progress. The majority of the nurse
participants felt that patients did not find the goal setting or the diary useful and
described reluctance by patients to use these tools for lifestyle change. They found
that patients wanted the nurse to write the diary for them, which was a source of
frustration for several nurse participants. Claire explained how the AHG “actually
requires them (the patient) to actually do something; the AHG actually requires

\textsuperscript{21} Rest Activity Cycle is a resource in the AHG to assist patients in assessing if they are doing too much or too
little exercise, and guides them to gradually increase or decrease their exercise accordingly.
them to put pen to paper and make a commitment and I tell you, they, they are not good at it”. Barbara agreed and said that patients “didn’t like the diary and they didn’t like writing in it or doing the diary”. Andrea in her interview argued that “for some people, the diary is too in-depth”, explaining that one patient has described the diary as being “too high maintenance.”

Yet, despite the patients apparent dislike of the diary, most of the nurse participants had at least one patient who used the diary effectively. An example of this came from Claire, who described how a patient had used the dairy for improving his exercise. She said, “he’s actually been the only one to really write down the distance covered, what he did and how he improved; it gave him the confidence to continue with his exercise”. Emma explained her experience of her patients’ use of the diary and symptom diaries in general saying:

I found that patients didn’t do much in the way of the diary; I found that they didn’t use those. My experience of people using symptom diaries (generally), and I have a little bit, have been (that) there are people who use them like religious bibles and fill up volumes and use them to communicate and recognise what’s happening to them. But, for as many people who are like that, I found a lot of people didn’t and none of the people that I saw used the diary in any consistent way. There’d be a few things written in but then it would sort of fall away and then you remind them.

Barbara was more sympathetic towards patients in relation to their use of the diary than the other nurse participants, suggesting she thought that they did not use the diary because “they have lots of other things they had (sic) to do and they didn’t have time, they were too tired with (doing) the exercises”. The use of the relaxation CD by patients was also discussed by the nurse participants.

Comments from the interviews indicated disagreement among the nurse
participants in regard to how useful the patients found the relaxation CD in supporting their recovery. Barbara found that:

They (patients) didn’t like it; they complained that they fell asleep, or it wasn’t for them because two of them were farmers and they weren’t used to sitting down and, (were) you know (too) manly\textsuperscript{22} macho, they weren’t going to sit down and listen to relaxation things.

Claire reported that one of her patients commented: “the CD was boring”; however, in contrast, another of her patients found the relaxation CD a useful form of support. Claire said:

I have had one client that’s used that (the relaxation tape) successfully and really found that to be a positive experience. He didn’t realise how “clenched” up he was and he actually used the CD and went out and bought more CDs to relax.

Glenda admitted that she personally struggled with relaxation and this hindered her in supporting patients saying:

That’s one thing I do find hard, myself, is (sic) the relaxation side of things. Before (the use of the AHG) we had a social worker available and we’re hoping to get one again, so that they could assist with that sort of thing (relaxation).

In contrast to Glenda, several nurse participants appeared to embrace relaxation and saw it as beneficial in supporting patients in their recovery, evident in Claire’s comment:” the AHG is the first program that puts relaxation on the map”. The nurse participants who liked the relaxation tape were positive about the benefits of relaxation for their patients. Claire said, “I think that we really are taking the art of

\textsuperscript{22} Manly: having or denoting those good qualities traditionally associated with men, such as courage, strength, and spirit (Oxford English Dictionary, 2012).
relaxation seriously and it’s made me sell the idea as an activity to relax.” Andrea agreed with Claire, saying, “the one thing that all my clients that had had (sic) been enrolled in the AHG (and) who have had previous cardiac events were particularly pleased with is the relaxation therapy”. Barbara, however, disagreed with Andrea and Claire and commented: “The relaxation CD weren’t (sic) bad (laughs); well one (patient) said they fell asleep and the other one wasn’t able to use it, and the other one: they (patients) all had excuses. I’ve forgotten all the excuses, but they weren’t happy”.

Interestingly, several nurse participants mentioned in their interview that the relaxation program was on a CD to be used on a computer and this hindered its use because patients were not computer literate. The relaxation CD and the CD with more general patient information were designed to be used on a home computer. However, computer literacy was viewed by nurse participants as a barrier to the usefulness of the AHG in supporting patients. Most nurse participants described during the interviews how some patients experienced difficulties relating to computer literacy. Barbara suggested that:

They (patients) aren’t computer literate, so all that lovely computer (information) -those CD that were given (sic_ - it was wasted on them (patients) because they couldn’t use it. Even if I showed them it (the CD) here (in her office) but it was wasted on them.

Claire agreed and commented: “CDs were a waste of time as elderly people are were not computer literate”.

As well as computer literacy some nurse participants described difficulties patients experience with literacy more generally. Patients’ literacy levels, the extent of their ability to read and write, was raised as an issue as part of the nurse participants’ experience. The majority of the nurse participants found that the reading age (10
years old) at which the AHG booklets were developed was acceptable for the majority of patients. Emma said:

I found one person was a tradesman, he wasn’t flummoxed by the language or the approach; the man who as I said came from a highflying executive background, he didn’t find it talked down to him at all. So I found that the actual scientific, the medical and the nursing information and the nursing approach from the AHG was well accepted.

Nevertheless other nurses were concerned that some patients might experience some difficulty understanding the AHG. Claire sounded somewhat frustrated when she found she had to find out “if they could actually read or write, as there’s a few people (patients) that I could have put on it (the AHG) but (I) found, of course, they left school when they were about six”. Barbara felt that even if patients could read “they don’t like reading about their illness, even though it’s a cartoon thing\(^{23}\), and for elderly people (late 70s or 80s) they weren’t familiar with the cartoon concept”.

Nurses confirmed my findings in this Sub-Category 1.2 usefulness of the AHG in supporting patients with lifestyle change relating to the diversity of nurse participants’ experiences with the patient diary, goal setting, relaxation and patient literacy (computer and in general) and use of the tools of the AHG. Emma, when commenting on literacy in her copy of the verification document noted that “the issues of literacy (computer or other) is valid and may be a barrier to (the use of) the diary etc. (AHG resources) as the lack of literacy can be hidden”. However, the second part of Emma’s comment was disputed by nurse participants, Glenda, Barbara and Andrea, during the videoconference, all of whom described some positive experiences with the diary and goal setting. This resulted in a discussion

\(^{23}\) The AHG has cartoons to illustrate particular points such as anxiety or depression; cartoons are used as a way to bring clarity and ease understanding.
during this video conference regarding the use of the diary and goal setting with a general agreement being reached that some patients did find the diary and goal setting useful while others did not.

4.3.2 Category 2: Challenges in the nurse/patient relationship when using the Aussie Heart Guide

The nurse participants, when describing during their interviews how the AHG could support patients in their lifestyle and recovery, also described challenges in developing their relationships with their patients. This led to the development of a second Category: challenges in the nurse/patient relationship when using the AHG.

The philosophy underpinning the use of the AHG is articulated as partnership between patients and nurses. The emphasis is on the nurse relinquishing the expert role, and working in partnership with the patients when using the AHG and planning their recovery and, or lifestyle change. True partnership relies on the active participation of the patient rather than him or her being a passive recipient of nursing care. Therefore fundamental to any partnership is the relationship between two or more parties, in this instance the relationship, on a professional and on a person to person level, between the patient and AHG nurse mentor. This partnership relationship may be crucial to the success or otherwise of the patient’s use of the AHG and therefore I asked nurse participants during their interview about their relationship with patients using the AHG for cardiac rehabilitation. As a result the nurse participants commented on their being distinct differences in their relationship with patients using the AHG when compared to their experience of hospital group programs or individual face-to-face contact with patients. An example came from Glenda, who found that her relationship with patients using the AHG was “good and friendly” but it took “longer for the worker (the nurse) to see the whole person (the patient)” because Glenda’s contact with her patients was predominately over
the telephone. Several nurses commented that because of the lack of face-to-face contact they felt the relationship with patients using the AHG was less personal. Barbara explaining this change when talking about her relationship with patients using the AHG said “well, it’s (the nurse/patient relationship) different; you don’t get to know them as well. There’s a problem (Pause)” she added, “its impersonal; it’s very impersonal over the telephone.” During the interview Barbara appeared to be struggling to describe what the challenge was with the lack of a personal relationship with her patients. Because of this, in an attempt to demonstrate to Barbara that I understood what she was saying, I asked, “so you don’t get that rapport with patients?” Barbara appeared relieved that I had understood and replied, “yes, that rapport with them is different”. I then asked, what impact the lack of rapport had on patients using the AHG. Barbara replied that “well, they (the patient) may not be encouraged (to) read the books and do things I suppose”. Emma, when describing the differences in her relationships with a patient she saw regularly face-to-face in a hospital based cardiac rehabilitation group as opposed to a patient at a distance using the AHG at home said, “I think the professional contact was unchanged (between the patient attending the group and the patient using the AHG)”; however, she felt there was a “slightly more personal element to the other one (relationship with patients who come to a group)”. Emma suggested that her relationship with the patients who came to her group “was certainly always a professional relationship but there just seemed to be an element of trust and a more personal connection than her relationship with the patient using the AHG.”

The lack of a personal relationship with their patient’s appeared to affect the nurse participants differently depending on their experiences. For example Barbara’s affect appeared somewhat ‘flat’ when discussing her lack of rapport with patients using the AHG. This was in contrast to Emma’s tone of voice, who when asked about her relationship with patients when using the AHG responded in a sad and wistful way perhaps because of the lack of personal relationship with her patients. However
Andrea, when discussing her relationships with patients felt that the AHG in contrast to her experience with another telehealth program gave the nurse the opportunity to be “more person-centred”, and to not view the patients as numbers or targets of the program as she believed happened in some other cardiac rehabilitation programs with which she was familiar. When asked to describe what she meant by “person-centred” Andrea said:

It’s working with (patients), where they are when they are ready to actually do something (lifestyle change), what feedback they are willing to give me. With some people I have to go really, really slow (sic) and that’s where the AHG is good because you can mould it around your client more.

Andrea commented during the videoconference that because of her personal view that the AHG enabled a “person centred relationship between nurse and patients she could not agree that there was a challenge to the nurse-patient relationship associated with using the AHG”. On the other hand Glenda, Claire, Barbara and Emma all confirmed this because they had found there were challenges in the nurse patient relationship when using the AHG. Barbara was definite about this in her comment made on her verification document that “the nurse/patient relationship was a challenge”

The majority of nurse participants discussed challenges in their relationship with patients during their use of the AHG. The lack of access to non-verbal communication was raised as being of particular concern about patients using the AHG, and some nurse participants expressed a feeling of uncertainty about the trustworthiness of patients’ verbal assessment of their progress or recovery when they were limited predominately to telephone contact. These challenges formed a Sub-Category of Category 2 that focuses on the challenges in nurse-patient communication, when contact is predominantly limited to telephone contact with patients using the AHG for home based cardiac rehabilitation.
4.3.2.1 Sub-Category 2.1: Challenges of telephone only contact in nurse/patient communication

Challenges more generally relating to telephone only contact in terms of relationship building have been identified in the overall Category (Category 2). I identified Sub-Category 2.1 because nurse participants spoke extensively during interview about their challenges with nurse/patient communication in programs predominately offered over the telephone. Contact between patient participants and their AHG mentor may have been predominately via the telephone or supplemented with some face to face contact in a clinic setting, according to the patient’s preference and accessibility to services for an unspecified amount of time. However, the balance of context (i.e. via the telephone or clinical based) in which the nurse practiced is with each patient participant is unknown. The duration of the contact or amount of time the patient used the AHG supported by the nurse is also unknown. Nurse participants commented that they felt challenged in their ability to assess patient’s needs and the effectiveness of their interventions without face to face communication with patients and family. For example, Emma suggested that she did not have “the full range of communication” without being able to “see (the patients) body language, their demeanour, their grooming and how much they care for themselves”. In addition some nurse participants were particularly doubtful that some patients had progressed or participated in the activities of the AHG to the extent which they reported. This resulted in some nurses expressing discomfort about relying on the patient’s description without their own visual confirmation. Therefore the challenges of predominantly telephone only contact, on nurse/patient communication, are explored in more detail within this Sub-Category.

A challenge in nurse patient communication identified by some nurse participants during their interviews was the nurse’s ability to undertake a full assessment of the patient using the AHG. Emma gives an example of this, commenting that assessing
patients over the telephone when using the AHG didn’t allow her to have “the full range of communication” with the patient and his/her carer. She commented:

You get to do a better evaluation of where people are at, from the point of view of their demeanour, their level of grooming and how much they care for themselves and things like that. I find I got a lot more (information) by seeing people face-to-face. I don’t know how I would find it if I had no face-to-face at all.

During interview Glenda agreed, commenting: “I don’t think you get as clearer (sic) a picture of the client if you don’t see them” and “it’s (cardiac rehabilitation is) not as easy over the phone is it?”

In the interviews several nurse participants described challenges with honesty in nurse/patient communication when their contact with patients was predominately via the telephone. Barbara explained:

Well it (telephone service delivery) was hard. It’s difficult over the telephone because they (the patient) can tell you something that isn’t true (but is) just what you want to hear so you don’t bother them (the patients) anymore because I was speaking to them every three weeks, or quite frequently, and they would just say yes, yes, yes to a lot of questions that you would sort of go through. And they weren’t honest; I don’t think they were that honest with you.

Claire was blunter, suggesting: “it takes more than two sessions to get below the layers of how many porkies they’re telling.” Emma related her lack of trust in the patient’s honesty to not being able to see the patient and read their body language, saying, “I sometimes get concerned that people will tell you what they think you want to hear rather than (you the nurse) looking at them and reading their body language”. When I sought clarification and asked “So you weren’t really confident
that the information you were getting over the phone was right because you couldn’t back it up with what you could see, touch and feel?” Emma replied:

Just the body language, those other communications (including), the facial expressions the stance, the lightening of their eyes, that sort of thing; and as I said I am just concerned that people, because they know that you’re trying to help (pause) and that’s my experience - it’s because they want to: (a) tell you you’re doing a great job; (b) tell themselves they’re doing a great job. I sometimes get concerned that people tell you what they tell you (because) they want to tell you what they think you want to hear.

Emma gave an example of what she meant by this comment when describing how she used non verbal communication to assess a patients’ exercise tolerance saying:

Rather than (when) you’re looking at them and thinking, well, I cannot see any real evidence (of improved exercise tolerance) I mean you just walked up the stairs to come and have a chat about this (exercise); you tell me you’re walking two kilometres a day, well it doesn’t look like it (because they are short of breath).

Claire felt that the face-to-face communication gave an “independent check” that the patient was progressing with their rehabilitation. Barbara agreed with Claire commenting in her interview “it (patient assessment) was better when we brought them (the patient) in and spoke to them face-to-face, you know, at pre-assessment, than when we got them (patients) back at the end (of the program) that was the true face of it all (when the nurse could undertake a full post program assessment using the full range of communication)”. Barbara also expressed her uncertainty about patients’ honesty when discussing whether or not her patients read the books comprising the AHG saying: “well, I think they did (read the information book) they told me they did, but whether they did or not, I don’t know.” Claire suggested that patients are not honest about their anxiety or depression commenting “I think
people lie, you know (about how) they are feeling”. However Claire also commented in the interview “I’ve used the techniques’ in the AHG on them (patients) and I’ve told them about anxiety and depression and they’ve gone well that’s alright I’m normal”.

Andrea suggested that if patients are dishonest about their progress, nurses have other ways of checking the validity of the patients’ responses. For example Andrea commented at the video conference:

They (patients) may try to fudge things when they’re in a telehealth program but if you’re actually following them up, it does show up in other areas that they’re not telling the truth, so in blood test results or contact with their GPs. So yes I found this section quite interesting because it was the complete opposite to what my experience was with the AHG and still is with telehealth.

In addition, when it came to reviewing the verification document and discussing my findings from the study during the video conference, those who had commented on issues about patient’s honesty in their health reporting during interview now chose to refute it. For example Emma commented “a valid point not having full range of communication body language etc. but strongly disagree that telephone based services “lets” patients get away with dishonesty”. Glenda and Barbara agreed with Emma regarding patients’ lack of honesty in their reporting about their health over the telephone. For example, Barbara commented “I don’t think patients lie to you; I can’t think of the word...they just detract from the truth a bit so they can hear you say something good (praise from the nurse to them”). These comments at the video conference and in the verification document are in direct contrast to comments made during Emma’s and Barbara’s interviews. For example Barbara said in her interview “And they weren’t honest; I don’t think they were that honest with you.”
Glenda suggested to Barbara during the videoconference that patients “stretched the truth”. Barbara agreed and said “yes, they (her patients) were doing what they said they were doing but not as frequently I’d say as they told me”.

When describing their experiences in relation to Category 2: Challenges in the nurse/patient relationship when using the Aussie Heart Guide and its Sub-Category (above) during their interviews, some nurse participants also compared and discussed their experience of hospital based cardiac rehabilitation as opposed to their experience of home based cardiac rehabilitation when using the AHG. This discussion gave rise to Category 3.

4.3.3 Category 3: Advantages and disadvantages of home based cardiac rehabilitation using the AHG for home based cardiac rehabilitation

During the interviews the nurse participants were asked what were the strengths and weaknesses of the AHG. The responses were commonly related to the comparison of their experience of hospital based cardiac rehabilitation as opposed to home based cardiac rehabilitation using the AHG; in essence the advantages and disadvantages of home based cardiac rehabilitation using the AHG. The advantages and disadvantages raised by the nurse participants appeared to be patient focused rather than the clinical or personal challenges the nurses experienced themselves.

Home based cardiac rehabilitation using the AHG is a new concept within Australia and the majority of nurse participants were unfamiliar with this type of program or home based cardiac rehabilitation in general. During the interviews they expressed their initial thoughts about being invited to use the AHG with patients and how, in their subsequent experience, patients felt about being involved in a new program. Barbara thought the AHG and home based cardiac rehabilitation was a “novel idea” and described her patients’ and her own initial enthusiasm in being asked to pilot
the program. Barbara commented “I thought it was quite a challenge, a chance to do something different and it’s the way of the future and they, patients, quite like being part of the future.” Emma said that her patients “liked being part of something new, a pilot”. Claire also found her patients liked “being part of the future, and they like being part of a study”. Glenda said she felt comfortable with the AHG immediately explaining, “like, I felt comfortable with it (the AHG) even though I’d only worked with a few patients, (pause) whether that’s an individual thing for me I am not sure”.

The AHG is used by patients at home with support from the AHG nurse mentor. During the interviews, when asked about strengths of the AHG for home based cardiac rehabilitation, all of the nurse participants thought it was advantageous that they could now offer a program to patients at home who were unable to attend a hospital based program due to a geographical distance. The overwhelming consensus from the nurse participants, all of whom worked with patients in rural areas, was that the AHG was a good alternative to hospital based rehabilitation for patients living in rural areas some distance from hospital based programs or for patients who have difficulties with transport. An example of this came from Barbara, who said she felt that “it was a good thing that you could give information to people who couldn’t make it to your group as they lived a fair distance away”. Emma’s experience was that “one fellow was living with his son on a property and (had) no transport. Another gentleman lived on a property (and) transport again was a problem but he also cared for a disabled child”. Emma felt being able to offer the AHG to these patients as their rehabilitation program was an advantage of the AHG program. Claire said that she felt that by offering the AHG she was “acknowledging that they (patients) need to get back to work, lived a long way (away from the hospital site) or had other priorities than attending a six-week program.” Interestingly, the nurse participants agreed that if access such as transport or distance was an obstacle for the patient, then being able to offer the AHG was advantageous; however, they differed in opinion regarding patient preference for a
particular program (hospital or AHG) if transport or distance to a program was not an issue.

In discussing the strengths and weaknesses of the AHG in regard to improving patient access to cardiac rehabilitation, I asked why patients had chosen the AHG as opposed to the hospital program. The nurse participants replied with comments from their experience with patients and also appeared to give their opinion of which program they felt patients would choose if there was equal access to both programs. Barbara stated that if transport or cost were not an issue, then her patients would have attended a hospital program:

As I said, use of petrol stopped them (rural patients) coming here (to the hospital for cardiac rehabilitation). If there was a (rehabilitation) program in (name of place) they would go to that; if there was something in (name of place) they would have gone to that.

Emma appeared frustrated that a patient was not prepared to wait a few weeks to commence the hospital program and had chosen the AHG:

One gentleman was very intense and had a lot of questions; he wanted to get into the thing (cardiac rehabilitation program) straight away and there was a few weeks wait to get into it (the hospital face-to-face program); it (the hospital program) was only a few weeks wait to get into the centre based program so he chose the AHG.

Glenda and Claire had a different experience and found in their rural areas that patients preferred the home based option. In relation to this Claire commented during her interview that: “being in this small environment that I am (pause), like, this year particularly I haven’t had that many clients, really, and they’ve all wanted to stay at home, be home based”. During a similar discussion in her interview Andrea said that some patients did not like groups or preferred to do their own
thing and suggested that for “clients who just don’t do groups, don’t want to (attend) groups at all there is an opportunity for the AHG to fill in the gaps”. Several nurse participants acknowledged that patients who wanted to return to work or had to wait for a vacancy in a group program might choose the AHG rather than waiting for the hospital program. As Emma who was working in a hospital where a number of patients were on a waiting list to attend a hospital cardiac rehabilitation program, said in her interview:

It (the AHG) was offered to them (patients awaiting a group program) because there was a waiting time and also because we had the program available (the AHG); it was a question of giving the option to patients so we would increase our uptake (of cardiac rehabilitation).

Despite their more positive comments about the AHG as a method of providing cardiac rehabilitation several nurse participants also made several less positive comments during their interviews. A number of these comments concerned the disadvantage for patients of the AHG being predominately telephone based and therefore resulting in minimal or no face-to-face contact with other patients. Nurse participants felt that the AHG disadvantaged patients because there was no peer support. Patients attending hospital face-to-face programs usually exercise in a group once or twice a week; however, this was rarely an option for those patients using the AHG at home. The disadvantage that the nurse participants associated with this was that it meant that patients using the AHG did not experience what they called the “group effect” of peer support that is, the support patients in the group gain from each other. Barbara explained this as:

The group is dynamic and they (patients) encourage people (other patients) to do things. You know when they’re (patients) in a group they have all (the) other people (other patients) telling them, and advising them what to do (explaining the group and the
recovery process), on how they reacted (to their cardiac disease) and they see how other
people have recovered and see what other people have done (in their recovery). Whereas
if it’s only a clinical person, over the telephone you know you can’t do that (peer
support).

Nurse participants suggested during the interviews that this peer support helped
patients in their recovery, improved patients’ motivation to change their lifestyle,
and assisted patients to maintain these changes. They suggested this lack of group
effect impacted on the effectiveness of the AHG, as this comment from Emma
demonstrates:

One of the weaknesses, I think, is that they (patients using the AHG) don’t have peer
support and my limited experience of cardiac rehab is that a lot of people find the peer
support valuable. I have found in following up people who have done a group based
program that many times they have requested (to repeat the program), and I am talking a
significant number of people. I know it’s anecdotal but, significantly, they have asked to
repeat the program because the peer support gives them (patients) the motivation and
gives them positive feedback, which encourages them to maintain changes.

Emma added that she thought that patients using the AHG might be “a little bit
isolated; they don’t have other patients to talk to or to experience the program
together”. She subsequently acknowledged, however, that the isolation might not be
an issue if patients had chosen that particular type of program, saying:

I don’t know, but I think in my experience (of hospital group programs) peer support
certainly has seemed to be important to some people. Now I don’t know whether it
(group support) was important to the people that I particularly spoke to, and that might
have been an issue itself (because the people were depressed), because these people chose
the individual program rather than the group session and so it may have suited them.
In contrast Andrea, in her interview, suggested that the groups were “quite impersonal for some people”; she also suggested that the AHG enabled the nurse to focus on individual patient needs better than the groups, saying:

I think the Aussie Heart Guide gives us a chance to be more person-centred. Some of the group based programs provide blanket information to participants and that can be a little confusing for them (patients).

