

The structures, processes and outcomes of a nurse mentor supported home based cardiac rehabilitation program for rural patients: A case study

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# The structures, processes and outcomes of a nurse mentor supported home based cardiac rehabilitation program for rural patients: A case study

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## **Abstract**

Cardiac rehabilitation (CR) has demonstrated positive benefits for patients recovering from myocardial infarction (MI), yet participation in it is suboptimal, especially in regional Australian settings. There is a need to improve patient access, uptake and completion of CR. Home based CR programs are effective and safe and have been introduced in many countries to improve access to after hospital care for patients unable to attend hospital based programs. The Aussie Heart Guide Program (AHGP) is a home based CR program delivered to patients mainly by telephone in their homes. The program has two integral components. First, audiovisual resources are provided to patients to provide information and education about coronary heart disease and self care in terms of lifestyle management. Second, the program is delivered to patients over a six week period by CR nurses who have undertaken specific training in the program including cognitive behavioural therapy, motivational interviewing, goal setting and audit and feedback. Based on a patient centred approach, nurse mentors support and guide patients in their homes by developing a therapeutic and mutual engaging relationship with patients. This aim of this study was to evaluate the structures, processes and outcomes (SPO) of a home based CR program for patients recovering from MI and who live in rural areas of Tasmania.

An explanatory case study was used in this research. Patients and nurse mentors were recruited from three metropolitan Australian hospitals between 2008 and 2011. The sample included 34 patients and seven mentors. Patients completed surveys and questionnaires that contained research instruments relating to their experiences of anxiety, depression, physical exercise, health related quality of life (HRQOL), illness representation and outcomes of self management both prior to and after completing the AHGP. A subsample of 13 patients were interviewed by telephone about their experiences relating to mentoring and the AHGP. Nurses were asked about their perceptions of their new role as mentors and the AHGP via an open ended e-mail survey. Mentor clinical notes used to record patient progress during the AHGP were also part of the data used in the study. Thematic analysis was conducted on data collected from semi structured patient telephone interviews, an open ended mentor survey and mentor clinical (patient) progress notes. The thematic findings were then

considered further in relation to the SPO and new themes categorised accordingly under the three SPO elements. Descriptive statistics were used to summarise quantitative data and paired t-tests used to identify changes over time.

Emergent findings from the qualitative analysis showed structures important for the program included timely recruitment of patients, specific mentor training and commitment to the mentor role, knowledge and skills associated with cognitive behavioural therapy and patient centred care. Processes included the therapeutic relationship and rapport between mentors and patients, suitability of the program within the Australian cultural setting, a patient-centred approach to care and promoting positive lifestyle behaviours. Outcomes suggested the AHGP assisted patients in their recovery from myocardial infarction. Patients were satisfied with the program's audiovisual resources and appreciative of the support, guidance and care provided by mentors during their hospitalisation through to their discharge from the program. It appeared the program influenced patient decisions to change unhelpful lifestyle behaviours. These perceptions suggest the program was valued by patients and was acceptable to them in terms of meeting their expectation of CR. Outcomes for mentors indicated that although there were rewards and barriers associated with being a patient mentor, the AHGP was easy to use and most were satisfied with their new role.

Results from the quantitative analysis demonstrated improvements for patients in relation to reducing their levels of anxiety and depression following completion of the program. There were also small to moderate improvements in activity levels and HRQOL after completing the program. While there are several limitations to this study, it provides conceptual insight into this relatively new home based, mentor supported CR program in the Australian context. Further improvements to the program in relation to mentor training, stakeholder engagement, governance issues and resource development are necessary if the program is to be adopted more widely.