Another disadvantage of home based cardiac rehabilitation using the AHG which a number of nurse participants raised during interview was the inability of the nurse to increase or decrease a patient’s exercise intensity. Patients using the AHG for home based cardiac rehabilitation exercised at home unsupervised, whereas patients attending hospital based cardiac rehabilitation programs engaged in group exercise programs supervised by nurses. This was perceived as a disadvantage of the AHG by some nurse participants because they felt it decreased its effectiveness when compared to hospital based programs. Claire said “the downfall of doing exercise at home, compared to doing it with the physio and I, is that we actually push them (the patients) a lot more and they don’t realise (this).” Emma’s comments made during her interview were in accordance with Claire’s on this issue. Emma described the difficulties she had in assessing a patient’s exercise capacity from only conversations over the telephone, especially one gentleman who she described as “physically strong” but without cardiovascular fitness\(^\text{24}\): “it was hard to know if he was doing too much or too little, whereas in the class (exercise program) we would have seen it”. Barbara commented:

Patients get there (fitness levels) in their own time and you’ve got limited time (for the

\(^\text{24}\) Cardiovascular fitness relates to how much exertion a person undertakes while exercising; to be cardiovascular fit it is recommended that patients exercise at a moderate intensity for 30 minutes daily. Cardiovascular fitness improves patient outcomes and assists with weight lost. (Giannuzzi, et al., 2003).
rehabilitation program, home or hospital). So (over the) telephone (for AHG patients) I don’t think you can get them (fitter). I think group sessions are probably better for that.

Andrea, however, did not feel that the inability to increase or decrease a patient’s exercise intensity was a disadvantage because she used the over-activity rest-cycle, that is, an AHG resource for guiding patient’s activity as a means of determining the patient’s exercise intensity.

The nurse participants confirmed my description of how this Category, the advantages and disadvantages of home based cardiac rehabilitation, emerged from their interview data as I explained this in the verification document (Appendix 9).

Barbara, at the videoconference commented:

Yes it (the AHG) was good because people have difficulty in getting to the program because of distance and travel and I thought it would be a great program for those types of people or people that wanted to go back to work. I thought it was rather a novel idea.

The nurse participants however were not able to confirm my findings regarding patients’ choice of program (AHG or hospital based) in instances where distance or access to a hospital program was not an issue. At the video conference Glenda and Barbara agreed with my finding that accessibility to a program influenced patient’s choice rather than preference for a particular program (hospital or home). In contrast Emma suggested from this quote in her verification document that for her the major benefit of the AHG was not accessibility, but that it offers patients a choice of program:

“The major advantage for individual patients is when they have real choice-not because rehab (sic) is only available on certain days/times, not because they are disadvantaged by distance, disability transport etc... but because they have access to a range of programs
equally and it is their own preference to do a particular program.

My finding from nurse participant’s interviews regarding the lack of peer support as a disadvantage of the AHG was not unanimously verified, with some disagreement about this between participants. For example, Barbara confirmed this finding commenting in the verification document “disadvantages of home based programs: 1) deprives those that live alone a chance to socialise; 2) deprive the couple from having a break from one another”. However, Glenda commented during the video conference that in her experience the lack of peer support did not hinder her patient’s recovery commenting that her patients who did not attend groups “recovered well with the AHG”. Surprisingly, given the nurse participants’ earlier comments regarding their challenges with patient assessments conducted predominately over the telephone, they unanimously disagreed with my finding regarding the disadvantage of the AHG being the inability to increase or decrease the patients exercise intensity. Thus Barbara during the discussion at the video conference concerning the patient’s exercise intensity that:

This is what the program (AHG) is all about; this is why they (patients) choose to do it, because they can do their own exercises in their own time and space and they can increase it as they feel fit without someone pushing them to do it. That’s the idea of the whole program (AHG) so I don’t think it’s an issue.

The nurse participants’ discussion about my description of their experience regarding the regulation of patients’ exercise intensity suggests that the nurse participants recognized they may have a different working relationship with patients using the AHG than those attending a hospital based program and this difference related to control over administering and monitoring the patient’s use of the AHG. This leads onto the next Category (Category 4) regarding partnership and control.
4.3.4 Category 4: Partnership and Control

Working in partnership with patients involves the nurse facilitating the patient’s own decision-making by working in a mentor-supporting role (in partnership with the patient and spouse and engaging in shared-responsibilities between patient and nurse) rather than an expert-provider role (with the nurse being the expert and controlling the delivery of care). The AHG encourages the patient, supported by the nurse, to identify his/her own lifestyle changes, set goals and develop plans aimed at making the identified lifestyle changes. Andrea described this way of working with patients during her interview as “putting the patient in the driving seat of their own rehabilitation” and she described how her patients discussed their experience of this and how she perceived this process. She said:

They (patients) talk about having control. I, actually, in a professional practice think about it more as self-management, but for them, for a lot of people I deal with, they feel that other people have control over their health conditions. They feel like their cholesterol is their doctor’s business; their exercise is their cardiac rehab nurse’s business; but the AHG actually gives it all back to them and basically tells them, we can’t make you do any of this stuff. That is for a lot of people a revelation.

Several nurse participants described how patients were not always comfortable with this and discussed during their interviews their difficulties with patients who expected the nurse to take control. This was evident in nurse participants’ comments that patients tended not to identify their own goals or set their own action plans, expecting the nurse to do this for them. This resulted in a sense of frustration for the nurse participants as they struggled to empower patients to take responsibility. An example is from Claire, commenting angrily in her interview on her patients’ reluctance to complete their diary: “it actually requires them (patients) to do something, the AHG. It actually requires them to put pen to paper and make a
commitment, and I tell you they’re not good at it”. Glenda found that patients expected her to control the rehabilitation process saying in her interview: “well, I try to keep them in charge (of the rehabilitation process), but I think they sort of wanted to put me in charge.” Similarly Glenda and Claire found that patients wanted to pass control to her and she wondered during the interview if this was particular to rural patients:

I’d have to say perhaps its country clients but, yes, they expect (that) I’m the mother really and I’m taking control. And you hand them the information and (ask) have you read this and its like, “no” (pause). And it’s very frustrating.

Emma commented that in her opinion it was a generational problem and suggested that older male patients were more used to being directed than younger patients:

Younger people who’ve got ideas about where they want to be in life and where they’re going, they seem to get the hang of it (goal setting) pretty quickly. But my experiences of older men working with goal setting and identifying what they want to do, it’s kind of, well, you tell me what I’m supposed to expect, or how do I know what I am supposed to be trying to achieve; I’ve never had a heart attack or never had cardiac surgery so what am I supposed to be able to do or aim for?

Claire, despite her frustration with patients expecting her to take control and feeling she was sometimes wasting her time, was empathetic, even philosophical, wondering whether she would be the same if the positions were reversed (i.e. Claire as the patient):

I find it interesting, but also frustrating because I would sit here and sometimes think, well, what am I doing here (with a patient)? Am I just sort of (wasting my time)? Would I be exactly the same (if I was the patient)? I do think that and would I be like the same; I’d be just as bloody slack.
Claire suggested that a media campaign might assist patients in understanding partnership and control better, saying:

I was just wondering if it (the AHG) works and you’re going to use that particular program, you have to do some education on at-home programs as for the general public, like some ads on TV or a bit of a campaign. Because it might be all part of the chronic care preventative thing. People still think hospitals are Big Brother and they’re not used to the fact we’re making them take responsibility. And, I don’t know, I think it’s going to take a couple of years for them to get used (to) that whole self-education tool managing stuff at home.

Barbara, in her interview, given her tone of voice, appeared ambivalent about the lack of willingness to take control by her patients, commenting: “well, I’ve given them the options (rehabilitation choices) and, whether they’ve taken those options, it’s up to them”.

As much of the discussion to date reveals, although the AHG encourages the patient to ‘take control’ of their rehabilitation it also advocates that nurses take a facilitative role, one of shared responsibility working in partnership with the patient and family to support the rehabilitation process. However, it was evident from many of the nurse participants’ comments that some tended to perceive the AHG, advocating that the patient play a central role in their own rehabilitation, as an opportunity to shed this responsibility themselves while others found it difficult to hand over control to the patient. An example, is from Claire’s interview, talking about patients’ reluctance to use the diary:

Well, the thing is, it’s interesting that they’re expecting me to write out their diary. And it’s: no, you have to write your diary out. I don’t have time for that (the patient says). Yes, you do; you’re at home (Claire said to the patient). So they’re expecting they still do (sic), that the nurse or the hospital worker does all the stuff. And it’s like (Claire said): no, you’ve got to write out the diary, you’ve got to think about what you eat.
The term “you’ve got to” is used several times indicating the shift of responsibility from nurse to the patient. However, Emma reveals a much greater understanding of the notion of shared responsibility and working in partnership with the patient when describing in her interview how the AHG works in what she calls a “professional partnership”:

It gives an understanding to the patient and the nurse about the nature of the intervention, what it is about, what you (nurse and patient) are trying to achieve; it also made it (the AHG) very clear that we were working together, that I wasn’t doing things for the patient or to the patient or on the patient and that they were equal,

Andrea described her role with patients in her interview as a “mentoring role, as me as the guide sort of walking them through things, me being the point of clarification, somebody who can clarify things for them, a conduit”. The struggle for shared responsibility was acknowledged by Claire during her interview: “It’s hard not to just tell them (patients) what they should do or how they should do it.” Glenda suggested in her interview that she also found shared responsibility for goal setting with patients the “hardest thing to grasp” because she had difficulty with patients identifying goals she did not see as important or could not measure. Barbara also expressed difficulty during the interview in sharing responsibility, preferring to take control in goal setting if she thought it was necessary, as demonstrated here setting a patient’s goals for daily weight and the reduction of alcohol, despite the patient’s preference for alcohol:

I wrote down the goals because he had heart failure, so I wrote the goals to weigh himself every day; for (limiting his) alcohol, because he liked a bit of alcohol. And I think it was quite useful to him because even though he didn’t continue on with it (the AHG) I think it cleared the air and showed him that he had to do these certain things to, you know, be alert to his heart condition.
Barbara appeared to openly acknowledge during the interview her limited experience and knowledge of shared responsibility with her patients in the quote below, emphasised by the frequent use of the word ‘I’ or ‘I’ve’:

As long as they’re happy and I’ve created that service for them, that I’ve given them what’s available and they’re happy with that service, then that’s fine with me. You know that’s all we can ask for. I can’t ask for anything more than that.

The nurse participants did not confirm my findings at the video conference or in the verification document (Appendix 9) regarding power and control as an accurate reflection of their experience. Barbara commented at the videoconference: “from the first meeting there was an understanding between patients and myself that the patient took control of their own rehabilitation process”. Glenda commented during the videoconference: “that doesn’t really reflect my experience. I found they wanted to have some control but perhaps they didn’t want all the control; they still wanted to be guided”. Andrea was offended by my comment taken from the interview data in the verification document which stated: “Despite the intent, nurse participants experienced difficulty in ensuring patients took control of the process”. Andrea read this comment out loud at the video conference and argued that “control is a myth and you really can’t ensure anything when you are dealing with participants in rehab programs, I don’t think”. Emma commented about partnership and control in general terms in her verification document and related her comments to the AHG writing:

I face the challenge of working in partnership with patients daily. It is rewarding and satisfying when engaging in a good relationship, but equally frustrating and disappointing when patients expect the nurse to “do stuff” for or to them. To fix their health issue and/or make choices, which as nurses we may not agree with. The AHG is no different to many other health initiatives in this (supporting partnership). It is well
structured in supporting nurses with an evidence based program and encourages patients to participate actively in their health care but it is not a magic bullet—it (the magic bullet) has yet to be found.

Although the nurse participants did not completely verify my findings regarding power and control there was an acknowledgement from Claire and Barbara in their verification document that they agreed that patients had difficulty with goal setting. Claire suggested in her verification document that “patients tended to look (at Claire) with bemusement, most declaring they didn’t have time”. Similarly, although Barbara declared in the videoconference that she disagreed with my findings she commented in the verification document “all of the patients had difficulty in the concept of goal setting/achievement, plus writing them down in their book. Help (from Barbara) and some ideas for goal setting ideas were required”.

4.3.5 Category 5: Patient and Nurse Engagement with the AHG

Home based cardiac rehabilitation using the AHG requires the active engagement in the program from both patients and nurses to facilitate the patient’s recovery and rehabilitation. Category 5 relates to how the patient and nurse together engaged with the AHG itself and in the process of rehabilitation. Unlike Category 4, where the focus was the influence of power and control on the partnership relationship between patients and nurses, this Category’s focus is the AHG itself and how it supports partnership between the patient and nurse in the process of rehabilitation. The rehabilitation process using the AHG, according to the nurse participants’ interviews, was successful if mutual engagement\(^\text{25}\) occurred. It was evident from the interview data, particularly in relation to responses to my request to nurses that they

\(^{25}\) Mutual engagement describes the process of the nurse and patient working in partnership and is a term I have used here to describe this process.
describe an instance where their use of the AHG with a patient appeared to work well or not so well with lifestyle change. Emma described where the AHG worked well with herself and a patient using the AHG to support the patient with a walking program to increase his exercise:

I certainly used the AHG and it appeared to have some success in getting him back into a walking program, and he certainly used the AHG guidance about the intensity and frequency of exercise. I certainly used that (the AHG) as a back up to the advice and sort of say well, let’s look (at the AHG), let’s go back and see what we need to be doing there. He did have a lot of psychological problems: he had been widowed twelve months previously, he was working away from home, and he thought he would not be able to continue work, (pause) and the psychology aspect of it (the AHG) I would have expected would have been the more immediate value (to the patient) but it was the walking that seemed to be working for him through the (use of the) heart guide.

Glenda, when discussing opportunities she felt the AHG offered patients, described how she and a female, who on the surface appeared to have minimal risk factors, engaged over increasing the patient’s exercise level using the AHG:

Her blood pressure was good, and her activity she was already doing as much as she felt she should, but when I talked (to her) about increasing activity she was keen to do that (increase activity). So once we got down to goal setting she found it quite easy. So she got the goals down to I’ll walk 10 minutes daily this week and 20 minutes daily next week. Once we broke it (the physical activity goals) down a bit it was a lot easier.

It was evident in these instances that engaging with patients in the process of rehabilitation gave the nurse participants job satisfaction, as Andrea suggested in her interview: when the process works “it’s very, very rewarding”. Nurse participants also described instances where one or both parties were not engaged in the use of the AHG or the rehabilitation process and this resulted in anger, frustration and
dissatisfaction for both parties. An example, is from Claire, who said in her interview: “you hand them the information and when you follow up you ask have you read this? And it’s no, it’s very, very frustrating”.

Interestingly, all of the nurse participants described in their interviews successful mutual engagement with the AHG using the tools (rest-activity cycle, information booklets) they and, in their opinion, the patients preferred as discussed in Category 1. An example of this is from Andrea, who used the rest activity cycle with a gentleman who found physical activity a big challenge:

He had actually developed over the years a habit of, he would have an admission to hospital, have treatment, go home and he would be really good for three or four weeks and then he would lose interest and just become completely inactive again. So with the Aussie Heart Guide I was able to convince him to use the graduated physical activity template (rest activity cycle), and with the diary he took control and actually started slowly then building up (his exercise), formulating goals and then meeting those goals slowly building himself up. When I did a follow up a month after, he was still continuing with his exercise because he slowly built himself up and could sustain it.

Some nurse participants also described incidents where one or both parties were not engaged in the use of the guide or the process of rehabilitation and mutual engagement didn’t occur. This resulted in anger, frustration and dissatisfaction with the AHG, the rehabilitation process and with each other (patient and nurse). An example is from Claire when expressing frustration with a patient’s lack of engagement during her interview said: ”they feel guilty when they haven’t done their homework. I’ve (the patient) been busy. For God’s sake, I’m going to hit you with it if you don’t do something”. Andrea suggested in her interview that if patients refused to engage, “it was a communication issue” and it was up to the nurse to “find ways around that or to even abandon that type of guided therapy for
the patient”. Barbara suggested in her interview that rehabilitation, regardless of the program type, was a process: “It’s (rehabilitation) just a process you go through. They’ve all (patients using the AHG or attending a group), all gone through the same processes”. Barbara provided examples of lack of engagement from patients when describing in the interview when the AHG was unhelpful, commenting “they weren’t interested” in the relaxation tape or “no, I don’t think people like writing things down, recording things” discussing the diary. Interestingly, Barbara found that the more familiar she was with the AHG, itself, the more engaged she and her patients were. Describing here, how with her first patient, she struggled to explain and use the AHG but with familiarity and more explanation she felt she used it well with her second patient, Barbara commented: “probably I would explain things a bit better to them (patients about the AHG)... The last one (patient) was (a) bit better than the first”. Unsurprisingly, the nurse participants described a lack of engagement using the tools (diary, relaxation tape) they or, in their opinion, their patients disliked.

In relation to Category 5 as a whole (see the above) all of the nurse participants, in their verification document (Appendix 9) and at the videoconference, confirmed my findings regarding their sense of mutual engagement with the patient when using the AHG. Emma, in the verification document, concluded that: “when engagement between patient and nurse works, it’s great! When it doesn’t it’s hard not to rue the waste of time/resources and feel a failure. AHG participants (nurses/patients) are no different (in that both groups) feel a failure”. Barbara, in her verification document, disputed my understanding from the interview data that the nurses were frustrated with the lack of patient engagement commenting “the lack of engagement in (patients) reading the information was not one of frustration, more disappointing that the patient was not taking advantage of the useful and beneficial information given to them”.

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During the interviews the nurse participants identified factors that in their opinion influenced either patients or their own engagement with the AHG. The factors were identified through discussing the opportunities and threats to the use of the AHG for home based cardiac rehabilitation. These influences were related to physical, social, psychological and organisational factors and, according to nurse participants, were different for patients when compared to them. These influences have been separated into two sub-categories to Category 5.

### 4.3.5.1 Sub-Category 5.1: Nurses’ perceptions of influences on patients’ engagement with the AHG

This Sub-Category emerged as the nurse participants discussed aspects of patient engagement with the AHG. Evidence supporting patient engagement was reflected in the patient actively making lifestyle changes and engaging with the nurse participant in the rehabilitation process. Nurse participants discussed during their individual interviews factors that they felt influenced patient engagement. In reviewing the interview data there was a commonality of influences identified by the nurse participants and this formed this Sub-Category: Nurse Participants suggested that a patient’s engagement with the AHG was influenced by their previous experience of cardiac rehabilitation or knowledge of CAD (if any), their transition from hospital to home, and the patient’s illness experience. Several nurses suggested in their interviews that patients who had previously completed cardiac rehabilitation engaged well with the AHG because it offered something different from their previous experiences. Andrea gave a reason for this, suggesting:

> For a lot of people who have had a cardiac condition for a few years, some types of cardiac rehab (sic) (can) become repetitive, so the AHG gives the rehab nurse and the patient the chance to fill in the patient’s knowledge and the patient’s previous recovery attempts.
In contrast some nurses suggested that engagement with the AHG for patients who felt they had a good knowledge of CAD was limited. For example, Barbara suggested that the AHG was “just reinforcement, really” to patients who have had heart problems for some time and if patients “engaged with the program they would have got some good information.” Glenda agreed describing a similar experience to Barbara and said she gave the AHG to a gentleman “who took it (the AHG) away, looked at it and brought it back and said, no, it wasn’t for him, as he seemed to think he had all this information before.” Emma, sounding more positive said she felt that having a “program with a timeline” helped patients with chronic disease such as CAD engage:

It (the AHG) was a contracted term of intervention and so there was an expectation that this was the service and at the end of it that would be the end, and that’s the difficulty that I find with a lot of people who have chronic health problems and I know that’s not necessarily the people who are doing cardiac rehab (sic). But with my other hat (her role as in supporting people with severe chronic disease such as heart failure or airways disease to remain at home) with chronic disease, is that because it’s never cured there is an expectation that (from patients at home) the support and the information and advice is there forever. So I find that having a timeline and the actual program (the AHG) was really well defined, and had goals and had an exit, I thought was appropriate (in contrast to her experience of other home support programs which do not have a timeline or exit date).

The illness experience of the patient (positive or negative) influenced the patient’s engagement with the AHG. The transition from hospital to home was also raised as a factor in influencing patient engagement with the AHG. Patients who have suffered a myocardial infarction are usually cared for in hospital for between three and seven days; early in their admission they have constant nursing and medical supervision and monitoring, which reduces prior to discharge. Several nurse participants suggested in their interviews that the patient’s experience of the
transition from hospital to home influenced their engagement with the AHG. Emma argued in her interview that “the transition from a perceived high technological area such as a Coronary Care Unit to a low technology home program meant that the patient did not value the importance of lifestyle change” and therefore engagement with the AHG might be limited. Alternatively, Andrea suggested that the AHG gave the patient the impetus to seize control of their health condition because patients “feel that other people have control over their health condition but the Aussie Heart Guide gives it all back to them”. Andrea also felt that the AHG enabled the patient to:

Focus on their own thoughts about their condition and what has happened to them, the procedures they have undergone, and gives them a focus for where they’re heading to in the future and actually help them formulate goals around their health.

This focus, Andrea believed, helped influence the patient’s engagement with the AHG. Glenda, however, commented that the patient’s own misconceptions about their recovery from a myocardial infarction based on historical or anecdotal information might influence their engagement with the AHG:

Probably, the (patient’s) misconceptions about cardiac problems that people have, that you can’t, like once you’ve had a heart attack, you can’t do anything for six weeks and things like that (patients following a heart attack are encouraged to be active). So it (the AHG) explains to a lot of people what to expect afterwards. Because, I mean when I first started work back in the early eighties, I think when I did start my training, 1980, we used to rest people (who had heart attacks). They weren’t allowed even up to the toilet or if they had to go on a wheelchair; how things have changed.

The patient’s perceived severity of their illness impacted on their engagement with the AHG. The interview data highlighted that some nurse participants suggested
that patients who had minimal invasive procedures engaged less than patients who had more invasive procedures such as surgery. Andrea gave a reason for this saying:

Those (patients) with stents (minimally invasive procedure, short hospital stay and rapid resumption of activity) think there is nothing wrong with them, as opposed to those (patients) who have had heart surgery (highly invasive procedure, longer hospital stay and slow resumption of normal activity), who feel it’s major.

Claire elaborated on this comparing her experience with patients who had minimally invasive procedures to those patients who had cardiac surgery saying, “I find with stent clients you’ve got to convince them to actually do rehab (sic) at all because they don’t think that they need it and they’re all right, they don’t need anything.” She compared this to engaging with patients who have had cardiac surgery where complications or risk of death during surgery is greater than for those patients who have stents implanted commenting:

She (the patient who had heart surgery) had to deal with a lot of other issues with the whole death and dying thing before we (could) start rehab (commence using the AHG as there is limited information regarding death and dying in the guide and the patient may not be psychologically ready to make lifestyle changes).

Emma disagreed with Claire saying in her interview she found with one of her patients who had “complications who was also a very highly intelligent man”, that the ability to tailor the AHG to the individual influenced his engagement because it could be used to answer “hard medical, physiological and technological” questions.

In the verification document (Appendix 9) and at the videoconference, all of the nurse participants confirmed my description of their experiences regarding the influences in patient engagement. There were few additional comments regarding the specific influences on patient engagement, but in the verification document
Barbara commented “overall the patients’ engagement with the AHG was good whether they (patients) actively made lifestyle changes or just thought about them. All of them (patients) benefited from being involved in the program”. In identifying what influences patient engagement, the nurse participants also recognised what influenced their own engagement with the AHG and patients. This formed data that gave rise to Sub-Category 5.2.

**4.3.5.2 Sub-Category 5.2: Nurses’ perceptions of what influenced their engagement with the AHG**

Engagement for nurse participants involved supporting patients to use the guide, working in partnership with the patient to change their lifestyle and embracing the rehabilitation process. The nurse participants’ interviews revealed that their engagement with the AHG was influenced by how the patient was recruited to use the guide. Patients who used the AHG for their home based cardiac rehabilitation were either recruited by choosing the guide as an option instead of hospital based rehabilitation or being offered the program if accessibility to a local program was limited. Recruitment of patients may have been undertaken by the AHG nurse mentor as part of the patient assessment (either face to face or over the telephone) or a third party such as a nurse working within the hospital setting who offered the patient the program prior to discharge. Recruitment of patients to use the AHG was mentioned in several nurse participants’ interviews as influencing their engagement with the AHG and patients. It appeared from the interview data that if recruitment was done by a third party this affected how they (the nurses) engaged with patients. Poor engagement occurred especially if, in the nurse participant’s opinion, the AHG was not appropriate for the patient for whom it had been selected, as described here by Andrea: “so if the AHG, if you like, falls into wrong hands (inappropriate patient) then it’s basically a useless tool”. Andrea was critical about the ability of the recruiting third-party to assess “appropriate” patients, suggesting that only a
specific type of patient should be given the AHG:

The only weakness, and I am not sure that it’s a weakness of the Heart Guide (AHG); I think it’s more a weakness of recruitment, because it is dependent on the recruiting nurse being able to assess the patient correctly or adequately judge whether the patient is actually going to be motivated enough to use the tools of the Heart Guide.

The AHG as a program was new to all of the nurse participants and several nurse participants, commented in the interviews that they found the AHG time consuming to use with patients and this influenced their engagement with the program and patients. The time needed to introduce it to the patient was a negative influence on the willingness of the nurse participants to use the guide. Claire, in her interview, appeared quite angry about the amount of time needed to introduce the guide to patients commenting:

(The time (it takes) is a disadvantage because you have to weave your way in before you can actually present it (the AHG to the patient). No matter what that pommy bloke said (English trainer for the AHG), I don’t know, but with Australian clients you cannot just do it (the rehabilitation process and use of the AHG) in an hour.

Emma, also found using the AHG time consuming, saying, “I found that the initial interview was probably just a little bit too pressured; perhaps with time and experience it might have been a smoother transition for patients.” Barbara agreed with Emma and Claire saying “it’s time consuming, it’s very time consuming”, but she found the AHG less time consuming the more she used the guide, commenting that “it got easier the more I used it, put it that way”. Glenda said in her interview that she allowed more time for patients using the AHG but suggested the extra time was because of the needs of her patients rather than the AHG itself, saying she “had to negotiate” more with cardiac clients. Andrea accepted that the AHG was time consuming to use with patients and suggested in her interview that this may be
because of the time it may take to develop the relationship with the patient to enable both to engage with each other; this she calls “person-centred care”, which she defines as:

To me, it means working with the client where they are. Whilst I have a lot of information that I want to give them, and I have a lot of targets that I want them to reach for, and I have a lot of actions that I want them following, if I just pour all that information on top of them there and they’re not ready to receive it, then we are both just wasting our time. So, often it can take a few weeks to build up a relationship with that client, so that’s where my person-centeredness comes from. It’s working with them where they are and what they’re actually ready to do. With some people I have to go really, really slow (sic).

The nurse participants’ experience with hospital based cardiac rehabilitation appeared to influence their engagement with home based cardiac rehabilitation using the AHG. Home based cardiac rehabilitation itself was a new concept for the nurse participants, many of whom worked with hospital based cardiac rehabilitation or had experience of hospital cardiac rehabilitation. Interestingly, several nurse participants suggested that the AHG might be a threat to the existence of hospital based programs and highlighted the potential for antagonism between hospitals based cardiac rehabilitation programs and home based cardiac rehabilitation programs as each attempted to attract patients. Andrea suggested in her interview that hospital based cardiac rehabilitation nurses might feel threatened by the emergence of the AHG because funding for cardiac rehabilitation might be redirected towards the AHG rather than hospital programs saying:

I should imagine that the AHG could be seen as a threat by centre based services. Some services may see it as a replacement-type therapy, so I could imagine that some rehab services might be reluctant to use it or offer it.
The nurse participants did not unanimously verify my findings about their experience regarding the influences on their engagement with the AHG; however the nurse participants did identify other influences on their engagement with the AHG. An example regarding the disagreement among nurse participants that the AHG was time consuming to use came from Glenda and Barbara. Glenda argued at the videoconference “It didn’t take any longer to use the AHG than it did for planning and conducting group sessions, whereas in her verification document Barbara wrote “it was time consuming, one had to be persistent with telephone calls”. The potential of antagonism between hospital and home based programs was disputed by Emma in her verification document (Appendix 9), commenting: “the AHG is an expensive but no less valid option for cardiac rehabilitation”.

The nurse participants within their verification document and at the videoconference suggested that the main influences on their engagement with the AHG was the challenge of learning a new program and new techniques with patients and patient attitudes. Andrea commented at the video conference “the true challenge for most of us (nurses) was actually learning new ways of establishing therapeutic relationships”. Emma, who did not attend the videoconference, similarly commented in her verification document: “my main problem with engagement with the AHG was the short psychological component and the motivational interviewing skills”, which she was taught as part of the training in working with patients using the AHG and which she said “despite attendance at many courses, I have difficulty with”. On reflecting on her use of the AHG in this Category, Claire in her verification document commented on partnership and patients’ attitudes saying:

The Aussie Heart Guide is the way of the future; it does require a change in the way the population thinks. Hopefully with the preventative care business etc. (health focus on prevention and self management) patients’ attitudes may change, but it will take time.
4.4 Conclusion

This chapter has discussed the findings from the patient and spouse questionnaires, the nurse participant interviews and the verification of my findings from the nurse participant’s interviews. The findings from the patient and spouses questionnaires were related to usefulness of the AHG, their relationship with the AHG nurse mentor and their likes or dislikes about the AHG.

Analysis of data from the nurse participant’s interviews gave rise to several categories and sub-categories. The categories were: usefulness of the AHG; challenges in the nurse/patient relationship when using the AHG; advantages and disadvantages of home based cardiac rehabilitation using the AHG; partnership and control; and finally, patient and nurse engagement with the AHG. The sub-categories were usefulness of the AHG in supporting nurses, usefulness of the AHG in supporting patients with their recovery and lifestyle change; challenges of telephone only contact in nurse/patient communication and finally nurses perceptions on what influences their own and their patients engagement with the AHG.

Verification of my findings from the nurse participants’ interviews was varied. The majority of my findings in the categories and sub-categories were verified by the nurse participants. Nurse participants verified my findings in relation to Category 1 and its two sub-categories regarding the usefulness of the AHG to patients and nurses. Nurse participants also verified Category 2, the challenges of nurse/patient relationship when using the AHG, and Sub-Category 2.1 relating to predominately telephone contact impacting on their ability to accurately assess patient’s needs. The majority of nurses verified Category 3, the advantages and disadvantages of home based cardiac rehabilitation using the AHG but there was some disagreement regarding verification of aspects of this Category. Category 5: patient and nurse
engagement and Sub-Category 5.1: patients influence on engagement was also verified by the nurse participants as being an accurate reflection of their experience.

Nurse participants did not verify Category 4 – Power and Control, and some findings within other categories (Category 2: the issues of lack of patient honesty in communication and the nurses’ ability to increase or decrease exercise in Category 3). In addition, there was disagreement amongst the nurse participants about the issues of patient choice and peer support in Category 3, with some nurses verifying my findings while others did not. Similarly in Sub-Category 5.2 there was also disagreement among nurses regarding whether or not the AHG was time consuming to use with patients.

In the final chapter of my thesis the findings reported in this chapter will be discussed in relation to the literature. Implications of the study for nursing practice and the wider community are also identified. The limitations of my study are next outlined and suggestions made for opportunities for further research. The chapter closes with a reflective conclusion of my study overall.
Chapter 5

5.0 Introduction

The aim of my study was to understand and describe the experience of patients with CAD, their spouses and nurses using the AHG to support home based cardiac rehabilitation by asking them to describe this experience. In this chapter, I discuss the findings of my study in relation to the literature which formed the study’s conceptual framework. This will be followed by an outline of the implications of my findings, recommendations emerging from it, limitations of the study and concluding comments about the study overall.

This discussion takes place in relation to the three themes and their related sub-themes which emerged from the literature: 1) the experience of CAD on patients and their spouses; 2) influences on the patient, spouse and nurse experience of home based cardiac rehabilitation; and 3) partnership between the patient, spouse and nurse in home based cardiac rehabilitation. These three themes and their related sub-themes will be used as headings under which the findings from my study will be discussed. In the introduction to each theme reference is made to my study’s objectives. The experience of CAD on individuals and their spouse will be discussed first.

5.1 The experience of Coronary Artery Disease for the patients and their spouses

Coronary Artery Disease (CAD) “is a chronic condition that requires ongoing management over a period of years” (Thomson, et al., 1995, p. 514; World Health Organisation, 2002) and has a significant impact on the individual and their spouse. Home based cardiac rehabilitation has demonstrated effectiveness in improving
patients’ clinical outcomes, improving quality of life and reducing anxiety and depression (Dalal, Zawada, Jolly, Moxham, & Taylor, 2010). However, little is known about the patient and spouse experience of home based cardiac rehabilitation.

This gap in the research was one of the motivators for me to undertake this study and is reflected in my studies first two objectives: 1) to describe the patient’s experience of home based cardiac rehabilitation using the AHG with support from an AHG nurse mentor and 2) to describe the spouse’s experience of home based cardiac rehabilitation using the AHG with support from an AHG nurse mentor. The third objective of my study relates to the nurse’s experience of home based cardiac rehabilitation and will be discussed later in this chapter. My fourth objective was to evaluate the usefulness of the AHG for lifestyle change and disease management and is discussed on page 39. Within the literature relating to the experience of patients with CAD and their spouses (discussed in Chapter 2) there were four sub-themes 1) impact of anxiety and depression on the patients experience of CAD, 2) impact of gender on the patient experience of CAD, 3) impact of age on the patient experience of CAD, and 4) impact of CAD on spouses experience. These sub-themes will be used to discuss the experience of patients and spouses included in my study. However, due to a limited amount of information sub-themes two and three regarding the impact of gender differences and patients’ age were merged for the purpose of this discussion. In discussing the experience of patients with CAD and their spouses using the AHG for home based cardiac rehabilitation it is important to note that there were only four patients and three spouses who took part in my study, therefore my findings from this participant group are limited. Further, to aid this discussion, findings from the nurse participants’ experience relevant to the discussion regarding the experience of patients with CAD and their spouses’ experience using the AHG is included.
5.1.1 Impact of anxiety and depression on the patient experience of CAD

Symptoms or a diagnosis of anxiety and depression can impact on a patient’s quality of life, their experience of CAD and cardiac rehabilitation, and are common in patients with CAD (Januzzi, Stern, Passternak, & DeSanctis, 2000; Ziegelstein, et al., 2000; Sirois & Bung, 2003; Yousaf, et al., 2004; Moser, et al., 2007; Rees, et al., 2007). The AHG has specific tools to support patients psychologically including a relaxation CD and information regarding anxiety and depression. My study did not specifically ask participants about their experience of anxiety or depression or their use of the relaxation tape but, nevertheless, patients’ commented positively about the psychological support they received from the AHG and their nurse mentor. Patient participants suggested that the psychological support provided by the AHG and their nurse supporting them during this program was useful. The patients’ positive experience regarding their psychological welfare was demonstrated in the positive comments about what patients liked about the AHG and their additional comments regarding their own personal outcomes related to their psychological welfare. A review of psychological interventions that benefit patients with CAD by Rees, et al., (2007) demonstrated similarly that patients benefit psychologically from cardiac rehabilitation through a reduction in the incidence of anxiety and depression. Rees, et al.’s (2007) review concluded that stress management to assist patients with managing their psychological welfare and reducing anxiety and depression should be an integral component of cardiac rehabilitation.

The aim of the AHG relaxation CD is to assist patients with stress management. Patient participants did not comment on their experience with the relaxation CD but the nurse participants reported mixed results. Some nurses found that patients used the tape and benefited from relaxation as part of their program, whereas other nurses reported that patients commented they did not like or use the relaxation tape. My findings are similar to other studies which found that implementing stress
management programs in cardiac rehabilitation is challenging due to the individual patients’ perceptions of stress management and limited nursing skill and knowledge in relation to stress management techniques (Sundin, et al., 2003; Lacey, Musgrave, Freeman, Tod, & Scott, 2004; Carless, Douglas, Fox, & McKenna, 2006).

Psychological support for patients attending hospital cardiac rehabilitation may also be enhanced by support from other patients. Peer support, that is support patients receive from other patients, was identified by the nurses within my study as assisting in improving patients’ psychological well-being. The lack of peer support for patients using the AHG was identified by the nurses as a disadvantage of the program. Despite the AHG being designed to be used predominately over the telephone with patients and to be an alternative program to hospital based cardiac rehabilitation, one patient in my study appeared to complete both a hospital based program and the AHG, evidenced by his comment that the support he received from the group was also beneficial. The literature supports the benefits of peer support on patients’ psychological and physical well-being; one of the benefits of group programs that patients rated highly is the camaraderie they have with others in the group who are sharing the same experience (Clark, et al., 2004; Jones, et al., 2009; Clark, et al., 2012). However, Jones et al., (2009) found similarly to my study that patients who participated in a home based rehabilitation program were positive about their experience and did not voice they had missed out on peer support by doing home based cardiac rehabilitation. However this may have been because they have no experience of group rehabilitation and peer support. From this, the impact of not being able to attend a group as part of the rehabilitation program appears inconclusive. Nevertheless, the findings from my study add to the literature regarding peer support within cardiac rehabilitation, although further studies are needed.
5.1.2 Impact of gender and age on the patient’s experience of CAD

The patients’ and their spouses’ experience of cardiac rehabilitation can be impacted by gender differences and the patients age (Dixon, et al., 2000; Moser & Dracup, 2004; Svedlund & Danielson, 2004; Worrall-Carter, et al., 2005; Bowman, et al., 2006; Thombs, et al., 2006; Smith & Liles, 2007; Budnick, et al., 2009). The small number of patients and spouses included in my study limited the amount of information I was able to obtain regarding the usefulness of the AHG to women, the elderly and younger patients. This is disappointing as there is a wealth of evidence reporting that these groups are excluded from cardiac rehabilitation (Beswick, et al., 2005; Kardis, et al., 2007; Smith & Liles, 2007; Budnick, et al., 2009). Further research is needed, to explore if home based cardiac rehabilitation using a program like the AHG is useful to these under-represented groups of patients, particularly as the literature suggests programs like the AHG may be a viable alternative to hospital based rehabilitation for women, the elderly and younger patients (Briffa, et al., 2009; Neubeck, et al., 2012). The nurses within my study however identified that the patients age may have an impact on the usefulness of the AHG for lifestyle change and disease management.

The age of the patient and their computer literacy may influence how useful patients and spouses find the AHG for lifestyle change and disease management. In my study the AHG was found to be useful to all of the patients regardless of age, evidenced by the positive comments and rating on the Likert rating scale regarding usefulness of the AHG for lifestyle change and disease management. The nurses, however, discussed the usefulness of the AHG in the context of computer literacy for patients. Similarly to nurses in a study by Bowles & Baugh., (2007), some nurse participants expressed a perception that elderly patients were not computer literate and this made the AHG less useful to them. The patients in my study did not comment specifically on the computer resources but did comment that they found
the resources provided as part of the AHG useful and two of these were elderly patients (aged over 65 years). The literature suggests similarly that nurses underestimate computer literacy in the elderly, as several studies have demonstrated that the elderly embrace technology such as computer resources (Chumbler, et al., 2004; Clark, et al., 2007; Inglis, et al., 2010), which would suggest the nurse participants’ perceptions in my study are not supported.

5.1.3 Impact of CAD on spouses’ experience

Spouses have a pivotal role in supporting patients with CAD (Stewart, et al., 2000; Svedlund & Danielson, 2004). They assist the patient in their management of a chronic illness and managing subsequent lifestyle change, while also supporting their emotional needs. Patients and their spouses are reported to experience similar emotions such as fear, anxiety, guilt and loss of control (O’Shea, et al., 2002; Berkman, et al., 2003). Spouses complain of being excluded from the patient’s recovery process and cardiac rehabilitation despite a desire to attend (Timmins & Kalisner, 2003; McLean & Timmins, 2007). None of the AHG nurse mentors in my study, all experienced cardiac rehabilitation nurses, make any comment in their interviews about spouse’s involvement in home based cardiac rehabilitation using the AHG or their role in supporting spouses. Findings from spouses about their experience are limited in my study as only three spouses chose to participate and only two commented on their experience by completing the questionnaire. However, from the responses of these two spouses using the AHG for home based cardiac rehabilitation their experience appears to have been positive. These two spouses found the information contained in the AHG useful in helping them to support their partner/husband, however their contact with the AHG nurse mentor appears less useful. McClean and Timmins (2007) found that spouses complained that the information they received from nurses about their husband/partners illness was not individualised, and that nurses provided information to the spouse based on what
the nurse thought the spouse needed to know. In contrast, my study found that spouses had a positive experience with the information contained in the AHG, because they commented that what they liked most about the AHG was it assisted them to understand what their partner/husband had to do and what was needed for their recovery. From this it seems, for these respondents at least, that the information contained in the AHG was useful.

Some researchers found spouses complain of being excluded from hospital based cardiac rehabilitation and contact with cardiac rehabilitation nurses (Timmins & Kalisner, 2003; McLean & Timmins, 2007). Little is known about spouse experience or involvement in home based cardiac rehabilitation or their contact with cardiac rehabilitation nurses. My findings were that one spouse found their contact with the AHG nurse mentor useful and another spouse commented that she had “very little” contact with the AHG nurse mentor. Spouses also reported how much contact their partner/husband had with the AHG nurse mentor and the frequency of contact reported was consistent within couples. Given the limited number of spouses within my study I am unable to draw any conclusions from my findings regarding the involvement of spouses in home based cardiac rehabilitation and contact with the AHG nurse mentor. This is disappointing as there is a specific section for spouses within the AHG which has had no formal evaluation.

The experience of CAD on individuals and their spouses has been found to have an impact on their relationship as a couple (Moser & Dracup, 2004; Svedlund & Danielson, 2004; Mahrer-Imhof, et al., 2007) with regard to how they communicate with each other, their relationship and subsequent living with a chronic illness such as CAD. Given the small number of spouses who participated in my study, it is not possible to draw any conclusions about their experience of CAD and its effect on their relationship with their husband/partner. There was however a difference in experience of home based cardiac rehabilitation between couples in my study. One
couple, according to their responses, appeared to work together for the patient’s improvement, evidenced by their positive experience of the AHG. The spouses overall comment suggested “they had got the result they were looking for” and their similar positive responses regarding the usefulness of the AHG and the nurse mentor indicated that the couples were working together. In comparison another couple appeared to have a different experience, with their responses indicating a less than positive experience for the spouse and little consistency in responses between patient and spouse. Couples describe their experience of the aftermath of a myocardial infarction (heart attack) and subsequent living with CAD as challenging, having a positive and in some cases a negative effect on their relationship (Moser & Dracup, 2004; Svedlund & Danielson, 2004; Mahrer-Imhof, et al., 2007). The impact of a positive or negative effect of CAD resulted in the couples feeling “togetherness or disenchantment” about their relationship and each other depending on their experiences of CAD and cardiac rehabilitation (Mahrer-Imhof, et al., 2007, p. 514). My findings, although limited support the findings of other studies that there needs to be more involvement of spouses in home based cardiac rehabilitation.

Nurse participants in my study failed to acknowledge the role of spouses and the usefulness of the AHG in supporting spouses to support patients in their lifestyle change and recovery. These nurses apparent lack of involvement with the spouses in their patients’ lifestyle management is not surprising given the evidence demonstrating spouses’ lack of involvement in cardiac rehabilitation (Svedlund & Danielson, 2004). It appears overall that increased education and guidance about supporting spouses in their partner’s rehabilitation would assist nurses to work alongside spouses in this process. Involving spouses in cardiac rehabilitation (hospital or home) has been found to have a beneficial impact on patients’ recovery (Jones, et al., 2007).
5.2 Influences on the patient, spouse and nurse experience of home based cardiac rehabilitation

Home based cardiac rehabilitation programs have demonstrated effectiveness in improving patient’s quality of life, reducing patient risk factors and morbidity from CAD (Jolly, et al., 2006; Dalal, et al., 2010). The aim of my study was to describe and understand the patient, spouse and nurse experience of home based cardiac rehabilitation, because despite the evidence discussed demonstrating effectiveness of programs, little is known about the experience of these participant groups. Within the literature four sub-themes emerged as influencing the patient, spouse and nurse experience of home based cardiac rehabilitation: 1) the patient, spouse and nurse experience of cardiac rehabilitation, 2) patient, spouse and nurse engagement with home based cardiac rehabilitation, 3) use of telehealth for home based cardiac rehabilitation and 4) patient, spouse and nurse experience of telehealth. These sub-themes will be used as headings for the following discussion with sub-themes three and four merged into one heading, namely the patient, spouse and nurse experience of telehealth when using the AHG for home based cardiac rehabilitation. The discussion in the following section is in relation to Objective 1) and 2): to explore the patient, spouse experience of home based cardiac rehabilitation with support from a nurse mentor using the AHG, Objective 3): to explore the nurse experience of home based cardiac rehabilitation using the AHG and Objective 5 ): to describe nurse patient engagement with the AHG.
5.2.1 The patient, spouse and nurse experience of home based cardiac rehabilitation

Patient participants in my study described a positive experience of home based cardiac rehabilitation when using the AHG which they attributed to the amount of information in the guide and their ability to monitor their own progress with the patient diary. There were no negative comments about the AHG or their experience of home based cardiac rehabilitation. The patients’ positive experiences were evidenced by their rating the AHG as very useful to their recovery on the Likert scale and by positive comments in general about their experience. None of the patients rated the AHG as not useful in helping them with their recovery. Jones, Greenwood and Jolly (2009) in their study regarding the patient experience of hospital and home based cardiac rehabilitation found similar findings to mine in that all patients in her study had a positive experience of home based cardiac rehabilitation (using The Heart Manual). Patient participants stated that the amount and type of information they received from the AHG, was adequate and valuable for their recovery.

In contrast, some nurse participants said that they were concerned when first giving the AHG to their patients that it contained too much information for the patient. However, these two findings are also consistent with other studies exploring information needs of patients with CAD, which have demonstrated patients require more information than nurses anticipate (Scott & Thompson, 2003; Timmins & Kalisner, 2003; Timmins, 2005). Jones, et al., (2009) found that patients thought that home based cardiac rehabilitation was a self improvement/monitoring program, which they felt was more useful than a hospital based program which they understood to be a short term treatment. This is also reflected in the patients’ positive experience of using the AHG; my findings indicated their experience of home based cardiac rehabilitation was enhanced by the opportunity to monitor their
progress and recovery through the use of the diary and subsequent action plan.

Regular contact between patients with CAD and nurses, can improve patients’ quality of life and improve patient outcomes when compared to no or limited contact with a nurse (Debusk, et al., 1985; Beckie, 1989; Jolly, et al., 2006; Inglis, et al., 2010). Similarly, to other studies (Debusk, et al., 1985; Beckie, 1989; Inglis, et al., 2010) patients in my study found that contact with the AHG nurse mentor was useful. The impact of the contact with the AHG nurse mentor in terms of improving patient outcomes is unknown, because my study was not designed to explore this and the patient numbers included in the study were small. My findings however demonstrate that patients in my study found the individualised approach to their health information needs combined with the AHG nurse mentors knowledge about CAD enhanced their experience. This finding was despite my lack of knowledge regarding the length and nature of the patient/nurse contact and evidenced by positive comments from two patients regarding their contact with the AHG nurse mentor. Recent studies have demonstrated similarly that an individualised approach to sharing of health information as used with the AHG is more beneficial to patients than a didactic approach (Timmins, 2005; McLean & Timmins, 2007).