# **Statement of Originality**

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

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Terence John Frohmader

Griffith University

July, 2017

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# **Glossary of Key Terms and Abbreviations**

AACVPR American Association of Cardiovascular and Pulmonary Rehabilitation

ABS Australian Bureau of Statistics

ACC American College of Cardiology

ACRA Australian Cardiovascular Health and Rehabilitation Association

ACSQHC Australian Commission on Safety and Quality in Health Care

AHA American Heart Association

AIHW Australian Institute of Health and Welfare

AHGP Aussie Heart Guide Program

BACPR British Association of Cardiovascular Prevention and rehabilitation

CDSM Chronic Disease Self-management

CHD Coronary Heart Disease

CR Cardiac Rehabilitation

CVD Cardiovascular Disease

EPP Expert Patient Program

HADS Hospital Anxiety and Depression Scale

heiQ Health Evaluation Impact Questionnaire

HRQOL Health Related Quality of Life

IPQ-R Revised Illness Perception Questionnaire

QOL Quality of Life

MacNEW MacNEW Health Related Quality of Life Questionnaire

MI Myocardial Infarction

NICE National Institute for Health and Clinical Excellence

NHFA National Heart Foundation of Australia

NHS National Health Service (United Kingdom)

PCC Patient Centred Care

PCI Percutaneous Coronary Intervention

RACGP Royal Australian College of General Physicians

RCT(s) Randomised Control Trial(s)

SPO Structures, Processes and Outcomes

WHO World Health Organization

# **Dissemination of Study Results**

The research reported in this thesis was completed under the supervision of Professor Wendy Chaboyer and Dr Frances Lin and resulted in the following refereed publications.

## **Refereed publications**

- Frohmader, T. J., Lin, F., Chaboyer, W. P. (2015). Patient perceptions of nurse mentors facilitating the Aussie Heart Guide: A home-based cardiac rehabilitation programme for rural patients. Nursing Open, 3(1),41-50. eCollection.2016. Jan.
- Frohmader, T. J., Lin, F., Chaboyer, W. P. (2017). Nurse mentor perceptions in the delivery of a home based cardiac rehabilitation program to support patients living in rural areas; An interpretive study. *Journal of Nurse Education and Practice*, May: 24:77-83. doi: 10.1016/j.nepr.2017.04.002. Epub 2017 Apr 5.
- Frohmader, T. J., Lin, F., Chaboyer, W. P. (2017). Structures, processes and outcomes of the Aussie Heart Guide program: A nurse mentor supported, home based cardiac rehabilitation program for rural patients with acute coronary syndrome. *Australian Critical Care*, May 6. pii: S1036-7314(17)30171-6. doi: 10.1016/j.aucc.2017.03.002. [Epub ahead of print]

## **Dedications**

I dedicate this thesis to all the stong women in my life, my grandmother, mother and sister and their unwaivering belief in me. Their strength empowered me especially during the tough times and many long hours of study.

Most importantly, special thank you to my beloved wife Elizabeth, and my two children Leila and Ashley. Thank you for your eduring love, hope, patience and support during my academic journey and the many hours we could not spend together.

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# **Chapter 1: Introduction**

## Introduction

Cardiovascular disease (CVD) is a major cause of death in Australia with one person dying from the disease every 12 minutes (Australian Bureau of Statistics [ABS], 2015). CVD refers to all diseases and conditions that involve the heart and blood vessels and include coronary heart disease (CHD), stroke and heart failure. The underlying cause of CVD is atherosclerosis (Australian Institute of Health and Welfare [AIHW] 2011), a disease characterised by the build up of fats, cholesterol and other substances in and on the walls of arteries (National Heart, Lung and Blood Institute, 2016).

The rate of acute coronary events has fallen since 1980 due to advancements in patient care and management (AIHW, 2014a), however, CHD continues to be the leading cause of death in Australia, killing approximately 20,000 people in 2014 (Australian Bureau of Statistics [ABS], 2015). Not only do many people die prematurely from CHD, many suffer significant disease burden, disability and poor QOL (AIHW, 2014b). CHD also contributes significantly to the nation's economic burden with health care expenditure (health and services) on cardiovascular disease (CVD) exceeding \$7,605 million during 2008-2009. CHD contributed to 27% of the total expenditure of CVD in that year (AIHWc, 2014).