Nurse participants in my study were positive about their experience of using the AHG as the structure of the guide assisted them to support patients, whatever their experience of cardiac rehabilitation. These nurses found the structure of the AHG useful in supporting them to support patients in lifestyle change and disease management. The support provided in the Guide and incorporated with it for those delivering the AHG was of most benefit to those nurses who were inexperienced in cardiac rehabilitation. Even if the nurse was experienced in cardiac rehabilitation the AHG was useful in assisting them to support patients. An example of this is from one nurse participant who suggested “it’s (the AHG) user friendly and worker friendly”. Other studies have demonstrated that cardiac rehabilitation nurses need
support and education to deliver evidence based programs (Davis, Jankovitz, & Cooper, 2001; Conway, McMillan, & Solman, 2006; Fernandez, et al., 2011). However to my knowledge this is the first study which has found that the structure of a home based program is beneficial as a support mechanism for nurses as well as patients.

Studies have demonstrated that hospital based cardiac rehabilitation nurses lack the ability to individualise their programs based on patients’ expressed need (Lau-Walker, 2004b; Fernandez, et al., 2011; Madden, et al., 2011). My study found that the structure of the AHG assisted the nurses to individualise programs for patients according to their needs rather than what the nurse thought the patient should know. This was in contrast to the nurse’s experience of delivering cardiac rehabilitation without the AHG. An example of this is from Claire describing how she developed a program for patients prior to using the AHG:

Well, not using the AHG, I’m setting up the program (with the patient) and I go ok well I’ll be discussing this (e.g. CAD) with you and in the next (session) we’ll be looking at your medications and we’re looking at this (e.g. diet, lifestyle) we’re looking at that (e.g. anxiety depression). And I tell them the plan of the program and then work out a suitable time (for the session).

Similarly Lau-Walker, (2004a) found that nurses delivered cardiac rehabilitation according to their own expectations of patient needs and the need to provide a service (Lau-Walker, 2004a). Wellard, (2007) suggests that providing individualised care to patients is a challenge within the constraints of modern health care; however my study demonstrates that the structure of programs like the AHG may support nurses to individualise care for patients. In the case of the AHG, the program, despite being a structured one is designed to be facilitated by negotiation, discussion and the active involvement of the individual patient so as to meet their individualised needs (Bidmead, et al., 2002).
Offering patients a choice of program (hospital or home) is a state priority within NSW hospitals (NSW Department of Health, 2006b). Patients in my study were therefore asked why they chose the AHG for their cardiac rehabilitation. My findings indicated that patients within my study were not given a choice of program, which is consistent with the literature suggesting that patients are rarely offered an informed choice regarding their rehabilitation (Madden, et al., 2011; Neubeck, et al., 2012). One study found that even if patients are offered a choice of program, home based cardiac rehabilitation is often offered as the default option when a patient is unable or unwilling to attend hospital cardiac rehabilitation (Wingham, et al., 2006). It is not clear from my study findings if patients were offered the AHG for home based cardiac rehabilitation as a default option, rather it appears from their comments that it was the only program offered to them. Nevertheless, one patient appears to have made an informed choice as Mary said she was “guided by the sister at the local hospital” as to which program would be useful.

Studies have demonstrated that offering patients a choice of program does not improve patient outcomes such as a reduction in anxiety and depression or improvements in their risk factor profile, but does increase attendance and completion of cardiac rehabilitation (Grace, et al., 2005; Dalal, et al., 2007). My study found that despite their lack of choice of program patients had positive perceptions of the benefit of the AHG and therefore may have been more willing to complete their program. In contrast Dalal., et al. (2007) and Grace., et al (2005), found that patients completing home based programs were positive about their experience and more likely to complete the rehabilitation if they were offered a choice of program.
5.2.2 Patient, spouse and nurse engagement with home based cardiac rehabilitation

While patient engagement with hospital cardiac rehabilitation has been found to be poor with less than 30% of referred patients completing their program, little is known regarding engagement with home based cardiac rehabilitation or nurse engagement with programs like the AHG (Beswick, et al., 2005). Therefore Objective 5 of my study was to describe patient and nurse engagement with home based cardiac rehabilitation when using the AHG. Engagement for nurse participants in my study involved supporting patients to use the guide, working in partnership with the patient to change their lifestyle and embracing the rehabilitation process. This was demonstrated when they described how they worked with patients using the AHG and discussing the challenges of working with patients. There appears to be a dearth of information relating to the positive and negative influences impacting nurses’ engagement or non engagement with a home based cardiac rehabilitation. Engagement by patients is identified by the completion of the sessions (over the telephone), using the AHG resources and changes in the patient’s lifestyle or management of their illness. Patient engagement with a home based cardiac rehabilitation program has been shown to be better than patient engagement in a hospital based cardiac rehabilitation program (Jolly, et al., 2006; Dalal, et al., 2007). Several studies have explored what influences patient engagement with hospital based programs however there is limited literature regarding patient engagement with home based programs (Jones, et al., 2007; Neubeck, et al., 2012). Patients in my study unfortunately did not specifically comment on their engagement with the AHG, however nurse participants discussed what they perceived influenced their patient’s engagement and these perceptions are the basis of my discussion.
5.2.2.1 Influences on patient engagement with the AHG

Patients had only positive comments regarding their experience of the AHG, indicating good engagement for patients involved in my study using the AHG; however the nurses’ experience about the patients’ engagement in the AHG was varied. The nurses identified factors they perceived influenced the patient’s engagement with the AHG which included previous experience of cardiac rehabilitation (if any), their transition from hospital to home and the patient’s illness experience. Although these factors were not highlighted in my patient findings, possibly due to the limited numbers of patient participants, they were reiterated by the nurse participants during the interview data verification process and are supported by the literature (Beswick, et al., 2005; Neubeck, et al., 2012).

The nurses perceived that an influence on patients’ engagement with the AHG was patients’ previous experience of cardiac rehabilitation (if any) and their pre-existing knowledge of CAD. Nurses suggested that patients who had previously attended hospital based cardiac rehabilitation found the AHG offered them something different and reinforced their previous knowledge about their illness and recovery. Few of the studies exploring hospital based cardiac rehabilitation engagement appear to have found that previous experience of cardiac rehabilitation has influenced patient engagement (Beswick, et al., 2005; Jones, et al., 2007; Jones, et al., 2009). Therefore offering patients who have previously attended a hospital program a home based program such as the AHG may assist in improving the uptake of cardiac rehabilitation. In contrast however the nurses also perceived that for some patients pre-existing knowledge of CAD influenced their engagement with the AHG. This was evidenced by a comment from a nurse participant who gave the AHG to a gentleman who “took it (the AHG) away, looked at it and brought it back and said, no, it wasn’t for him, as he seemed to think he had all this information before”. Neubeck, et al., (2012) in their systematic review into participation in cardiac
rehabilitation, also found that an influence on patient participation was their existing level of knowledge of CAD and thus the perceived extent of benefit of the program.

Nurse participants also identified that the patient’s transition from hospital to home influenced patient’s engagement with the AHG. The transition from hospital to home is often a source of anxiety or jubilation for patients and influences their illness and rehabilitation experience (Bowman, et al., 2006). Nurse participants suggested that patient engagement was influenced by the patient’s experience of hospital and their subsequent discharge home. Other studies reported similar patient factors such as ill health, fear and perceived lack of benefit influenced patients’ engagement to hospital based cardiac rehabilitation (Jones, et al., 2007; Neubeck, et al., 2012). This finding regarding the influence of the patient’s transition from hospital to home on a patient’s engagement with home based cardiac rehabilitation adds to this body of knowledge.

5.2.2.2 Influences on nurse engagement with the AHG

The factors that influenced nurses to engage or to not engage with the AHG were patient selection, patient engagement and the time constraints of using the AHG. All of the nurses commented on the process used to recruit patients to the AHG and suggested that for some patients it was an inappropriate program for their needs. However, the judgement of the appropriateness of the AHG for particular patients appeared to be based on the nurse’s skill, knowledge and experience regarding suitability of the program, and it was not clear whether or not discussion with the patient about their rehabilitation preferences had occurred. The nurses’ judgement about program suitability appeared to be influenced by the age of the patient (some nurses thought the AHG was not suitable for the elderly) and the nurses’ perceptions of how the patient engaged with them (rapport, communication and goal setting). The literature identified that patients are rarely consulted about their
options in relation to cardiac rehabilitation (Leung, Brual, Macpherson, & Grace, 2010). Although, more generally focusing on nursing care, Henderson, (2003) also found that nurses made decisions regarding nursing care without consultation with patients with the prevailing belief being that nurses know best, based on their expert knowledge. Similarly Lau-Walker, (2004a) found that cardiac rehabilitation nurses relied on their own interpretation of the importance of a patient’s expectations and this was influenced by their own beliefs of what the patient’s needs for cardiac rehabilitation were. Therefore further investigation is needed on how cardiac rehabilitation nurses assess appropriateness of programs for patients (Leung, et al., 2010).

Some participants’ comments identified that facilitating the AHG with patients appeared to be time consuming, a feature that appeared to influence nurses’ engagement with the AHG. Jones (2013) explored the impact of time on registered nurses workload and found that time pressures impacted on nurses’ work and have negative consequences for patients. This was reflected by some of the nurse participants in my study who felt that the AHG was more time consuming to use with patients than they initially anticipated. It was not clear however how much of an influence this was in the nurses’ decision to offer the patient the AHG. One participant emphasised this when saying:

[The] time [it takes] is a disadvantage because you have to weave your way in before you can actually present it [the AHG to the patient]. No matter what that pommy bloke said, I don’t know, but with Australian clients you cannot just do it [the rehabilitation process and use of the AHG] in an hour.

Some of the nurse participants in my study expressed a preference for hospital cardiac rehabilitation based on how time consuming the AHG was to use and suggested that this may influence their engagement with the AHG. However not all
nurses perceived the AHG to be more time consuming than hospital based cardiac rehabilitation with one stating “It didn’t take any longer to use the AHG than it did for planning and conducting group sessions”.

The nurses suggested that the AHG was time consuming because of the need to work in partnership with the patient using open communication. In a partnership both parties discuss, negotiate and agree a plan of action. Nurses in my study found negotiation and open discussion time consuming and challenging especially if communication with patients was via the telephone. Similarly other studies have found that offering patients a choice in nursing care and open communication was time consuming (McCabe, 2004; Eriksson & Nilsson, 2008). However, McCabe (2004) found that even if more time is available, nurses did not practice open communication. Further education and support for nurses in regard to open communication and negotiation with patients may assist in nurse engagement with programs like the AHG (Eriksson & Nilsson, 2008). The nurse participants in my study, although recognising the influences which affected their engagement with the AHG, suggested this type of program was the way of the future. This is encouraging because several studies have highlighted the need for innovative models of care such as the AHG however none of these studies have included the views of the nurse delivering the program (Grace, et al., 2005; Neubeck, et al., 2012).

In other studies the demands of the health care organisation on the nurse have been highlighted as a factor influencing their engagement with cardiac rehabilitation programs (Lau-Walker, 2004b; Fernandez, et al., 2011). Interestingly, none of the nurse participants in my study discussed whether or not any action or communication from their health care organisation had influenced their engagement with the AHG. A model developed to optimise outcomes for patients with chronic disease, also identifies that the health care organisation is pivotal in supporting nurses to engage with programs that encourage partnership with patients (Wagner,
Austin, & Von Korff, 1996). Because of the literature indicating the influence of the health care organisation on nurse engagement with programs like the AHG, a recommendation from my study focuses on the role of the health care organisation in supporting nurses.

5.2.3 The patient, spouse and nurse experience of telehealth when using the AHG for home based cardiac rehabilitation

Telehealth, “the use of telecommunication technology to remove time and distance barriers in the delivery of health care services” has been found to improve clinical outcomes for patients with CAD (Artinian, 2007, p. 7). However little is known about the patient, spouse and nurse experience of using telehealth for home based cardiac rehabilitation programs. The AHG may be delivered predominately over the telephone thus it could be considered as a telehealth program. Programs offering structured telephone support similar to the AHG have been found to assist in improving patient’s quality of life and disease management (Inglis, et al., 2010). Patients and spouses within my study did not specifically mention telehealth in relation to their use of the AHG. However, the nurse participants identified telehealth as a challenge when using the AHG. The lack of face to face contact with patients impacted on the nurse’s ability to visually assess patient’s needs and resulted in nurses feeling unsure about the honesty of their communication, and rapport with patients. The nurse participants’ descriptions of their experiences of telehealth when working with patients using the AHG shed further light on their overall experience of using the AHG for home based cardiac rehabilitation (Objective 3), and the development of the nurse patient relationship when using this program (Objective 6). Further, these nurses’ comments about the nurse-patient relationship when using the AHG highlighted a number of important issues, particularly in the light of this model’s emphasis on the centrality of a partnership approach between patient, spouse and nurse when using this model of cardiac
Nurses found that telehealth influenced their experience of using the AHG. The lack of face to face contact when communicating predominantly via telephone with patients using the AHG impacted on what Anderson (1991) has termed ‘nursing activity’. She suggests that nursing activity is a process of enquiry that applies and shapes the nursing intervention (Anderson, 1991). It is the process of nursing assessment where the nurse gathers information from a variety of sources to plan the patient’s care (Anderson, 1991). However, predominately telephone only communication prevents visual access to the patient, thus precluding visual assessment of the patient. It requires finely tuned communication skills, including listening skills, on the nurse’s part plus the ability to facilitate information from the patient and the ability to provide information (education) to the patient over the phone. Nurses in my study expressed several difficulties with this including difficulty in being able to assess, plan and evaluate their nursing care based on a patient’s needs, because of the lack of non-verbal communication including the ability to monitor visual cues via the patients’ body language. One nurse participant commented:

You get to do a better evaluation of where people are at, from the point of view of their demeanour, their level of grooming and how much they care for themselves and things like that. I find I got a lot more (information) by seeing people face-to-face. I don’t know how I would find it if I had no face-to-face at all.

Other studies exploring telehealth have found similarly that nurses were challenged in assessing patients’ health needs (Wahlberg, et al., 2003; Snooks, et al., 2008). This finding would suggest that nurses using telehealth for home based cardiac rehabilitation need to place a greater reliance on active listening skills as a nursing activity. Additional education and support may be needed to facilitate this because
the skills required for telehealth have been identified as different to those of face-to-face nursing and do not allow therapeutic touching or face to face interaction with the patient (Hughes, 2003; Peck, 2005a). Consequently, in my study, the lack of face to face contact resulted in nurses feeling uncertain about their clinical assessment and overall relationship with patients.

Nurses found that the experience of telehealth created uncertainty in terms trust in their relationship with patients. One example of this is from one nurse participant who, when describing her relationship with patients using the AHG said, “it was certainly always a professional relationship but there just seemed to be an element of trust and a more personal connection than her relationship with the patient using the AHG.” Fundamental to successful telehealth is a trusting relationship between health care professionals/facilitators, patients and family members (Moffatt & Eley, 2010). Relying solely on what the patients described about their progress or recovery, rather than having their own visual confirmation, left the nurse participants feeling uncomfortable. Several nurse participants expressed concern that patients were perhaps telling the nurse what she wanted to hear for the nurse’s well-being rather than being honest about their true progress. This finding was however disputed in the verification process.

When I sought verification of my findings regarding the nurse participants’ perception that patients may not be honest in their communication, they disputed my interpretation of their experience despite the evidence that some nurses commented that patients were less than honest. One example of one nurse’s expression of this lack of honesty made during her interview was “it takes more than two sessions to get below the layers of how many porkies they’re telling “. At the videoconference in disputing my findings a nurse participant said “I don’t think patients lie to you; I can’t think of the word... they just detract from the truth a bit so they can hear you say something good (praise from the nurse) to them”. The
discrepancy between the interview and video conference findings highlight a
disadvantage of taking data back to participants for validation. Participants may
dispute and not validate findings, particularly those which are uncomfortable or
challenging. This results then in a discrepancy between the researcher’s
interpretation of the findings and the participant’s view. Subsequently the validity
and reliability of the study are compromised and the researcher as an ethical
dilemma in regard to the publication of the results. Goldblatt, Karniel-miller and
Neumann (2011) agree and suggest that participant’s the period of time which lapses
from interview to the validation; self-reflection and exposure to negative comments
from others may alter the participant’s perceptions of their experiences. However “in
a case of difference, the researcher is entitled to present the academic voice alongside
the participant’s with an acknowledgement of the differences in perspectives “(Goldblatt, Karniel-miller and Neumann, 2011 p395).

Other studies into telehealth have found similarly to my findings that nurses doubt
the credibility of the patient, preferring to rely on their own assessment and intuition
(Demiris, et al., 2006; Hollmstrom & Holgund, 2006). Hollmstrom & Holgund (2006, p. 1865) also found that there was a difference in values and beliefs between nurses
in regard to the credibility of the patients and suggested it was an “ethical dilemma
for telephone nursing”. This too was reflected in my study findings as there were
differences between nurse participants in regard to their beliefs about patient
honesty with predominately telephone only communication. It also appears from the
literature that a lack of trust between patients and nurses is not confined to instances
where face to face contact is not possible (Lau-Walker, 2004b; Florin, et al., 2005). This
finding regarding uncertainty of trust in the relationship suggests that nurses need
to rely on a wider range of sources from which to assess dependability of patient
information and need to recognise and deal with their own personal assumptions
regarding honesty in their communication with patients. Nurses may also need to
develop their communication skills in regard to active listening and questioning. A
combined approach, using telehealth and in person contact may be more advantageous than telehealth alone. However, whatever the approach, a trusting nurse patient relationship is essential for effective health care intervention (Berg & Danielson, 2007; Bell & Duffy, 2009).

Telehealth has been described as a “faceless encounter” as nurses have found it difficult to establish a rapport with their patients (Hollmstrom & Hoglund, 2006, p. 1865). Patients and nurses in my study differed in opinion in regard to rapport in the relationship between them when using the AHG for home based cardiac rehabilitation. Unsurprisingly, given the challenges in delivering cardiac rehabilitation to a rural population (Dollard, et al., 2004), the nurses welcomed the opportunity to use the AHG, especially with their patients who had limited access to hospital based cardiac rehabilitation.

However, despite their enthusiasm, several nurses described a less than positive experience in regard to their ability to develop rapport in the relationship with their patients. The nurses’ perception of a lack of rapport with patients was viewed as a major disadvantage to using the AHG. Nurses participating in this study described their relationships with patients as impersonal and the majority of them said they preferred the face-to-face contact in the hospital based cardiac rehabilitation group. Illustrating this, one nurse participant said, “well, it’s different; you don’t get to know them as well“. “There’s a problem” she also said, “its impersonal; it’s very impersonal over the telephone”. The lack of rapport with patients resulted in feelings of dissatisfaction about their patient relationships and the AHG for some nurse participants.

Others have found this lack of rapport left nurses feeling uncertain and anxious about their patient relationships which they attributed to the lack of human interaction (Demiris, et al., 2006; Hollmstrom & Hoglund, 2006, p. 1865). While one
nurse participant in my study had only telephone contact with her patients using the AHG others seemed to have a mixture of face to face interaction with some of their patients and telephone only with others. However, even when some face to face contact was used as well as telephone contact, the contact between patients and nurses was predominately over the telephone. Nevertheless, nurse participants who had a combination of face-to-face and telephone contact with their patients felt this was better than telephone only contact which they had with other patients. A study exploring the provision of hospice care at home via telehealth for cancer patients found similarly that the combined approach (telephone and face-to-face) was best for optimal nursing care (Demiris, et al., 2006).

In contrast to the nurse’s experience regarding rapport, patients in my study responded positively about their relationship with their AHG nurse mentors with Fred stating: “she (the nurse) was very friendly and helpful”. Similarly studies exploring the patient experience of telehealth have found that patients did not find the lack of face to face contact with the nurse a problem (Chumbler, et al., 2004). Some studies demonstrated that patients preferred telehealth to face to face contact with nurses (Dimmmick, et al., 2000; Mass, et al., 2001). My study is too small to fully explain this difference in perception of rapport between patients and nurses using the AHG for home based cardiac rehabilitation. This explanation is also hampered by the nature of contact (face to face or telephone only or a combination) between the patients in my study and their AHG nurse mentor being unknown. Nevertheless, my study has highlighted a number of factors that may influence the nurse patient relationship while using telehealth.

Nurse’s inexperience with telehealth may have influenced their relationship with patients. Health care policy advocates flexible home based cardiac rehabilitation programs utilising telehealth (NSW Department of Health, 2008; Briffa, et al., 2009; National Heart Foundation of Australia, 2010), yet some nurse participants in my
study indicated that their lack of experience with telehealth impacted on their rapport with patients. This resulted in nurses acknowledging that their limited experience of telehealth influenced their relationship with patients. An example is from one nurse who suggested that her limited experience with telehealth as opposed to her extensive experience with group based programs may have contributed to her concern and uncertainty about her rapport with her patients. The suggestion that some nurses lack of experience with telehealth impacted on their rapport with patients was supported by another nurse who had extensive experience of telehealth and had no concerns regarding rapport in her patient relationships. It is not clear from my findings how much a lack of rapport impacted on the nurses’ use of the AHG itself or their ability to engage with patients in partnership. There appears to be no other studies supporting this finding that inexperience with telehealth influences the relationship between patients and nurses. Anderson (1991) however suggests that the environment in which the nurse practices can influence how the nurse works with the patient to facilitate self-care skills or initiatives. It appears from my study that the working environment of predominantly telephone only communication impacts nurses subsequent relationships with patients. Therefore further training and support for nurses regarding developing patient relationships when using telehealth is needed (Moffatt & Eley, 2010).

5.3 Partnership between the patient, spouse and nurse in home based cardiac rehabilitation

Partnership between patients, spouses and nurses in the management of chronic illness such as CAD has led to increased patient self-esteem, improvement in patient outcomes and a reduction in health care costs (Wagner, et al., 2001; Gallant, et al., 2002; Bidmead & Cowley, 2005; Hook, 2006; Wiggins, 2008; Beasley, 2010). The AHG for home based cardiac rehabilitation advocates a partnership between patients and nurses. Crucial to any partnership is the relationship between both parties, however
the nurse patient relationship and its impact on partnership within home based cardiac rehabilitation appears not to have been explored. Therefore an objective (Objective 6) of my study was to explore the nurse patient relationship when using the AHG for home based cardiac rehabilitation. The relationship between patients and nurses was explored through the patient and spouse questionnaires enquiring about their contact with the AHG nurse mentor, and through prompts used in my interview with each nurse encouraging conversation about the nurse participant’s relationship with her patient. My findings indicated that patients were happy with their relationship with the AHG nurse mentor; however the nurse participants appeared less happy in their relationship with patients using the AHG and identified differences as compared to their usual nurse-patient relationships. These differences are discussed within the sub-themes of 1) power and control, 2) communication of information, and 3) changing the role of nurse as ‘expert’ to nurse as ‘facilitator’.

5.3.1 Power and control

Power and control on the nurse’s part impacts on the nurse patient relationship (McCormack, 2003a). Moving the patient from dependence to independence on this continuum requires nurses to develop relationships with patients during their interactions. Power and control influence the relationship between nurses and patients and can hinder partnership (Henderson, 2003; Summer, 2008). Nurse’s nurse: they do things to and for patients where as in a partnership there is mutual cooperation in the development of a trusting relationship through working together to bring about change (Bidmead, et al., 2002; Bidmead & Cowley, 2005). Nurses using the AHG for home based cardiac rehabilitation are encouraged to work in partnership with patients; power and control are shared. Power within a nursing partnership is acknowledged as the nurse recognising that her role is not to share or give power but to help patients realise that power and control are shared (Doss, et
al., 2011). Similarly to other studies, nurses within my study thought that sharing power and control was positive for patient care (Henderson, 2003; Wellard, et al., 2003). However, similar to the pilot study for the AHG discussed in Chapter 1, nurses suggested that in their experience this shift in roles and responsibility was challenging and resulted in frustration for themselves, their patients and dissatisfaction in the nurse patient relationship.

The majority of nurses in my study stated that they found the shift in power and control from the nurse to the patient required in a partnership approach, such as that advocated by the AHG, challenging. Nurses reported that patients struggled to take control, demonstrated by their inability to set or complete their goals for recovery; this was a source of frustration for some nurses. This quote from Claire reflects that frustration, she said “it actually requires them [patients] to do something, the AHG. It actually requires them to put pen to paper and make a commitment, and I tell you they’re not good at it”. The frustration expressed by some nurses in my study and their acknowledgement of it being related to the shift in power and control required by a partnership approach is in contrast to other studies which found that nurses were unaware of the influence of power and control in their relationships with patients (McCabe, 2004; Berg & Danielson, 2007; Summer, 2008). Several nurse participants reported that the patients wanted the nurse to take control and maintain their more traditional ‘dependency’ on the health care provider. This finding is similar to studies by Henderson, (2003) and McCabe (2004) which found that nurses understand public participation and partnership but in clinical practice they found that patients were passive recipients of care (Henderson, 2003; McCabe, 2004). In my study it appeared that some nurses did not understand that responsibility in a partnership was shared, preferring instead to give all the responsibility to the patient to care for themselves rather than this care being transacted between nurse and patient in a partnership approach. In contrast some nurses did not overtly discuss power and control in relation to themselves but nevertheless their interviews
indicated they wanted to maintain the expert role as they acknowledged they struggled with shared responsibility as this example from Glenda demonstrates ‘It’s hard not to just tell them [patients] what they should do or how they should do it”. Changing from an expert to a facilitative approach, one working with the patient in a way consistent with partnership is a challenge for some nurses who gain their job satisfaction by meeting the needs of patients themselves, thus maintaining a more traditional nurse patient relationship (Joel, 2002; Henderson, 2003; Summer, 2008; Wiggins, 2008). These findings relating to the difficulties some nurses faced with power and control are similar to other studies which have demonstrated that nurses may understand the concept of shared responsibility but their clinical practice does not reflect that understanding (Henderson, 2003; Wellard 2007b; Summer, 2008).

My findings regarding power and control were not verified by the nurse participants. This is unsurprising given that power and control is often hidden in nursing (Henderson, 2003; McCabe, 2004). According to Henderson (2003) and McCabe (2004) power and control is not only often hidden but it is also a controversial subject and rarely openly acknowledged in nursing (Henderson, 2003; McCabe, 2004). However my study has highlighted that there is a struggle for power and control within the nurse-patient relationship when using the AHG for home based cardiac rehabilitation. . I would argue similarly to Rundqvist and Lindstram, (2006., p. 25), that in nursing, power and control is often hidden within the term ‘empowerment’ which they define as “getting you to come round to a way of behaving that I, the expert, knew in advance was good for you, whilst encouraging you to think that changing your behaviour was your idea in the first place”. My findings suggest that partnership in the nurse patient relationship may be rhetoric rather than reality for nurses and patients using the AHG in this study, evidenced by this comment from a nurse participant who described shared responsibility for goal setting as the “hardest thing to grasp” because she had difficulty with patients identifying goals she did not see as important or measurable. This finding indicates
that nurses need more support facilitating care rather than delivering care.

5.3.2 Communication of information

Patients and spouses complain of a lack of information about CAD and their recovery (Scott & Thompson, 2003; Hanssen, et al., 2005; McLean & Timmins, 2007). This is a reasonable complaint because in order to understand their condition patients and spouses need accurate relevant information to enable them to make informed choices about their lifestyle and the management of their illness (Wagner, et al., 2001; Glasgow, et al., 2008; Mead, Andres, Ramos, Siegel, & Regenstein, 2010). A primary role of the nurse using the AHG for home based cardiac rehabilitation is that of an educator working alongside patients in the provision of information about their condition and recovery. Anderson (1991) suggests that the educator role of the nurse is to facilitate the patient’s education needs rather than provide the education didactically. This requires nurses working as an educator within a partnership model to acknowledge the patients’ existing knowledge of their illness and involve them in the planning and implementation of their own education (Bidmead, et al., 2002). Building knowledge and providing information about patients’ illnesses in a partnership approach requires the nurse to listen to, assess and discuss the patient’s information needs through a facilitative process involving the patient and their spouse as active partners (Jordan, et al., 2008). This is a key role for nurses using the AHG which is designed to build on existing knowledge and, or provide new knowledge about the patient’s illness and how he or she and their spouse can manage this. Often this involves imparting a significant amount of information contained in a variety of resources. In other studies patients have complained that nurses give information based on their own presumption of what information the patient needs rather than involving patients in the discussion (Hanssen, et al., 2005; McLean & Timmins, 2007). In contrast patients in my study were positive about the information they received from the AHG and from their AHG nurse mentor. Nurses
were also positive regarding the usefulness of the AHG in communicating information to patients but disputed the usefulness of some of the resources.

Patients and nurses differ in opinions on what information is necessary for their recovery (Scott & Thompson, 2003). Although there were a limited number of patients within my study they found the information contained in the AHG useful and they liked the ability to monitor their recovery through the patient diary. They also found that the AHG gave them enough knowledge to be confident about their CAD and recovery process. This is in contrast to other studies exploring the information needs of patients with CAD, which have found that patients are dissatisfied with the amount and type of information they receive (Scott & Thompson, 2003; Hanssen, et al., 2005; McLean & Timmins, 2007). Unlike the patients in my study however, nurse participants held varying opinions about the usefulness of the AHG resources. The nurses differed in opinion about how useful the resources within the AHG (diary, relaxation CD, rest activity cycle, booklets) were for patients; this opinion appeared to be based on the nurse’s perception of the usefulness of the resources rather than the patient’s actual use of the resources. An example of this is the AHG booklets in that some nurses thought these contained too much information to give to the patients, other nurses thought it was the right amount and patients themselves liked and appeared to use the booklets. The nurses own perception regarding the usefulness of certain resources may influence whether or not these resources are offered to patients. Similar results were found in other studies exploring the information and resource needs of patients with CAD following myocardial infarction, in that nurses provide information and resources based on their perceptions of usefulness or relevance rather than what the patient’s needs actually were (Scott & Thompson, 2003; Timmins & Kalisner, 2003; Timmins, 2005). Therefore my findings suggest that if nurses are to fulfil patients’ educational needs they need to listen to the patients ideas/comments about the resources being given to them and not rely on their own perceptions of the usefulness of certain
5.3.3 Changing the role of nurse as ‘expert’ to ‘facilitator’

Partnership within nursing requires open communication between patients and nurses within a trusting relationship (Gallant, et al., 2002). Open communication and a trusting relationship with patients enable health care intervention, described within Anderson’s (1991) Intervention: Nursing Roles and Functions Model as the transition of actions from the nursing activity to improve the patients’ outcomes. Simply described, intervention is what actions the nurse implements with or for the patient to improve their physical, social and psychological well-being. Supporting patients’ use of the AHG for home based cardiac rehabilitation using a partnership approach requires a change of emphasis of the role of the nurse, from that of health care giver to health care facilitator in the delivery of nursing intervention (Anderson, 1991). This may be challenging for some nurses as it involves balancing the role of “expert” with that of “facilitator” in delivering nursing care (Anderson, 1991; Wiggins, 2008). Health care facilitation requires that both parties, patient and nurse, discuss and negotiate the needs of the patient in a partnership relationship (Bidmead & Cowley, 2005).

A partnership relationship involves shared values, open communication, support, trust, and shared responsibility for decision-making (Gallant, et al., 2002; Wiggins, 2008). Open communication between patients and nurses is an essential component of a partnership (Gallant, et al., 2002). Despite the challenges and doubts about the reliability of patients’ information, nurse participants described how they communicated with patients through a process, for the purpose of my study, is called mutual engagement. Mutual engagement was described by several nurse participants in relation to their own or their patient’s engagement with the AHG in the process of home based cardiac rehabilitation, evidenced by comments regarding...
the success or failure of the patient engaging with the nurse and using the AHG. This example from one nurse participant who described using the AHG with a patient to increase exercise demonstrates mutual engagement:

Felt she should, but when I talked (to her) about increasing activity she was keen to do that (increase activity). So once we got down to goal setting she found it quite easy. So she got the goals down to I’ll walk 10 minutes daily this week and 20 minutes daily next week. Once we broke it (the physical activity goals) down a bit it was a lot easier

Mutual engagement gave the nurses job satisfaction, as described here by one nurse participant “when the process works its very rewarding”. However if engagement with the patient was poor this was a source of sadness and dissatisfaction for nurses. One nurse participant suggested that when mutual engagement did not occur it was a “communication issue”. However it was not clear from the nurses what type of communication (open or closed) they used or thought facilitated mutual engagement. Open communication facilitates partnership by encouraging discussion through questions which require more than one word answers such as yes or no, as used in closed communication. A study by Lowenberg (2003) found similar results in that those patients who felt they had good open communication with their nurses engaged well, as opposed to another study where closed communication between patients and nurses was observed and it was found that patients disengaged (Henderson, 2003). This, that is the type of communication nurses envisage as facilitating mutual engagement, is important information because several studies have found that nurses prefer closed communication because it saves time and enables the nurses’ agenda to be met (McCabe, 2004; Lloyd-Williams, et al., 2005). My study’s findings indicate the importance of open communication when using programs like the AHG for home based cardiac rehabilitation.
5.4 Summary overview of findings in relation to the literature and objectives from my study

The aim of my study was to describe the experience of patients, spouses and nurses using the AHG for home based cardiac rehabilitation and these experiences have been discussed from all of these participants’ perspectives. In summary this discussion has sought to present my findings in the context of the literature so as to demonstrate how I have addressed the study’s aim and objectives. My first three objectives were to describe the experience of each of the three participant groups (patients, spouses and nurses). Patients and spouses described a positive experience of home based cardiac rehabilitation using the AHG. The positive experience was enhanced by the amount and quality of information in the AHG, the ability to monitor their own progress/recovery and their contact with the AHG nurse mentor. These findings complement existing literature demonstrating patients have a positive experience of home based cardiac rehabilitation and value information about their condition and support from nurses (Beckie, 1989; Scott & Thompson, 2003; Anderson, 2007; McLean & Timmins, 2007; Jones, et al., 2009; Neubeck, et al., 2009).

Nurses involved in my study also described their experience using the AHG as generally positive. The positive aspect of their experience was the usefulness of the guide in providing support for themselves in structuring and delivering their program, and the usefulness of the AHG for their patients. However the nurses were uncertain about their relationship with their patients when using the AHG, and they identified some challenges in using the AHG, including the use of its resources and communicating with patients predominantly via telephone only. The literature supports some of my findings in regard to nurse’s concerns regarding telephone communication and their perception of the value of the resources useful to patients (Scott & Thompson, 2003; Peck, 2005b; Hollmstrom & Hoglund, 2006).
The AHG was useful to patients, spouses and nurses for lifestyle change and disease management. In fulfilling my fourth objective regarding the usefulness of the AHG in assisting with and supporting lifestyle change and disease management, my findings indicated that all three participant groups found the AHG useful. Patients found the ability to monitor their own progress and recovery useful, and although limited in number the spouses in my study also found the AHG useful in supporting them to support the patient. Nurses were positive about the AHG as a useful tool for assisting them to support patients with lifestyle changes especially when patients had previous experience of cardiac rehabilitation, as a means of giving information to patients and when the nurse and patient experienced mutual engagement in goal setting. My discussion demonstrated that my findings were similar to the literature in that patients and spouses found cardiac rehabilitation beneficial for lifestyle change (Clark, et al., 2004; Jones, et al., 2009; Neubeck, et al., 2012). My findings regarding the nurses’ experience of the usefulness of the AHG for lifestyle change and disease management are helpful for planning programs of this nature and as a means of supporting nurses to support patients.

My fifth objective was to describe patient and nurse engagement with the AHG and my discussion demonstrates that there are a number of factors which influence engagement with this program. Patient engagement was influenced by their previous illness experience (if any) and their transition from hospital to home. Nurse engagement was influenced by patient selection, time constraints and whether or not they perceived mutual engagement between themselves and their patients. My findings regarding engagement with the AHG reflect other studies which have explored patient and nurse engagement in chronic disease management and cardiac rehabilitation (Jordan, et al., 2008; Neubeck, et al., 2012).

There is limited literature regarding partnership within cardiac rehabilitation, therefore the sixth objective of my study was to describe the nurse patient
relationship when using the AHG. My findings in relation to this demonstrated that the measure of ability and willingness by nurses to communicate information to the patient and spouse according their needs, and an awareness of a need to change the traditional role of nurses and patients in terms of the balance of power and control, influenced whether or not the AHG was delivered by nurses in an expert or more facilitative style consistent with the partnership approach advocated by the AHG. These findings were considered and explored using a variety of literature relating to the changing role of nurses within a partnership approach to health care delivery (Anderson, 1991; Gallant, et al., 2002; Henderson, 2003; Bidmead & Cowley, 2005; Wiggins, 2008). Consideration and exploration of cardiac rehabilitation from a partnership perspective appears not to have been addressed previously by researchers in the context of CAD.

5.5 Strengths and limitations of my study

My study has cast light on the patients’, spouses’ and nurses’ experiences of home based cardiac rehabilitation using the AHG. The strength of my study is the use of qualitative descriptive methodology; this enabled me to discover and capture participants’ experience of the research question from their expression of this and to use their words to illustrate their experience. Therefore I was able to stay true to my participants’ reflections and present the data with minimal interpretations. My study has highlighted that patients and spouses value information regarding their health and that their relationship with the nurse is crucial to their experience of cardiac rehabilitation. A further strength of my study is that it illuminates features of a cardiac rehabilitation program that patients (and their spouses) found useful and valued. This might assist others developing or delivering similar programs. An additional strength of the study was that although, in this instance, there were few spouses’ involved in the study this involvement did acknowledge that spouses often
play a vital part in supporting patients undertaking cardiac rehabilitation programs at home.

The ageing population, increased use of technology and the geographical size of Australia means that home based cardiac rehabilitation programs using telehealth are rapidly being developed and implemented in clinical practice. When evaluation of these programs has occurred studies have usually used quantitative rather than qualitative methodologies. My study appears to be the first of a qualitative nature and this has allowed exploration of nurses’ experiences of this type of home program. This exploration has, in turn, resulted in a better understanding of the opportunities and challenges that cardiac rehabilitation nurses face not only when working in partnership with patients, but also when introducing new models of practice.

Limitations of my study relate to the challenges in implementing my proposed recruitment methods resulting in a limited number of participants. My original recruitment strategy was that I would approach the potential participants about taking part in the study however this was deemed unethical as I was considered in a position of power. In addition there was a possibility that nurses may not have recruited patients to the study because of concern about what patients may say to me about them given my role as a clinical nurse consultant in cardiac services. Nevertheless, conducting my own recruitment may have improved the number of patients, spouses and nurses recruited because I was not relying on a third party who may not have had an interest in the study and therefore not have been committed to recruitment of participants for it. I acknowledge, however, that this is an issue that many researchers face. There was also a long wait for ethical approval resulting in a considerable delay in data collection from participants and this may have impacted recruitment as their inclination to take part in the study or their ability to recall their experience may have been limited. There are further limitations
of my study in regard to the patient and spouse questionnaire. In hindsight it would have been helpful to ask more questions about the patients’ and spouses’ relationship with the nurse so as to have been able to learn more about this aspect of the patients and spouses experiences. To enhance the spouse questionnaire, questions relating to the relationship between the couple and more specific questions about the spouses relationship with the AHG nurse mentor may have also added more detail to the description of their experience. It would also have been useful to ascertain geographically where patients included in my study lived. This would have assisted understanding about whether or not having the AHG for home based cardiac rehabilitation was beneficial to rural patients given their limited access to cardiac rehabilitation.

Limitations of my study in relation to nurse participants were their limited experience with the AHG and the lack of information regarding the nature and duration of their contact with their patient’s. The nurse participants in my study had limited experience with the AHG having only facilitated the guide with one or two patients. Nurses who had used the AHG with a larger number of patients would have a greater and broader depth of experience from which to draw and may have provided different insights into the usefulness of the AHG and engagement with the AHG. The AHG is designed to be used predominately over the telephone with patients and it appears that some nurse participants in my study may also have had face to face contact. However, it was unknown how much contact was face to face and how much was by telephone only. In addition the duration of the contact between the patient and AHG nurse mentor was also unknown. This limits the depth of my findings regarding the use of telehealth for home based cardiac rehabilitation. Finally a further limitation of my study and most other qualitative research studies is that that their findings are not generalisable.
5.6 Implications of my study findings

My study has explored the patient, spouse and nurse experiences of home based cardiac rehabilitation using the AHG. The findings discussed in this chapter have resulted in the following implications for each of the participant groups (patient, spouse and nurse). In addition my findings have highlighted implications for health care organisations and further research.

5.6.1 Implications of patient findings

1. The patient participants were positive about the amount and quality of information contained in the AHG. Given that this program provides extensive information for patients this indicates that at least some patients require a significant amount of information about CAD and its management.

2. Patients’ previous illness experience (duration and severity) or experience of cardiac rehabilitation (positive or negative) and their existing knowledge of CAD may impact on their engagement with home based cardiac rehabilitation. This suggests that patients should have a choice of program and be actively involved in selecting the program which is most suitable for their needs.

3. Patients participating in my study liked the ability to monitor their own progress and recovery, although some patients struggled with the development of their own goals and actions, preferring to rely on the nurse directing their recovery. This indicates that patients need support and education regarding working in partnership with nurses.

4. Patients valued the support and their relationship with their AHG nurse mentor, although the importance of their role in supporting patients may have been
underestimated by the AHG nurse mentors. This indicates that patients undertaking home based cardiac rehabilitation programs like the AHG should have the opportunity to access support from nurses.

5.6.2 Implications of spouse findings

1. Spouses involved in my study who used the AHG found it useful in providing them with information and support for their husband/partner about CAD, the patient’s recovery and lifestyle or behaviour change. This indicates that it is important that spouses are actively engaged, and that materials are provided for them within education packages relating to home health programs such as cardiac rehabilitation.

2. Spouses reported varying involvement with and/or support from the AHG mentors and the usefulness of this. However, given the very limited number of spouse participants in this study it is difficult to draw any implications from this. Nevertheless, it is interesting to note that nurse participants did not comment about the role of spouses in supporting patients during the interviews. This may indicate that nurses working within cardiac rehabilitation programs should increase their awareness of the need to actively communicate, involve, and support spouses of patients undergoing cardiac rehabilitation, especially when the patient is using the AHG which advocates a partnership approach between nurse mentors with both patients and their carers.

5.6.3 Implications of findings for clinical practice

1. Nurses were mainly positive about their relationship with patients and their use of the AHG for home based cardiac rehabilitation. Using the AHG appeared to have given the nurse participants’ job satisfaction when they were engaged in the process
of cardiac rehabilitation with their patients. This indicates that nurses are likely to consider the AHG program an acceptable model of care for patients requiring home based cardiac rehabilitation.

2. Nurses rely on a full range of communication (verbal and non verbal) skills and, in my study, found predominately telephone only communication with patients challenging. The challenges they experienced related to their ability to accurately assess patient needs, honesty in their communications and their perception of a less personal relationship with their patients. This appears to indicate that nurses may benefit from additional support from those more experienced in telehealth and involvement in opportunities such as clinical supervision and/or education when first using the AHG. This might facilitate discussion about these challenges and assist in building the skills required when using predominately telephone administered models of health care delivery.

3. Some nurse participants appeared to find working in partnership with patients challenging when using the AHG for home based cardiac rehabilitation, especially in relation to issues such as power and control and shared responsibility for health care between patient and nurse. In my study, the challenges experienced by nurse participants were in relation to their perceptions about the patient’s ability or desire to share responsibility. It also appeared from their interview data that nurse participants’ found relinquishing their expert role and taking up one of ‘partnership’ challenging. This suggests that further education and support is needed for nurses and patients to work in partnership when using home based programs like the AHG.

4. The delivery of the AHG which advocates working in partnership with patients when using this program requires the nurse to develop existing and/or build new skills relevant to a more facilitative role including open communication, negotiation
and trust. Nurses within my study found working in a more facilitative role difficult because the lack of face to face communication resulted in concerns regarding their patient’s honesty and facilitating the AHG was time consuming. This indicates that nurses need support to develop new skills in working in partnership with patients and to understand the change in emphasis and balance required in their role between health care giver with that of health care facilitator.

**5.6.4 Implications for health care organisations**

Nurses within my study indicated that the AHG was time consuming to use with patients and this impacted on their workload and ability to use the AHG. However it may be that one reason for this was that nurse participants were unfamiliar with using the AHG and its negative impact on their workload might decrease as their familiarity with it builds. Nevertheless, it might also indicate that managers of health care organisations/services must consider this when identifying work force levels and requirements as well as education and support for nurses using this program.

**5.6.5 Implications for future research**

1. There was little representation in my study from women, the elderly or younger patients. The implication of this is that there is still limited research regarding these groups, which are under-represented in many studies, in the context of home based cardiac rehabilitation.

2. Patients within my study appear not to have been given a choice of program, and there is little research regarding patient selection of appropriate models of rehabilitation. Choice of program where feasible can facilitate good patient engagement as a program is more likely to be chosen and used if it suits the patient’s perceptions of their needs. However there is limited information regarding patient
choice of program therefore there is a lack of understanding of its influence on patient engagement.

3. Some patients within my study enjoyed using monitoring tools such as the patient diary offered in the AHG. The implication of this is that patients may like to take control of their illness and recovery, and therefore tools through which to facilitate this should be identified and their usefulness assessed.

4. There were a limited numbers of spouses within my study and the AHG spouse information booklet was not formally evaluated. The implication of this is there is still limited information regarding the usefulness of home based rehabilitation for spouses and therefore its benefit cannot yet be determined.

5.7 Recommendations for clinical practice

The implications for clinical practice from patients, spouses and nurses have resulted in the following recommendations from my study.

1. Patients in my study found the AHG, as a model for home based cardiac rehabilitation, acceptable and useful in assisting them with lifestyle change and disease management. While recognising the limited numbers of participants that took part in my research, it is recommended that programs such as the AHG should be made available to patients as an alternative to hospital based cardiac rehabilitation to enable them to have a choice of program.

2. In my study it appears spouses were not actively involved in the process of home based cardiac rehabilitation. Therefore it is recommended that spouses are encouraged to be actively involved in cardiac rehabilitation (hospital and home) and nurses receive education, encouragement and support to facilitate spousal
involvement in the rehabilitation process.

3. My findings from nurse participants suggested that patients had difficulty understanding the changing nature of their relationship with nurses that is demanded in such a program (the AHG) that emphasises both parties must work in partnership with each other. A recommendation from my study is that an education or public awareness campaign should be developed, promoting to the Australian public the concept of self-management with the support of a health professional, particularly in instances of chronic illness such as CAD.

4. My findings highlight challenges for nurses working within home based cardiac rehabilitation where partnership is advocated. My study suggested working in partnership with patients and spouses required nurses to take a different approach from one of being the expert, to that of a facilitator of health care albeit with the ability to impart expert knowledge when required. To support nurses with the transition to a role of health care facilitator my fourth recommendation is that nurses receive further education and support regarding a) working in partnership with patients and spouses; b) communication strategies and sharing responsibility within a partnership approach.

5. Nurses expressed difficulty with predominately telephone communication and this difficulty related to their ability to assess patients' needs, rapport in the relationship and honesty in their communication. Therefore it is recommended that nurses need to develop new skills required when working with patients without face to face contact in programs utilising telehealth.

6. My study indicated that nurse participants were excited to implement a new program for cardiac rehabilitation such as the AHG; however they found the program time consuming and challenging to understand when working in
partnership with patients. Therefore I recommend that nurses need additional time and support when implementing new programs of home based cardiac rehabilitation which require new approaches to their delivery.

5.8 Conclusion

My research question asked “What is the experience of patients, spouses and nurses using the AHG for home based cardiac rehabilitation? The findings of my study answer this question by describing the experience of each participant group: patients, spouses and nurses. My main finding was that the AHG for home based cardiac rehabilitation was found to be an acceptable and useful program for a limited number of patients and nurses within Australia. I was unable to ascertain if it was acceptable to spouses given the limited numbers in my study. My study highlighted the experience of patients and nurses using telehealth and some of the challenges of engaging in a partnership approach to health care delivery. A specific finding from the nurse participants was the many challenges they experienced in the delivery of home based cardiac rehabilitation however there was an acknowledgement that home based cardiac rehabilitation is the way of the future.

Finally, I recommended that programs like the AHG for home based cardiac rehabilitation are made available to patients and spouses as an alternative to hospital based cardiac rehabilitation. Spouses require specific support programs to be included within home based cardiac rehabilitation programs and nurses may need additional support and education on how to meet spouses’ needs. Nurses may require further education and support in regard to working in partnership with patients and their spouses (or carers) and in the transition process involved in moving from a role that emphasises care giving as an expert, to one of care facilitation. Ideally the education for nurses would emphasise communication skills and shared responsibility and, in the context of telehealth, the skills needed to
deliver this model of health care. To support this, a public education campaign would be useful to inform the public of the changing nature of health care and their changing role within it.

On a personal note, I would like to conclude by stating that this study has at times been rewarding, challenging, and frustrating but most of all satisfying. A quote from Ann, a spouse participant, summarises what I hope is the experience of the patients, spouses, nurses, research supervisors, editor and myself in participating in this study: “we got through the program and found the result we were looking for very pleasing. Thank you.”
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Appendices

Appendix 1: Nurse Mentor recruitment information statement

The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Australian Heart Guide for Home Based Cardiac Rehabilitation using qualitative description methodology.

Introduction

The Australian Heart Guide (AHG) is a new model of home based cardiac rehabilitation for people with coronary heart disease (CHD) within Australia. Not much is known about how acceptable and adaptable this model is to the Australian public and Australian cardiac rehabilitation nurses. Therefore there is a need to research this with a view to getting that understanding and using the information to improve the experience of future clients using home based cardiac rehabilitation. As well as assisting in gaining an understanding of the opportunities and barriers to partnership in home based cardiac rehabilitation.

This study is being conducted by Dawn Mcivor as part of a Masters degree at The University of Newcastle under the supervision of:

Dr Deborah Sundin
Dr Diana Keatinge
Dr Kerry Inder

The study will focus on the use of the AHG on the client’s recovery from acute myocardial infarction, lifestyle change and support for the client’s significant other. The nurse client relationship and its impact on working in partnership to achieve good health outcomes for the client will also be studied. The aim being to understand and describe the experience of clients with CHD, their significant others and their nurse mentors experience of using the AHG to support home based cardiac rehabilitation.
The study has ethical approval from Hunter New England Health Ethics Committee (ethics number here) and the Director of Nursing and Chief Executive of HNEH has given permission for the study to take place in sites across the area with clients, significant others and willing nursing staff to take part.

**Importance of the study**

- Improving access and adherence to CR is a NSW state priority.
- NSW Health policy recommends offering an alternative approaches to CR such as Home Based Cardiac Rehabilitation (HBCR)
- Scarcity of Australian evidence about HBCR using an structured approach such as The Australian Heart Guide (AHG)
- Limited evidence about client experience of HBCR
- No evidence about significant other or nurses experience of HBCR
- No evidence about working in partnership within HBCR

**Who can be involved in the study?**

**Inclusion Criteria Clients**
- Have had a hospital admission with ACS and used the AHG
- Be able to provide informed consent
- Use the AHG within 6 months of the clients discharge from hospital
- Completed 6 weeks with AHG and speak English or agree to use of interpreter

**Inclusion Criteria Significant other**
- Be a significant other of a client who was discharged from hospital with ACS who used the AHG
- Be able to provide informed consent
- Use the AHG within 6 months of the clients discharge from hospital
- Completed 6 weeks with AHG and speak English or agree to use of interpreter during data collection.

**What can AHG mentors do to assist study**

1. Send the information sheets to clients using or have used the AHG and their significant others offering them the chance to take part in the study
   In to prevent coercion and to ensure the study complies with ethical guidelines the researcher cannot approach clients/significant others and ask them to take part. Therefore the AHG mentor can assist with the study by sending the information packs which contain information sheets, consent forms, and stamped
addressed envelopes to clients and their significant others who are using or have used the AHG on their caseload.

2. Provide information to potential participants about the study
As clients and significant others who use the AHG may have contact with the AHG mentor they may make contact with their mentor for further information about the study. Therefore AHG mentors can assist by providing the potential participants with information about the study. The information sheets contain all the study details and contact numbers for the researchers should the AHG mentor require further assistance in answering the queries.

4. Be available if possible as a support for focus group in case of problems
The client and significant others take part in an hour long interview and a focus group of 1-2 hours. In case a participants becomes distressed during the focus group HNEH ethical committee request that a second person should be available to provide support for the participant. To assist with this the nurse mentor would need to be available in the building (local health care facility) where the focus group is taking place, this should be approximately for 1-2 hours.

5. Deal with any client/significant others medical/psychosocial issues which may be raised as part of the interviews or focus groups.
Although the researcher is a cardiac rehabilitation nurse, during the interviews or focus groups the researcher cannot provide health support or advice to the participants, unless it is a clinical emergency. This it to differentiate between the researcher role and the nurse role and is a essential part of ensuring the study complies with ethical guidelines. If the participants have a health or psychosocial issue which needs further support then the researcher would like to contact the participants AHG mentor (with the participants permission) for assistance after the interview or focus group. This ensures that the participant receives support from an appropriate health professional that has an understanding of their clinical condition and history.

6. Be a nurse participant
The AHG mentor can assist the study by agreeing to be a nurse participant, this will ensure that the AHG mentors experience of using the AHG is documented and used to inform the use of the AHG within Australia. To take part as a nurse participant the AHG mentor must:
• Be registered Nurses
• Have undertaken and completed the AHG training and be an accredited mentor
• Have facilitated the AHG with a client to completion (6 weeks)
What do nurse participants have to do?
To take part as nurse participants AHG mentors agree to:

An Individual interview
Face to face or telephone
Approx. 60 minutes
Mutually convenient time and place
A Focus group with other AHG mentors who agree to take part in the study
1-2 hours duration
Travel expenses available
Local venue
NB. Participants can choose to have interview only but not a focus group only

How can nurses take part?
• The nurse will receive a letter from ACRA describing study and asking them to take part.
• The nurse needs to read the information sheet and contact the researchers if there are questions
• If the nurse wishes to take part then complete a consent form and return it to the researcher in the envelopes provided. The researcher will then contact the nurse to arrange a time for the interview.
• The nurse can refuse to be a participant and still assist with recruiting of clients and significant others

Benefits to taking part!!!

No personal benefit but
• Contributing to development of AHG for other clients and significant others
• Informing ACRA of the opportunities and barriers to the AHG within Australia
• Assisting in understanding the use of the AHG for cardiac rehabilitation nurses
• Helping Dawn get her Masters

Thank you for your time
Appendix 2a: Client Participant Information Statement

AHG STUDY

Client Participant Information Statement

HUNTER NEW ENGLAND
NSW HEALTH

Information statement for the research project: The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Australian Heart Guide for home based cardiac rehabilitation.

Study Coordinator: Dawn Mcivor

1. INTRODUCTION

You are invited to take part in the research project identified above which is being conducted by Dawn McIvor from Hunter New England Health as part of a Masters degree in research under the supervision of Dr Deborah Sundin from the University of Newcastle. You are being invited to take part as you were given the Australian Heart Guide following your admission to hospital with heart problems.

This Participant Information statement contains detailed information about the research project. Its purpose is to explain to you as clearly as possible everything that is involved in this project before you decide whether or not to take part.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document, or discuss the project with a family member, friend, colleague or your doctor.

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

The purpose of the research is to explore your experience of home based cardiac rehabilitation using the Australian Heart Guide with a view to understanding how it helps
your recovery. The information obtained from this study may assist in future editions of the Australian Heart Guide and the development of home based cardiac rehabilitation programs within Australia.

You will have recently been in hospital with a heart attack or angina and you will have been invited to undertake cardiac rehabilitation. Cardiac rehabilitation is exercise, education and support for clients following angina or heart attack. You have chosen to use the Australian Heart Guide to assist with your home based rehabilitation. Home based cardiac rehabilitation using The Australian Heart Guide is a new method of cardiac rehabilitation within Australia, there is therefore limited information known about the usefulness and acceptability of this type of program. Exploring your experience of using the Australian Heart Guide enables this information to be obtained.

3. **WHO IS BEING ASKED TO PARTICIPATE**

Between 5 and 10 people who have used the Australian Heart Guide after being admitted to hospital are being asked to participate. In addition, 5 to 10 significant others and approximately 11 nurses will also be invited to take part in the study.

If you previously completed a hospital cardiac rehabilitation program or you completed your cardiac rehabilitation using the Australian Heart Guide more than twelve months ago then this study is not suitable for you.

4. **PARTICIPATION IS VOLUNTARY**

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect your care or access to health services.

If you decide to participate you may withdraw from the project at any time without giving any reason and any data collected about you will be withdrawn from the study, destroyed or returned to you.

The researcher may withdraw a participant if it is considered in the participant’s best interest or if it is appropriate to do so for another reason. If this happens the researcher will explain why and advise you about any follow up or alternative arrangement if appropriate.

5. **WHAT YOU WILL BE ASKED TO DO**

If you agree to take part in this study you will be asked to:

1. Provide some personal information including your age, gender, diagnosis, where you live and your employment status.

2. Participate in an audio taped interview at a venue of your choice with the study coordinator to discuss your experience. The interview will focus on your physical and emotional recovery, your lifestyle changes and your experience of working with your heart mentor. Your partner, friend or relative may be present for the interview or they can choose to have an individual interview with the study coordinator. The interview may take
approximately 60-90 minutes. With your permission the interview will be taped and you may ask for the tape to be stopped and sections of it edited or erased at any time during the interview.

Following your interview you will receive a written copy of the interview for you to confirm or change any details which you are not happy with. If you do not return the written copy in the stamped addressed envelope provided within 2 weeks the study coordinator will assume you are happy with the interview transcript.

There is $10 reimbursement for travel expenses to the interview.

3. Attend a 1-2 hour audio taped group discussion, known as a focus group, at a local health care facility with other clients who have used the Australian Heart Guide to discuss your experience. This group discussion will focus on the information obtained from the interviews. Your spouse, partner, or significant other will be invited to attend a separate focus group.

You may choose to participate in the interview only without participating in the focus group. The focus group session will be referring to and enlarging upon material gathered in the interviews, so the choice to participate in the focus group only is not offered.

Any information obtained during the interview or focus groups which are of an illegal nature or threaten the safety and welfare of an individual will be disclosed to the appropriate persons.

There is $10 reimbursement for travel expenses to the focus group.

6. **WHAT ARE THE RISK AND BENEFITS OF PARTICIPATING**

As a participant in the study there may be no individual benefits in taking part.

There is are minimal risk to your participation in that you may feel anxious or get upset during the interview or focus group. If you do feel anxious or upset appropriate support will be provided by a counsellor through Hunter New England Health.

Participants in the focus groups cannot be given guarantees of anonymity or confidentiality as the researcher cannot guarantee that individuals who participate in the focus group will not divulge personal information to others. However, we will ask that all members of the focus groups respect each other’s privacy and treat the discussions as confidential.

7. **HOW YOUR PRIVACY WILL BE PROTECTED**

All of the information collected during this study will be kept confidential by the study team. Your interview and focus group transcripts will be coded so that information connecting you personally with the record will be kept separately. The details will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the *NSW Health Records and Information Privacy Act 2002*. Upon completion of the research study all information collected will be securely stored at the School of Nursing and Midwifery the University of Newcastle. It will be kept for a period of 15 years to comply with ethical standards.

Any information obtained during the interviews or focus groups which are of an illegal nature or threaten the safety and welfare of an individual will be disclosed to the appropriate persons.

8. **HOW THE INFORMATION COLLECTED WILL BE**
The data will be submitted in Ms McIvor’s thesis and reported or presented in scientific journals and scientific conferences. The information reported will be a compilation of the interview and focus group data. Pseudonyms will be used in all presentations of data from this project to protect your confidentiality.

9. **ETHICAL GUIDELINES**

This project will be carried out according to the National Statement in the Conduct of Human Research (March 2007) 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.

10. **COMPLAINTS**

This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference No

Should you have any concerns about your rights as a participant in this research or have a complaint about the manner in which the research is conducted, it may be given to the researcher or if an independent person is preferred then please do contact:

The Professional Officer

Dr. Nicole Gerrand  
Hunter New England Research Human Ethics Committee  
Locked Bag 1  
New Lambton NSW 2305  
Telephone 02 49214950 or 02 49213000Fax No. 02 49214818  
Email:Nicole.Gerrand@hnehealth.nsw.gov.au

11. **WHAT DO YOU NEED TO FIND OUT MORE ABOUT THE STUDY AND/OR HOW TO PARTICIPATE**

Please read this information statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand or have questions contact the researcher.

Principle Researcher  
Dr Deborah Sundin  
School of Nursing and Midwifery  
The University of Newcastle  
Callaghan NSW 2308 Australia  
Tel: 02 4926759 Fax 02 49616301  
Email: Deborah.Sundin@newcastle.edu.au

Student Researcher  
Dawn McIvor  
Hunter New England Health  
Locked Bag No. 1.  
Hunter Region Mail Centre 2310  
Tel:02 49214209 Fax: 02 49214210  
Email: dawn.mcivor@hnehealth.nsw.gov.au

If you would like to participate please complete and return the attached consent form in the reply paid envelope provided, this will be taken as your informed consent to participate. I will
then contact you to arrange a time convenient to you for the interview and subsequent group session.

Thank you for considering this invitation

Dr Deborah Sundin
Principal Investigator
Appendix 2b: Significant Other Participant Information Statement

AHG STUDY

**Significant Other Participant Information Statement**

**Information statement for the research Project:** The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Australian Heart Guide for home based cardiac rehabilitation.

**Study Coordinator:** Dawn McIvor

1. **INTRODUCTION**

You are invited to take part in the research project identified above which is being conducted by Dawn McIvor from Hunter New England Health as part of a Masters degree in research under the supervision of Dr Deborah Sundin from the University of Newcastle. You are being invited to take part as your spouse, partner, or significant other chose the Australian Heart Guide for cardiac rehabilitation following admission to hospital with either a heart attack or angina.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible everything that is 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, or discuss the project with a family member, friend, colleague or your doctor.

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**

The purpose of the research is to explore the spouse, partner or significant other’s experience of home based cardiac rehabilitation using the Australian Heart Guide. This will assist us to
better understand how using the Australian Heart Guide at home in conjunction with the mentor (nurse) enabled you to support your spouse, partner or significant other, in their recovery. Information from this project may assist in the development of future editions of the Australian Heart Guide and development of support programs for significant other of clients with heart disease.

Your spouse, partner or significant other will have recently been in hospital with a heart attack or angina and they and you may have been invited to undertake cardiac rehabilitation. Cardiac rehabilitation is exercise, education and support for clients after a hospital admission with a heart attack or angina. Cardiac rehabilitation aims to assist your spouse, partner or significant other in their recovery.

Your spouse, partner or significant other has chosen to use the Australian Heart Guide to assist with their home based rehabilitation. Home based cardiac rehabilitation using The Australian Heart Guide is a new method of cardiac rehabilitation within Australia which we are seeking to evaluate from the patient’s, their supporting significant other and their nurse mentor’s perspective.

3. WHO IS BEING ASKED TO PARTICIPATE

5-10 significant others of clients using the Australian Heart Guide within Hunter New England Health service will be asked to take part in the study. 5-10 clients and 10 nurses using the Australian Heart Guide will also take part in the study.

If you or your spouse, partner or significant other has previously completed a hospital cardiac rehabilitation program or have completed their cardiac rehabilitation using the Australian heart Guide more than twelve months ago you are unable to take part in this study.

4. PARTICIPATION IS VOLUNTARY

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect.

If you decide to participate you may withdraw from the project at any time without giving any reason and any data collected about you will be withdrawn from the study, destroyed or returned to you.

The researcher may withdraw a participant if it is considered in the participant’s best interest or if it is appropriate to do so for another reason. If this happens the researcher will explain why and advise you about any follow up or alternative arrangement if appropriate.

5. WHAT YOU WILL BE ASKED TO DO

If you agree to take part in this study you will be asked to:

1. Provide personal information in regard to your age, gender, where you live, employment and relationship to the client using the Australian Heart Guide.
2. Participate in an hour long audio taped interview at a venue of your choice with the study coordinator to discuss your experience. The interview will focus on your physical and emotional reaction to your spouse, partner or significant other’s illness, your involvement in any lifestyle changes they may have to make, the experience of working with the heart mentor (if applicable) and your use of the Australian Heart Guide. Your spouse, partner or significant other may be present for the interview or you can choose to have an individual interview with the study coordinator. With your permission the interview will be taped and you may ask for the Tape to be stopped and edited or erased at any time during the interview.

Following your interview you will receive a written record of the interview (transcript) for you to confirm or change as you please any details which you are not happy with. If you do not return the written copy in the stamped addressed envelope provided within 2 weeks the study coordinator will assume you are happy with the interview transcript.

There is reimbursement up to a maximum of $10 for travel expenses to the interview.

3. Attend a 1-2 hour audio taped group discussion at a local health care facility with other spouse’s, partners or significant others who have used the Australian Heart Guide with their spouse, partner or significant other to discuss your experience. The group will focus on the information obtained from the interviews. Your spouse, partner, or significant other will be invited to attend a separate group...

You may choose to participate in the interview only without participating in the focus group. The focus group session will be referring to and enlarging upon material gathered in the interviews so the choice to participate in the focus group only is not offered. However all members of the focus group will be asked to respect each other’s privacy and maintain confidentiality.

Any information obtained during the interview or focus groups which are of an illegal nature or threaten the safety and welfare of an individual will be disclosed to the appropriate persons.

There is reimbursement up to a maximum of $10 for travel expenses to the focus group.

6. WHAT ARE THE RISK AND BENEFITS OF PARTICIPATING

As a participant in the study there may be no individual benefits in taking part.

There is are minimal risk to your participation in that you may feel anxious or get upset during the interview or focus group if this is the case appropriate support will be sought from a counsellor with Hunter New England Health

Participants cannot be given guarantees of anonymity or confidentiality, as the researcher cannot guarantee that individuals who participate in the focus group will not divulge personal information to others.

7. HOW YOUR PRIVACY WILL BE PROTECTED

All of the information collected during this study will be kept confidential by the study team. Your interview and focus group transcripts will be coded so that information connecting you personally with the record will be kept separately. The details will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002. Upon completion of the research study all information...
collected will be securely stored at the School of Nursing and Midwifery the University of Newcastle. It will be kept for a period of 15 years to comply with National and International Guidelines.

Any information obtained during the interviews or focus groups which are of an illegal nature or threaten the safety and welfare of an individual will be disclosed to the appropriate persons.

8. HOW THE INFORMATION COLLECTED WILL BE USED

The data will be reported in Ms McIvor’s thesis and scientific journals, and presented at scientific conferences. The information reported will be a compilation of the interview and focus group data and no individual participants will be identified in reports arising from this project.

9. ETHICAL GUIDELINES

This project will be carried out according to the National Statement in the Conduct of Human Research (March 2007) 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.

10. COMPLAINTS

This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference No

Should you have any concerns about your rights as a participant in this research or have a complaint about the manner in which the research is conducted, it may be given to the researcher or if an independent person is preferred then please do contact:

The Professional Officer

Dr. Nicole Gerrand
Hunter New England Research Human Ethics Committee
Locked Bag 1
New Lambton NSW 2305
Telephone 02 49214950 or 02 49213000Fax No. 02 49214818
Email:Nicole.Gerrand@hnehealth.nsw.gov.au

11 WHAT DO YOU NEED TO FIND OUT MORE ABOUT THE STUDY AND/OR HOW TO PARTICIPATE

Please read this information statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand or have questions contact the researcher.
If you would like to participate please complete and return the attached consent form in the reply paid envelope provided, this will be taken as your informed consent to participate. I will then contact you to arrange a time convenient to you for the interview and subsequent group session.

Thank you for considering this invitation

Dr Deborah Sundin
Principal Researcher
Appendix 3a: Client Consent Form

AHG STUDY

Client Consent Form

Researcher
Ms Dawn McIvor
Masters Student of
The University of Newcastle
Tel: 02 49214209
Mobile: 0416950635
Email: Dawn.Mcivor@hnehalth.nsw.gov.au

Consent Form for the research Project: The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Australian Heart Guide for home based cardiac rehabilitation.

Study Coordinator: Dawn McIvor

Name
Address
Preferred Contact Number

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the information statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to:

- Providing personal information on my age, gender, diagnosis, where I live and my employment status.
- An audio taped interview at a health care facility or my own home for approximately 60-90 minutes
- Attend a focus group or 1-2 hours duration

Yes/No (Please delete as appropriate)

I understand that my personal information will remain confidential to the researchers.

I have the opportunity to have questions answered to my satisfaction.

I understand that 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.

____________________________________  ___________________
Signature of Participant               Date

____________________________________  ____________
Printed name of Participant            Time
I have explained the nature and purpose of the study to the Subject named above.

____________________________________   ______________________
Signature of Investigator                Date

____________________________________   _________
Printed name of Investigator             Time

A copy of the information sheet and signed consent form will be given to you to keep.
## Appendix 3b: Partner, Relative, Friend Participant Consent Form

| AHG STUDY | Researcher  
|-----------|-------------|  
| SIGNIFICANT OTHER CONSENT FORM | Ms Dawn McIvor  
| | Masters Student of  
| | The University of Newcastle  
| | Tel: 02 49214209  
| | Mobile: 0416950635  
| | Email: Dawn.McIvor@hnehealth.nsw.gov.au |

**Consent Form for the research Project:** The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Australian Heart Guide for home based cardiac rehabilitation.

**Study Coordinator:** Dawn McIvor

---

Name  
Address  
Preferred Contact Number

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the information statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to:

- Provide personal information on my age, gender, where I live, employment and relationship to client using the Australian Heart Guide.

- An audio taped interview at a health care facility or my own home for approximately 60-90 minutes

- Attend a focus group or 1-2 hours duration Yes/No (Please delete as appropriate)

I understand that my personal information will remain confidential to the researchers.

I have the opportunity to have questions answered to my satisfaction.

I understand that 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.

---

Signature of Participant ___________________________  
Date ___________________________
I have explained the nature and purpose of the study to the Subject named above.

Signature of Investigator ___________________________ Date ________________

Printed name of Investigator ___________________________ Time ________________

A copy of the information sheet and signed consent form will be given to you to keep.
Appendix 4a: Patient Participant Information

Aussie Heart Guide Study

Patient Participant Information

Dear

You are being asked to take part in this research project as you were given the Aussie Heart Guide following your admission to hospital with heart problems.

We recently wrote to you asking you and your partner, relative or friend to take part in a research project into the use of the Aussie Heart Guide for home based cardiac rehabilitation. The initial invitation asked if you would take part in an interview and focus group about your experience of using the Aussie Heart Guide. We are now asking if instead of the interview and/or focus group you and your partner, relative or friend would be willing to complete and return the attached short questionnaire.

The purpose of the research is to explore the experience of using the Aussie Heart Guide for home based cardiac rehabilitation. This will assist us to better understand how using the Aussie Heart Guide at home in conjunction with the nurse mentor who supported you, assisted in your recovery and lifestyle change and enabled your partner, relative or friend to support you. Information from this project may assist in the development of future editions of the Aussie Heart Guide and development of support programs for partners, friends or relatives of clients with heart disease.

The research is conducted by Dawn McIvor from Hunter New England Health as part of a Master’s degree in research under the supervision of Dr Deborah Sundin from the University of Newcastle. Participation in this research is entirely your choice. Only those people who return the questionnaire will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect your care or access to health services.

If you agree to take part you will be asked to

1. Provide information about your age, gender, where you live, your employment status and your type of heart problem.

2. Complete and return a short questionnaire focusing on your physical and emotional recovery, your lifestyle changes and your experience of working with your heart nurse.
mentor. Your partner, friend or relative may also complete a separate short questionnaire focusing on their experience supporting your recovery.

**How your privacy will be protected**

All of the information collected during this study will be kept confidential by the study team. Your questionnaire will be collated and coded so that information connecting you personally with the record will be kept separately. The details will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the *NSW Health Records and Information Privacy Act 2002*. Upon completion of the research study all information collected will be securely stored at the School of Nursing and Midwifery the University of Newcastle. It will be kept for a period of 15 years to comply with ethical standards.

**How the information collected will be used**

The data will be submitted in Ms McIvor’s thesis and reported or presented in scientific journals and scientific conferences. The information reported will be a compilation of the questionnaire data. Individuals will not be identifiable.

**Ethical Guidelines**

This project will be carried out according to the National Statement in the Conduct of Human Research (March 2007) 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.

**Complaints**

This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference No 09/06/17/4.01

Should you have any concerns about your rights as a participant in this research or have a complaint about the manner in which the research is conducted, it may be given to the researcher or if an independent person is preferred then please do contact:

Dr Nicole Gerrand PhD  
Manager, Research Ethics and Governance,  
Hunter New England Health  
Locked Bag 1 NEW LAMBERTON NSW 2305  
Ph: (02) 4921 4950 Fax: (02) 4921 4818  
nicole.gerrand@hnehealth.nsw.gov.au

**What to do if you wish to take part or need to find out more about the study?**

If you would like to participate please complete and return the attached questionnaire in the reply paid envelope. If there is anything you do not understand or have questions and wish to discuss it please do not hesitate to contact the researcher.

Thankyou, for considering this invitation

---

Principle Researcher  
Dr Deborah Sundin  
School of Nursing and Midwifery  
The University of Newcastle, Callaghan NSW 2308 Australia  
Tel: 02 4926759 Fax 02 49616301  
Email: Deborah.Sundin@newcastle.edu.au
Appendix 4b: Partner, Relative, Friend Participant

Information Statement

Aussie Heart Guide Study
Partner, Relative, Friend Participant
Information

Information statement for the research project: The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Aussie Heart Guide for home based cardiac rehabilitation.

Study Coordinator: Dawn Mcivor

Dear

You are being asked to take part in this research project as your partner, relative or friend was given the Aussie Heart Guide following admission to hospital with heart problems.

We recently wrote to you asking you to take part in a research project into the use of the Aussie Heart Guide for home based cardiac rehabilitation. The initial invitation asked if you would take part in an interview and/or focus group about your experience of using the Aussie Heart Guide. We are now asking if instead of the interview and/or focus group you would be willing to complete and return the attached short questionnaire.

The purpose of the research is to explore the experience of using the Aussie Heart Guide for home based cardiac rehabilitation. This will assist us to better understand how using the Aussie Heart Guide at home in conjunction with the nurse mentor who supported your partner, relative or friend during their recovery and lifestyle change. We are also interested whether using the Aussie Heart Guide supported you in understanding and supporting your partner, friend or relative’s heart problems. Information from this project may assist in the development of future editions of the Aussie Heart Guide and development of support programs for partners, friends or relatives of clients with heart disease.

The research is conducted by Dawn Mcivor from Hunter New England Health as part of a Masters degree in research under the supervision of Dr Deborah Sundin from the University of Newcastle. Participation in this research is entirely your choice. Only those people who return the questionnaire will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect your care or access to health services.

If you agree to take part you will be asked to
1. Provide information about your age, gender, where you live, your employment status and you’re your relationship to the patient.
2. Complete and return a short questionnaire focusing on the use of the Aussie Heart Guide in relation to its usefulness in assisting and supporting your partner, relative or friend’s
physical and emotional recovery, lifestyle changes and your experience of working with the heart nurse mentor.

**How your privacy will be protected**

All of the information collected during this study will be kept confidential by the study team. Your questionnaire will be collated and coded so that information connecting you personally with the record will be kept separately. The details will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the *NSW Health Records and Information Privacy Act 2002*. Upon completion of the research study all information collected will be securely stored at the School of Nursing and Midwifery the University of Newcastle. It will be kept for a period of 15 years to comply with ethical standards.

**How the information collected will be used**

The data will be submitted in Ms McIvor’s thesis and reported or presented in scientific journals and scientific conferences. The information reported will be a compilation of the questionnaire data. Individuals will not be identifiable.

**Ethical Guidelines**

This project will be carried out according to the National Statement in the Conduct of Human Research (March 2007) 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.

**Complaints**

This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference No 09/06/17/4.01

Should you have any concerns about your rights as a participant in this research or have a complaint about the manner in which the research is conducted, it may be given to the researcher or if an independent person is preferred then please do contact:

Dr Nicole Gerrand PhD  
Manager, Research Ethics and Governance,  
Hunter New England Health  
Locked Bag 1, NEW LAMBTON NSW 2305  
Ph: (02) 4921 4950  Fax: (02) 4921 4818  
nicole.gerrand@hnehealth.nsw.gov.au

**What to do if you wish to take part or need to find out more about the study?**

If you would like to participate please complete and return the attached questionnaire in the reply paid envelope. If there is anything you do not understand or have questions and wish to discuss it please do not hesitate to contact the researcher.

Thankyou, for considering this invitation.

Principle Researcher

Dr Deborah Sundin  
School of Nursing and Midwifery,  
The University of Newcastle, Callaghan NSW 2308 Australia  
Tel: 02 4926759 Fax 02 49616301

Email: Deborah.Sundin@newcastle.edu.au
Appendix 5a: Client questionnaire

Aussie Heart Guide Study

Client Questionnaire

Questionnaire for the research project: The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Aussie Heart Guide for home based cardiac rehabilitation.

Study Coordinator: Dawn McIvor

Please complete the questionnaire and return in the stamped addressed envelope attached.

Please tick the appropriate answer

Personal Information

1. How old are you

   Age
   □ 30-45  □ 45-55  □ 56-65  □ 66-75  □ 76 -85
   □ 86+

2. What is your gender
   □ Male  □ Female

What is your highest level of education?

   □ Primary schooling only
   □ Secondary schooling completed
   □ Secondary schooling not completed
   □ Trade qualification or TAFE:
   □ University or other tertiary study
   □ Other or not applicable: please describe:

4. What is your current employment status
Employed full-time  Employed part-time-time  Self employed
Retired  Unemployed

5. What was the reason for your recent hospitalisation for heart problems?

Heart Attack
Angina
Post Stent implantation
Heart Failure
Acute Coronary Syndrome
Post Cardiac surgery
Other (please state)

The Aussie Heart Guide

6. Why did you choose the Aussie Heart Guide for your Cardiac Rehabilitation?

7. Did you use the Aussie Heart Guide?
   Yes (If Yes, go to Q8)
   No (If No please state why)
8. How useful was the Aussie Heart Guide in assisting in your recovery?

☑️ Extremely useful ☐ Very useful ☐ Moderately useful ☐ NOT very useful ☐ NOT at all useful

9. How useful was your contact with your nurse mentor?

☐ Extremely useful ☐ Very useful ☐ Moderately useful ☐ NOT very useful ☐ NOT at all useful

10. How often did you have contact with your nurse mentor?

☐ Once ☐ Twice

☐ 3-5 times ☐ 6 or more times

11. What did you like most about the contact with your nurse mentor?

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12. What did you like least about the contact with your nurse mentor?

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13. What did you like most about the Aussie Heart Guide?


14. What did you like least about the Aussie Heart Guide?


13. Other Comments: please provide any other comments about using the Aussie Heart Guide


Thank you for completing this Questionnaire
Appendix 5b: Partner, relative or friend questionnaire

Aussie Heart Guide Study
Partner, relative or friend questionnaire

Student Researcher
Dawn Mcivor
Hunter New England Health
Locked Bag No. 1.
Hunter Region Mail Centre 2310
Tel: 02 49214209 Fax: 02 49214210
Email: dawn.mcivor@hnehealth.nsw.gov.au

Questionnaire for the research project: The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Aussie Heart Guide for home based cardiac rehabilitation.

Study Coordinator: Dawn Mcivor

Please complete the questionnaire and return in the stamped addressed envelope attached.

Personal Information

Please tick the appropriate answer

1. Age
   - 30-45
   - 45-55
   - 56-65
   - 66-75
   - 76-85
   - 86+

2. What is your highest level of education?
   - Primary schooling only
   - Secondary schooling completed
   - Secondary schooling not completed
   - Trade qualification or TAFE:
   - University or other tertiary study
   - Other or not applicable: please describe:
3. What is your gender  □ Male  □ Female

4. What is your current employment status
   □ Full-time  □ Part-time  □ Self employed  □ Retired  □ Unemployed

5. What is your relationship to the person using the Aussie Heart Guide?
   □ Spouse  □ Partner  □ Relative  □ Friend

The Aussie Heart Guide

6. What did you like most about the Aussie Heart Guide?

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7. What did you like least about the Aussie Heart Guide?

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8. How much contact (number of sessions) did you or your spouse partner, significant others have with your nurse mentor?

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9. How useful was the Aussie Heart Guide in assisting you in assisting your spouse, partner, significant other in their recovery?

10. How useful was your contact with your nurse mentor?

11. How useful was the Aussie Heart Guide in helping you understand your spouse / partner / significant other’s illness and their lifestyle change or recovery?

12. Other Comments: please provide any other comments about using the Aussie Heart Guide

Thank You for completing this questionnaire
Appendix 6: Letter for AHG Nurse mentors inviting them to take part in the study

Dear Nurse Mentor

Thank you for your support of the pilot of the Australian (Aussie) Heart Guide (AHG). The information you have provided in regard to your patients has made a significant contribution to the development of the AHG and its use within Australia.

To further improve our understanding of the AHG in Australia and to assist us in the development of training for nurse mentors, I am writing to ask if you would participate in a study about your experience of using the AHG with your clients.

The study is conducted by Dawn Mclvor as part of a research masters degree, supervised by Dr Deborah Sundin, Professor Diana Keatinge and Dr Kerry Inder at the University of Newcastle. The study aims to explore the experience of the client, their significant other and the nurse mentor’s use of the AHG through interviews and focus groups.

While you may not directly benefit from taking part in this study, your participation will assist ACRA in understanding the opportunities and barriers to the use of the AHG for cardiac rehabilitation nurses in Australia.

Enclosed is an information sheet about the study and a consent form, should you wish to take part please complete the consent form and return in the reply-paid envelope provided. You will then be contacted by Dawn soon after to arrange an interview on a date and time of your convenience.

Thankyou

Paula Candlish
President
4 February 2010
Appendix 7: Nurse Participant Information Statement

AHG STUDY

Nurse Participant Information Statement

Information statement for the research project: The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Australian Heart Guide for home based cardiac rehabilitation.

Study Coordinator: Dawn McIvor

1. INTRODUCTION

You are invited to take part in the research project identified above which is being conducted by Dawn McIvor from Hunter New England Health as part of a Masters degree in research under the supervision of Dr Deborah Sundin from the University of Newcastle. You are being invited to take part as you are a nurse using the Australian Heart Guide with clients following admission to hospital with Acute Coronary Syndrome.

This Participant Information statement contains detailed information about the research project. Its purpose is to explain to you as clearly as possible everything that is involved in this project before you decide whether or not to take part.

Please read this Participant Information statement carefully. Feel free to ask questions about any information in the document, or discuss the project with a family member, friend, colleague or your manager.

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 this Participant Information statement and the Consent Form to keep as a record.

2. PURPOSE

The purpose of the research project is to explore the nurse experience of home based cardiac rehabilitation using the Australian Heart Guide with a view to understanding how it differs from your experience of hospital based cardiac rehabilitation. In addition your
experience of working in partnership with your client and the nurse client relationship within cardiac rehabilitation will be explored. Information obtained from this study may assist in the development of future editions of the Australian Heart Guide and identify potential training needs for nurses facilitating the program.

As a trained heart mentor you may have been involved in the pilot of the Australian Heart Guide which is focusing on client outcomes in relation to anxiety, depression, quality of life and risk factor modification. As this is a new approach to home based cardiac rehabilitation within Australia, there is a need to explore the nurse’s experience of this model of care. With a view to gaining an understanding of the acceptability and adaptability of the Australian Heart Guide to the Australian cardiac rehabilitation nurse, as well as understanding the nurse-patient relationship and its impact on working in partnership in home based cardiac rehabilitation.

3. WHO IS BEING ASKED TO PARTICIPATE?

Approximately 10 nurse participants facilitating the Australian Heart Guide from Hunter New England Health who have facilitated the Australian Heart Guide with at least one patient (who may or may not be in the study) will be asked to take part in the study. 5-10 clients and their partner/friend/relative will also take part in the study.

You need to have used the Australian Heart Guide with a client in the last twelve months to take part in this study.

4. PARTICIPATION IS VOLUNTARY

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect your employment with Hunter New England Health, your clinical role or your role as a heart mentor for the Australian Heart Guide.

If you decide to participate you may withdraw from the project at any time without giving any reason and any data collected about you will be withdrawn from the study, destroyed or returned to you.

The researcher may withdraw a participant if it is considered in the participant’s best interest or if it is appropriate to do so for another reason. If this happens the researcher will explain why and advise you about any follow up or alternative arrangement if appropriate.

5. WHAT YOU WILL BE ASKED TO DO?

If you agree to take part in this study you will be asked to:

1. Provide information around your age, gender and the number of years you have worked as a nurse and your experience as a cardiac rehabilitation Nurse, and how many clients you have mentored using the Australian Heart Guide

2. Participate in an audio-taped interview at a venue of your choice with the study coordinator to discuss your experience. This interview will focus on your experience of using the Australian Heart Guide, your perception of its role in the physical and emotional recovery of your client, its advantages and disadvantages in relation to risk factor modification and the
process of partnership working with your client. This interview may take approximately 60-90 minutes. With your permission the interview will be taped and you may ask for the tape to be stopped and have it edited or erased at any time during the interview.

Following your interview you will receive a verbatim copy of the interview (transcript) for you to confirm or change any details which you are not happy with. If you do not return the written copy in the stamped addressed envelope provided within 2 weeks the study coordinator will assume you are happy with the interview transcript.

3. Attend a 1-2 hour audio taped group session at a local health care facility with other heart mentors who have used the Australian Heart Guide to discuss your experience. This group session will be facilitated by the study coordinator and the group discussion will be audio taped and focus on the information obtained from the interviews.

You may choose to participate in the interview only without participating in the focus group. The focus group session will be referring to and enlarging upon material gathered in the interviews, so the choice to participate in the focus group only is not offered.

6. WHAT ARE THE RISK AND BENEFITS OF PARTICIPATING?

As a participant in the study there may be no individual benefit in taking part. If you wish you will receive a written report of the study findings.

There are minimal risks to your participation in that you may feel anxious or get upset during the interview or focus group. If this is the case appropriate support will be sought through the Employee Assist Program (EAP).

Participants in the focus groups cannot be given guarantees of anonymity or confidentiality, as the researcher cannot guarantee that individuals who participate in the focus group will not divulge personal information to others. However all participants in the focus groups will be asked to expect each other's privacy and maintain confidentiality.

7. HOW YOUR PRIVACY WILL BE PROTECTED

All of the information collected about your experiences during this study will be kept confidential by the study team. Your interview and focus group transcripts will be coded so that information connecting you personally with the record will be kept separately. The details will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002. Upon completion of the research study all information collected will be securely stored at the School of Nursing and Midwifery the University of Newcastle. It will be kept for a period of 15 years to comply with national and international guidelines.

However, to comply with the Australian Nursing and Midwifery Council (ANMC) regulations, if you chose to disclose information that constitutes unlawful or harmful conduct I will have an obligation to report it.

7. HOW THE INFORMATION COLLECTED WILL BE USED?

The data will be submitted in Ms McIvor’s thesis and reported or presented in scientific journals and scientific conferences. The information reported will be a compilation of the interview and focus group data. Pseudonyms will be used in all presentations of data from
this project to protect your confidentiality. Further, any potentially identifying information about the institutions you work in that may be raised in your interviews or the discussion group will be removed or elided prior to submission of the thesis or publication.

**8.0. ETHICAL GUIDELINES**

This project will be carried out according to the National Statement in the Conduct of Human Research (March 2007) 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.

**9.0. COMPLAINTS**

This research has been approved by the Hunter New England Human research Ethics Committee of Hunter New England Health, reference 09/06/17/4.01.

Should you have any concerns about your rights as a participant in this research or have a complaint about the manner in which the research is conducted, it may be given to the researcher or if an independent person is preferred then please do contact:

The Professional Officer

Dr. Nicole Gerrand  
Hunter New England Research Human Ethics Committee  
Locked Bag 1  
New Lambton NSW 2305  
Telephone 02 49214950 or 02 49213000Fax No. 02 49214818  
Email:Nicole.Gerrand@hnehealth.nsw.gov.au

**11 WHAT DO YOU NEED TO FIND OUT MORE ABOUT THE STUDY AND/OR HOW TO PARTICIPATE**

Please read this information statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand or have questions contact the researcher.

Principle Researcher  
Dr. Deborah Sundin  
School of Nursing and Midwifery,  
The University of Newcastle,  
Callaghan, NSW 2308 Australia  
Tel: 02 492 6759 Fax 02 4921 6301  
Email: Deborah.Sundin@newcastle.edu.au

Research Student  
Ms Dawn McIvor  
Research Masters Student  
The University of Newcastle  
Tel: 02 49214209  
Mobile: 0434072699  
Email: Dawn.Mcivor@hnehealth.nsw.gov.au

If you would like to participate please complete and return the attached consent form in the reply paid envelope provided, this will be taken as your informed consent to participate. I will then contact you to arrange a time convenient to you for the interview and subsequent group session.
Thank you for considering this invitation

Dr Deborah Sundin
Principal Researcher
Appendix 8: Nurse Consent Form

Consent Form for the research Project: The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Australian Heart Guide for home based cardiac rehabilitation.

Study Coordinator: Dawn McIvor

Name
Address
Preferred Contact Number

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the information statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to:

- Providing information on my number of years in nursing, my experience as a cardiac rehabilitation nurse and the number of patients I have mentored using the Australian Heart Guide.

- An audio taped interview at a health care facility or my own home for approximately 60-90 minutes

- Attend a focus group or 1-2 hours duration Yes/No (Please delete as appropriate)

I understand that my personal information will remain confidential to the researchers.

I have the opportunity to have questions answered to my satisfaction.

I understand that 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.
Signature of Participant ___________________________ Date

Printed name of Participant ___________________________ Time

I have explained the nature and purpose of the study to the Subject named above.

Signature of Investigator ___________________________ Date

Printed name of Investigator ___________________________ Time

A copy of the information sheet and signed consent form will be given to you to keep.
Appendix 9: Verification Document: Findings Summary
Review Document

Preliminary Findings from Interviews with Aussie Heart Guide (AHG) mentors participating in the study titled: The experience of clients with coronary heart disease, their significant others and cardiac rehabilitation nurses using the Australian Heart Guide for home based cardiac rehabilitation

Introduction
Last year you and other nurses kindly participated in interviews relating to the above study. The information from those interviews was transcribed and through a process of reading and rereading the transcripts I identified common experiences for yourself and the other nurses who agreed to be interviewed. The common experiences were then labelled as categories and sub categories. The categories being the main elements I detected coming form the interviews during the analysis process and the sub categories commonly mentioned elements in the main categories. The categories and sub categories are described in the summary document attached.

The summary attached is my interpretation of the information you and other nurses provided during the interviews. This summary will then be used to develop the overall findings from the study and describe your experience of using the Aussie Heart Guide. I would like to give you the opportunity to review the categories and sub categories to ensure that I have accurately summarised your experience of using the Aussie Heart Guide. This will ensure that the findings from the study accurately reflect your experience, not just my interpretation of that experience. This will add to the value of the study. Please follow the instructions below for the next stage of the study to assist in the validation of your experience.
**What you are being asked to do**

1. Prior to the videoconference on 27th June I would be grateful if you would read the titles and the descriptions of each of the Categories and Sub-categories below and think about whether these reflect your experience with using the *Aussie Heart Guide* with patients. As you consider each Category and Sub-Category please comment (where requested) on whether or not these reflect your experiences of the Aussie Heart Guide (AHG) and add any additional comments that you feel are relevant to you. Please also respond to the request at the conclusion of the following document to prioritise, in order of importance, the Categories as outlined in this document.

There are no right or wrong responses; I am seeking your thoughts about whether and how well these Categories and Sub-categories reflect your experiences of using the AHG in practice. They reflect common issues discussed by the nurse participants during the interviews. I need to check whether, when you reflect again on your practice with the AHG, they are key features of your experience of using this.

If you need more space to comment please write on a separate piece of paper and note the section number you are commenting on.

2. Please have this completed document (with your comments etc.) readily accessible to you when we engage in the videoconference. During this videoconference I will be seeking to engage all those participants who have agreed to be contacted for the videoconference in a discussion about these Categories and Sub-Categories and respond to any questions they may have about the process of their identification. I will also be seeking the view of participants about any adjustments they agree should be made to either the titles of the Categories/Sub-Categories or to their description and any other comments that participants might like to add.

**Please do not, as a result of the videoconference, make any adjustments to this Findings Summary Review Document on which you will have already responded to the requests for comments. Instead, following the**
videoconference, please forward this to me in the stamped addressed envelope provided.

If you have any questions please do not hesitate to contact me on
Telephone: 02 49214209, 0416950635 or Email dawn.mcivor@hnehealth.nsw.au

Thank you
Category 1: Usefulness of the Aussie Heart Guide (AHG)
The above Category was derived during the analysis of all the interviews conducted with the nurse participants, almost all of which discussed different and similar aspects of the usefulness of the AHG. Nurse participants identified that the various components of the AHG (educational resources, patient-led consultation either face-to-face or via the telephone, and opportunity for goal setting) were useful in providing support to both nurses and patients. One nurse suggested: “It’s a good program really, its user friendly as well as worker friendly”.

Please comment on whether or not Category 1: Usefulness of the Aussie Heart Guide (AHG) reflects your experiences with AHG. Add any additional comments you might have.

Although nurse mentors suggested that the AHG overall provided a support mechanism for nurses and patients, their comments suggested that the way in which the AHG provided support for nurses was different to the way it provided support for patients. Therefore, two sub categories emerged from the interview data in relation to Category 1.

Sub-category 1.1: Usefulness of the AHG in supporting nurses
To use the AHG with patients, the participating nurses undertook a single day of training. Four nurse participants found the most helpful elements of the training were behaviour change theory, motivational interviewing and the rest activity cycle. One nurse participant suggested that the AHG “looked quite simple for any health person to be able to pick it up and use”. Only nurses who have completed the one-day training can facilitate the AHG with patients and this nurse participant felt that this hindered service provision in rural areas. Arguing if she “left like (sic) the health care and there isn’t anyone else (another nurse) that’s done the training, in how to use it (the AHG). It would leave a reduced service in my area” as there were no other nurses in her rural area who had completed the AHG training.

The structure of the AHG was seen by the participating nurses as also being a useful means of support for themselves, especially if a nurse had little cardiac rehabilitation experience. The evidence base and format of the AHG gave nurses more confidence to work with patients. As one nurse participant explained: “I don’t have recent coronary care experience, nor do I have specialist cardiac training in cardiac rehab but I certainly found the structure useful”. Even though some participants were experienced in cardiac rehabilitation, a number of them suggested that the structure provided support to help them keep track of their patient’s progress, focus the consultation and standardise the program. An example of this came from Betty (pseudonym) who said that “the good thing about the AHG is that if I am getting lost and the client is maybe confusing me, the AHG has got a format where I guess there is a fall back position”.

Please comment on the above Sub-category 1.1: Usefulness of the AHG in supporting nurses, considering whether or not it reflects your experiences. Please add any additional comments below.
Sub-category 1.2: Usefulness of the AHG in supporting patients with their recovery and lifestyle change

Nurse participants identified that support for patients was provided by the educational resources in the AHG. All of the nurse participants thought it was beneficial that the patient could access all the information in the resources at home. The resources (patient and carer information booklets, CD, diary and relaxation tape) received mixed reviews from the nurse participants. One nurse participant thought that “the information was compact” and another nurse participant said “It [AHG] was too much information to give in one go”. Several nurse participants commented on computer literacy and patients’ own literacy levels, suggesting that “DVDs were a waste of time as elderly people were not computer literate” or in relation to literacy “you have to find out if they can actually read and write”. One nurse participant mentioned the carer booklet, saying she “thought it was a good thing to be able to give the carers something for themselves”.

Nurse participants identified that patients preferred the information booklets and the rest activity cycle as opposed to the diary and relaxation tape because the information booklets and rest activity cycle were more helpful to them. An example of this came from a nurse participant when she explained how a patient told her that she he benefited from the rest activity cycle because: “I [the patient] don’t have to get all my floors done in one day, and I don’t have to get the dusting done as well on the same day and I don’t have to change the sheets on the same day”. The majority of nurse participants liked the relaxation tape evident in one nurse participant’s comment that: “the AHG is the first program that puts patients on the map”. However, in contrast they found that patients did not like the tape and few used it. One nurse participant said ‘they are farmers they don’t just sit and listen”. Another nurse participant said that patients “found the tape boring”.

Patients using the AHG are asked to set individual goals relating to their recovery and complete a daily diary on their progress in achieving the goals. All of the nurse participants felt that the patients did not find goal setting or the diary useful and described reluctance by patients to use these tools for lifestyle change. Most of the nurse participants found that patients wanted the nurse to set the goals as described here by Claire (pseudonym) “it (the AHG) actually requires them (the patient) to
actually do something, the AHG actually requires them to put pen to paper and make a commitment and I tell you they are not good at it”. Several nurse participants commented that they thought the diary was not very useful for patients for tracking their progress. The reasons suggested by one nurse participant were “people just do not like writing things down”. Another nurse participant suggested that “some people use them (diaries) like religious diaries and fill them but for as many people who are like that a lot of people don’t fill them in”. All of the nurse participants described at least one patient who found the goal setting or the dairy useful.

Please comment on the above Sub-category 1.2: Usefulness of the AHG in supporting patients with their recovery and lifestyle change, considering whether or not it reflects your experiences. Please add any additional comments below.
Category 2: Challenges in the nurse/patient relationship when using the AHG

All nurse participants were asked about their relationship with patients when using the AHG. The nurse participants indicated that there are distinct differences in the relationships built up between nurses and patients who attend group cardiac rehabilitation programs and nurses and patients who use the AHG.

One nurse describing the differences in her relationships with patients in group based programs as opposed to those using the AHG suggested the professional contact is unchanged but there is a slightly more personal element to the relationship when you see them weekly (in a group)”. Another nurse said that her relationship with patients using the AHG “was good and friendly” but it took “longer for the worker (the nurse) to see the whole person (the patient)” when she used the AHG. The challenges in establishing a personal relationship were perceived by the nurse participants as more of a problem for them than for the patients.

Please comment on whether or not Category 2: Challenges in the nurse/patient relationship when using the AHG reflects your experiences with AHG. Add any additional comments you might have.

The main challenge identified by the participating nurses in developing the relationship was that the contact with the patient was predominately over the telephone with the AHG rather than face-to-face. This led to some difficulties for the nurses in regard to developing a rapport with patients, difficulties with communication because of the lack of non-verbal communication and a feeling that patients were perhaps not honest about their progress or recovery. These challenges formed one sub category:
Sub-category 2.1: Challenges of telephone only contact in nurse/patient communication

The AHG is designed as a home based program and as such communication with patients is usually only via the telephone. The majority of nurse participants identified the lack of face-to-face communication as a challenge for them and a weakness of the AHG. They explained that this impacted their rapport with patients. As one nurse described: “It’s different [the relationship] because you don’t get to know them as well. It’s impersonal; it’s very impersonal.” The impersonal nature of the relationship was a challenge for the majority of nurse participants with only one nurse suggesting that it made no difference to her relationship with patients. Nurse participants also felt challenged in their ability to assess a patient’s needs and evaluate the effectiveness of their interventions without face-to-face communication. One nurse participant felt that she did not have “the full range of communication” without being able to “see the (the patients’) body language, their demeanour, their grooming and how much they care for themselves”. The nurse participants felt uncomfortable relying solely on what the patients described rather than having their own visual confirmation.

Some nurse participants were particularly doubtful that some patients had made the progress or participated in the activities of the AHG to the extent that they reported. The nurse participants suspected that patients did not, or may not report honestly about their progress in rehabilitation or the way they were using the AHG. They found it challenging that the AHG did not give them the opportunity to visually assess this progress themselves and required them to rely on patients’ reports about this provided over the telephone. Several nurse participants said that “patients lie about the changes they are making to their lifestyle” or suggested that “patients can tell you anything over the phone”. Some nurse participants suggested that the patients were dishonest about their progress because they did not want to disappoint the nurse or themselves about their lack of progress or use of the AHG. One nurse illustrated this in her comment that: “They [the patient] want to tell you [the nurse] that you’re doing a great job and tell themselves they’re doing a great job”.
Suspicion of dishonesty was expressed by a nurse participant when she said “they [the patient] said they read the books”; however, she commented that “whether they did or not I do not know”. This suggested she had doubts about the honesty of this patient’s comment. Another nurse was suspicious of patients’ honesty in relation to their reporting of accurate anxiety and depression levels.

Please comment on the above Sub category 2.1: the challenge of telephone only contact in nurse/patient communication. Reflects your experience with the AHG and add any additional comments you may have.
Category 3: Advantages and disadvantages of home based cardiac rehabilitation using the AHG for home based cardiac rehabilitation

The AHG is a home based cardiac rehabilitation program that aims to offer patients who are unable or unwilling to attend hospital based face-to-face programs an alternative option. Several nurse participants felt that the AHG was a novel idea. They expressed excitement at being involved in something different and new as described here by one nurse participant: “I thought it was quite a challenge and a chance to do something different” and “it’s the way of the future and they [patients] quite like being part of the future”.

The AHG is used by patients at home with support from the nurse mentor over the telephone. One advantage of the AHG acknowledged by the nurse participants was that it was a good alternative to hospital based rehabilitation programs for patients living in rural areas some distance from hospital based cardiac programs, or for patients who may have difficulties with transport. One nurse commented that “it was a good thing that you can give the information to people who couldn’t make it to your group as they lived a fair distance away”. The issue of access was seen by the nurse participants as a benefit for patients predominately in rural areas.

Another advantage highlighted by most nurse participants was that patient preference for home based or hospital based programs could now be considered, although there was a difference of opinion between nurse participants in relation to patient preference in program (either face to face or via the AHG) if access or transport was not an issue. Some nurse participants suggested that if a group program was accessible then patients would choose that program over the AHG. Other nurse participants disagreed with this, suggesting that for “clients who just don’t want to do groups and don’t want to do groups at all, there is an opportunity to fill in the gaps”.

Several nurse participants acknowledged that patients who wanted to return to work, or who had to wait for a vacancy on a group program, may prefer to use the AHG. Despite the nurse participants’ apparent enthusiasm for the advantages of the AHG, their experience also raised some disadvantages of the AHG which they felt impacted on the effectiveness of the AHG and home based programs generally.
Patients attending hospital face-to-face programs usually exercise in a group once or twice a week for a number of weeks. One disadvantage of the AHG highlighted by the majority of nurse participant was the lack of a “group effect” or peer support: this comment refers to the support patients in the group gain from each other. Nurse participants suggested that this peer support helped patients in their recovery, improved patient’s motivation to change their lifestyle and assisted patients to maintain these changes. The nurse participants suggested this lack of group effect impacted on the effectiveness of the AHG as one nurse explained: “They [patients using the AHG] did not have any peer support and a lot of people in cardiac rehab find that valuable to maintain lifestyle changes”.

Another disadvantage of home based cardiac rehabilitation using the AHG was the inability of the nurses to increase or decrease a patient’s exercise intensity which the group hospital exercise based program facilitates. The majority of nurse participants suggested that this ability contributed to the effectiveness of hospital based programs and was something that was more challenging using the home based AHG.

*Please comment on Category 3: The advantages and disadvantages of home based cardiac rehabilitation using the AHG for home based cardiac rehabilitation. Please add any additional comments below.*
Category 4.0: Partnership and control

Traditionally the nurse has made the suggestions and recommendations about what changes the patient should make to his/her life style and guided the patient through the development of his/her goals and subsequent action plan. Instead of the nurse ‘directing’ the rehabilitation process in this way, the AHG, as one nurse participant explained, aims to “put the patient in the driver’s seat” of their own rehabilitation process with the nurse working in a partnership role with him/her. This enables the patient to become responsible for his/her own rehabilitation process and outcomes rather than the nurse, although the nurse remains in the mentor/supportive role for this process. Working in partnership involves the nurse facilitating the patient’s decision making when identifying his/her lifestyle changes, setting goals and developing plans to make these changes.

Despite the intent, however, all of the nurse participants experienced difficulties in ensuring patients took control of their rehabilitation process. This was evidenced in patients’ tendency not to achieve goal identification or completion of action plans and/or tasks within these plans, such as increasing exercise. Nurse participants demonstrated a sense of frustration that patients were not willing to take responsibility for their own recovery: for example, one said “you hand them the information, then ask have you read this and it’s like no…and it’s very frustrating”.

Some nurse participants appeared to have a lack of understanding about shared responsibility between the patient and nurse in a partnership, appearing to want to shift all of the responsibility to the patients as demonstrated here by a nurse participant who stated: “They [the patients] are still expecting that you, the nurse, will do all the stuff, instead of them doing it”. Another appeared to be suggesting how difficult it was to relinquish control and work in partnership when she said “It’s hard not just to tell them [patients] what they should do and how they should do it”. Several nurses clearly acknowledged that they found it difficult to give control to the patients, stating: “I like to be in charge” or “I convinced him to set this goal”.

Please comment on whether or not Category 4: Partnership and control reflects your experiences with AHG. Add any additional comments you might have.
Category 5.0: Patient and nurse engagement with the AHG

The AHG itself is a guide the patient uses to support them in their recovery from their cardiac event, as a part of using the guide the patient and nurse embark on a process of rehabilitation involving active engagement of both parties in order to support the patient’s recovery. This category of engagement relates to how the patient and nurse are engaging with the AHG itself and engaging in the process of rehabilitation. The nurse participants described incidents where mutual engagement between nurse and patient was apparent: with one nurse illustrating an example of this as “When you do a follow-up consultation with them [the patient], and they actually say something like “oh, on page 23 I read such and such and I am not sure what it means”. Engaging with the participant in the process of rehabilitation gave the nurse participant job satisfaction because, as one nurse suggested, when the process works “it’s very, very rewarding”. The nurse participants also described incidents where one or both parties were not engaged in the use of the guide or the process of rehabilitation. This resulted in anger, frustration and dissatisfaction with the AHG, the rehabilitation process and with each other (patient nurse). An example is from one nurse participant expressing her frustration with a patient’s lack of engagement in reading the information “you hand them (the patient) the information and when you follow up you ask have you read this? And its no. Its very frustrating”.

Please comment on whether or not Category 5: Patient and nurse engagement with the AHG reflects your experiences with AHG. Add any additional comments you might have.
The nurse participants also described factors that in their opinion influenced either patients’ or their own engagement with the AHG. These influences were related to physical, social, psychological and organisational factors and, according to nurse participants’, were different for patients when compared to themselves. These influences have been separated into the two sub-categories below.

**Sub-category 5.1: Nurses’ perceptions of influences on patients’ engagement with the AHG**

Engagement by patients according to the nurse participants was reflected by the patient actively making lifestyle changes and engaging with the nurse mentor in the rehabilitation process. Nurse participants suggested that a patient’s engagement with the AHG was influenced by their previous experience of cardiac rehabilitation (if any), their transition from hospital to home, and the patient’s illness experience.

Several nurses suggested that patients who had previously completed cardiac rehabilitation engaged well with the AHG because it offered something different from their previous experiences. One nurse participant describing this: “For a lot of people who have had a cardiac condition for a few years some types of cardiac rehab become repetitive, so the AHG gives the rehab nurse and the patient the chance to fill in the gaps in the patient’s knowledge and the patient’s previous recovery attempts.”

Several nurse participants suggested that the patient’s experience of the transition from hospital to home also influenced the patient’s engagement with the AHG. A nurse participant suggested that “the transition from a perceived high tech area to a perceived low tech home program meant that the patient did not value the importance of the lifestyle change”. Therefore engagement with the AHG may be limited. However, although another nurse participant argued that the AHG gave the patient the impetus to seize control of their health condition “They (the patient) feel that other people have control over their health condition, they feel their cholesterol is their doctor’s business, their exercise is their cardiac rehab nurse’s business but the Aussie Heart Guide gives it all back to them, we (health professionals) can’t make you do this and for some patients this is a revelation”. 
Nurse participants also suggested that the patient’s illness experience and perception of the severity of that illness influenced their engagement with the AHG. One nurse participant suggested this was because “those (patients) with stents think there is nothing wrong with them as opposed to those (patients) who have had heart surgery who feel its major”. Another elaborated on these comments saying “I find with stent clients you’ve got to actually convince them to actually do rehab at all because they think they are all right”. Another nurse participant, discussing engaging with patients who have had cardiac surgery where complications or risk of death during surgery is greater than for those patients who have stents implanted found that “We’ve had to deal with a lot of other issues with the whole death and dying thing before we start on the rehab bit”.

Please comment on whether or not this Sub-category 5.1: Nurses’ perceptions of Influences patient engagement with the AHG reflects your experiences with AHG. Add any additional comments you might have.
Sub-category 5.2: Nurses’ perceptions on what influenced their engagement with the AHG

Nurse engagement with the AHG according to the nurse participants involved supporting patients to use the guide, working in partnership with the patient to change their lifestyle and embracing the rehabilitation process. This engagement was influenced by patient selection, patient engagement and organisational influences such as time constraints.

Several of the nurse participants explained that recruitment of the patients to the AHG was often done by a third party and this affected how they (the nurses) interacted and engaged with patients. If, in the nurse participants’ opinion, the AHG was not appropriate for the patient for whom it had been selected, as described here by a nurse participant, “the AHG was a waste of time” as “it was in the wrong hands (inappropriate patient)”. Suggesting that the nurse felt only a specific type of patient should be given the AHG; other nurse participants were not as blatant about suitability but did make judgments about patient’s motivation to change their lifestyle or the patient’s ability to maintain lifestyle change. An example of this is from Betty (pseudonym) describing the difficulties a patient had with developing an action plan “I think he just wanted to ignore it (his health) all. He didn’t want to know, he buried his head in the sand”. The nurse’s perception of the suitability of the patient to use the AHG and their own judgements influenced how well the nurse engaged with individual patients and the patient’s success of using the AHG.

All of the nurse participants commented that using the AHG with patients was time-consuming. This influenced their motivation and their enthusiasm to use the AHG and to engage with the patient trying to adhere to it. One nurse participant appeared quite angry and described how she thought the training (about how to use of the AHG) had been unrealistic: “(the) time (it takes) is a disadvantage because you have to weave your way in before you can actually present it (the AHG to the patient). No matter what that pommy bloke said, I don’t know but with Australian clients you cannot just do it (the rehabilitation process and use of the AHG) in an hour”. Another nurse said, “It’s time consuming, it’s very time consuming” and because of this she “felt it was just (a) process you go through”.

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One nurse participant suggested that “hospital based cardiac rehabilitation nurses may be threatened by the emergence of the AHG” as funding for cardiac rehabilitation programs may be redirected towards the AHG rather than hospital programs. Another nurse participant agreed suggesting “it (the AHG) is the way of the future) However, while this implied a negative influence on whether or not they were willing to engage with patients in the use of the AHG, participants did not comment on this directly.

*Please comment on whether my interpretation of the Sub-category 5.2: Nurse Perceptions on what influenced their engagement of with the AHG reflects your experience and add any additional comments you may have*
Priorities in the importance of Categories emerging from the study

In order to assist with possible recommendations for the future resulting from this study, please prioritise the five Categories (not the sub-categories) identified above from the most important to the least important using the scale below:

1. Most important
2. Very Important
3. Important
4. Not very important
5. Least Important

Category 1: Usefulness of the AHG
Priority

Category 2: Challenges in the nurse patient relationship when using the AHG
Priority

Category 3: Advantages and disadvantage of home based cardiac rehabilitation using the AHG
Priority

Category 4: Partnership and Control
Priority

Category 5: Patient and nurse engagement with the AHG
Priority

Thankyou for your help with this study
Please return this to me in the enclosed envelope
Appendix 10a: Prompt for patient Interviews

1. Topic Area: Adherence to home cardiac rehabilitation

The purpose here is to understand the client's adherence to home cardiac rehabilitation and why.

- Why did you choose the AHG?
- How often did you refer to or use the AHG?
- Which sections did you find more useful and why?
- Which sections did you find least useful and why? use more than others?
- Why did you continue using the AHG?
- Why did you stop using the AHG?
- Would you recommend the AHG to other people who had experienced a heart attack or angina attack? If so, why? If no, why not?

2. Topic Area: Nurse patient relationship

The purpose here is to have the client discuss their relationship with the nurse mentor while using the AHG for home cardiac rehabilitation.

- Who assisted you most in your recovery and why?
- How would you describe your relationship with your nurse mentor?
- How would you describe the communication between you and your nurse mentor?
- Did your nurse mentor help with your recovery? If so how? If not why?
- How much contact did you have with your nurse mentor?

3. Topic Area: Lifestyle changes

The purpose here is to discuss how useful the AHG was in assisting with lifestyle/behaviour change.

- What behaviours contributed to your heart attack/angina attack?
- What things can you do to reduce your risk of another heart attack/angina attack?
- How did using the AHG at home assist with your understanding of the lifestyle/behaviour changes you needed to make?

4. Topic Area: Psychological Recovery

The purpose here is to discuss the patient’s experience of home based cardiac rehabilitation using the AHG and its impact on psychological recovery.
• Describe how you felt emotionally after your heart attack/angina attack?
• What or who assisted you with understanding your emotions?
• Describe how helpful/unhelpful you found the AHG in understanding your emotions?
Appendix 10b: Prompt for spouse Interviews

1. Experience of spouse in relation to their information needs and assisting their significant other with lifestyle changes.

The purpose here is to gain an understanding of how using the AHG met the significant other’s information needs and supported the significant other to support the client with lifestyle changes.

- Were you happy/unhappy with the information given to you prior to discharge?
- Were you invited to take part in your significant others cardiac rehabilitation assessment and if so how involved did you feel?
- Why do you think [insert patient’s first name] had a heart attack/angina attack?
- What things do you think [insert patient’s first name] needs to do reduce the risk of another heart attack?
- How did [insert patient’s first name] using the AHG at home assist with the understanding of the change’s they needed to make?
- Was the AGH helpful in assisting with your understanding of how you could help [insert patient’s first name] with lifestyle changes?
- How helpful was the partners section of the AHG?

2. Experience of significant other in relation to assisting their significant other with psychological recovery?

- How did using the AHG at home assist with [insert client’s first name] psychological recovery?
- Was the AGH helpful in assisting with your understanding of how you could help [insert patient’s first name] with psychological recovery?

3. Experience of the significant other in relation to their support following the client’s illness.

The purpose here is to gain an understanding of the support needed by the significant other and the impact of the support available from the AHG.

- What support was available for you following [insert client’s first name] illness?
- Which sections of the AHG did you find useful?
- Which sections of the AHG need improvement in your opinion?
- Did having the AHG help your support needs?
- Would you recommend the AHG to significant others in the future?

4. Experience with the nurse mentor
The purpose here is to gain an understanding of the significant other’s perception of the relationship between the nurse mentor and client.

- How helpful/unhelpful do you think the nurse mentor was in assisting [insert client’s first name] in coming to terms with their illness?
- Describe the relationship between the nurse mentor and [insert patient’s first name]
- How much interaction did you have with the nurse mentor?
Appendix 11: Prompts for Nurse Mentor Interviews

1. Topic Area Nurse Experience of home based cardiac rehabilitation using the AHG

The purpose here is to have the nurse mentor discuss their experience of home based cardiac rehab using the AHG

- Describe your experience of home based cardiac rehabilitation using the AHG
- What were the strengths of using the AHG?
- What were the weaknesses of using the AHG?
- What opportunities arose from using the AHG?
- What were the threats that came from using the AHG?

2. Topic Area Experience and usefulness in assisting with lifestyle changes

The purpose here is to gain an understanding around the Nurse mentor’s perception of the AHG’s usefulness in lifestyle change and disease management.

- Describe an incident where you used the AHG for lifestyle change or disease management
- How helpful/unhelpful was the AHG with this process?

3. Topic Area Nurse patient relationship

The purpose is to have the nurse mentor discuss their relationship with the client when using the AHG at the client's home

- How would you describe your relationship with patients who are using the AHG at home?
- What differences are there from your usual patient relationships?
- What are the key elements in the nurse-patient relationship when using the AHG from your point of view
- What were the advantages/disadvantages of the relationship with your patients when using the AHG
Appendix 12: Audit trail of the data analysis process

There were two phases comprising the data analysis of the interviews with the nurses.

1. Stage 1
Using different coloured highlighter pens, I identified and highlighted common themes. I gave a name to each identified theme.

2. Stage 2
I then explored the themes further for similarities and differences. Those that were similar were merged and, where possible, were grouped into categories. Within the categories, the themes were further explored and sub categories developed as I re-read the transcripts relating to individual categories. In order to contextualise the data, I kept referring back to whole interview transcript.

3. Stage 3
Once the categories and sub categories were identified, I reviewed each for relevance to the main research question and a general description of the topic was formed.

The research question is: What is the experience of clients, their significant others and nurse mentors when using the Aussie Heart Guide for home based cardiac rehabilitation? There were also several aims of the study. A table was compiled highlighting the responses from the nurses in each category that reflected the research question and aims. If no responses reflected the research question, they were charted in a separate column as additional findings. An example of this word table using one of my research aims is shown below:
<table>
<thead>
<tr>
<th>Aim</th>
<th>Nurse response</th>
</tr>
</thead>
<tbody>
<tr>
<td>To describe nurse mentors perception of the impact of home based</td>
<td>1. “The group is dynamic and they encourage people to do things, where as if its only a clinical person, you know when they’re in a group you have all</td>
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<tr>
<td>cardiac rehabilitation using the AHG with a client recently</td>
<td>other people telling them, and advising them what to do on how they reacted and they see how other people have recovered and see what another person</td>
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<td>hospitalised with Acute Coronary Syndrome</td>
<td>can do. Over the telephone you know you can’t do that.” Nurse 2 page 6 middle paragraph</td>
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<td>2. “The downfall of doing exercise at home compared to doing it with the physio and I, is that we actually push them a lot more.” Nurse 3 page 7 last</td>
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<td>paragraph</td>
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<td>3. “They don’t want to come to the six week program; they don’t want to do six weeks.” Nurse 3 page 3 para 4</td>
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