Trends in the decline of CHD mortality are not uniform in Australia with people living in regional and remote areas experiencing higher rates of mortality and morbidity in the year 2012-2013 (AIHW, 2014b). CHD death rates are 15% to 40% higher for people living in rural and remote areas, especially if they are from diverse cultural backgrounds, are Aboriginal or Torres Strait Islander people and have low socioeconomic status (ABS, 2011). This suggests rurality might be considered a risk factor for heart disease in its own right (Nadel, Hewitt & Horton, 2014) with a person's risk of dying from heart disease increasing the further they live from a metropolitan centre (AIHW, 2011). Clearly, while primary prevention is important in reducing rates of CHD mortality, secondary prevention is also a priority to lessen this health disparity, with gaps in health funding (AIHW, 2010) and access to health services poorer in rural and remote areas of Australia even though they exhibit great need (AIHW, 2005a).

Cardiac rehabilitation (CR) is associated with better patient recovery post myocardial infarction [MI] (Anderson et al., 2016). Consistent with contemporary secondary prevention guidelines from other countries (National Institute for Health and Care [NICE], 2014; Piepoli et al., 2016), in Australia CR is freely available to many patients recovering from MI and it is usually offered in hospitals or in the outpatient setting. While many patients living in city or metropolitan areas have a choice to attend hospital or outpatient CR, many of those who reside in rural and remote areas have difficulty in accessing CR (Clark et al., 2014). Contemporary research continually highlights the importance of improving CR accessibility to rural patients (Clark et al., 2015; National Rural Health Alliance, 2015) as they are more likely to die from cardiovascular disease (AIHW, 2011; Chew et al; 2013). People with CHD who live rurally also rate their health poorer, are less active, are overweight or unable to follow a heart friendly diet (Sangster et al., 2013). Rural patients also have limited access to after hospital care, medical facilities and possess low levels of education and health related knowledge concerning the risks associated with CHD (National Rural Health Alliance, 2015; Alston et al., 2017).

In view of this, there have been calls to develop and implement non conventional or alternate delivery models of CR to provide an attractive solution to the lack of CR resources available in rural and remote Australia (Dollard et al., 2004; De Angelis, Bunker and Shoo, 2008; Clark et al., 2013a). In addition, Briffa and colleagues (2009) suggest CR programs must be flexible, culturally safe and integrated with the patient's primary health care provider. To date, developing innovative secondary prevention programs to provide the necessary information, support and guidance to *all* patients despite their geographical location remains a challenge. Improving accessibility has the potential to provide more patients with the benefits of CR. While it has been reported that most Australians live within 60 minutes of CR services (Clark et al., 2014), others propose that telephone based CR programs may improve cardiac health outcomes for persons unable to access city or metropolitan based CR services due to their remoteness (Neubeck et al., 2009).

# Overview of the study

In Australia, the Aussie Heart Guide Program (AHGP) is a CR program delivered by nurse mentors to patients recovering from MI in their own homes. Although a new CR program in Australia, the AHGP was adapted from the "Heart Manual" (Lewin et al., 1992), a home based CR program widely used in the United Kingdom (UK), designed to provide CR to patients living in rural or remote settings. The AHGP aims to assist patient recovery by providing continuity of care after discharge from hospital, disease specific information to aid in their understanding of their illness and provide practical and emotional support to patients through the provision of specially trained nurse mentors. This research investigated the AHGP in regional Tasmania, Australia. The theoretical framework for this study was Donabedian's structure, process and outcome (SPO) framework for the evaluation of quality health care (1966). Using this framework, an explanatory, embedded single case study with multiple units of analysis (Yin, 2009) was conducted to explain the various aspects of the AHGP. Case studies can be used to evaluate programs in depth when they are innovative, unique or implemented in a new setting. Explanatory case studies assist researchers to answer the "what happened" questions resulting from program implementation. These include what actually occurred during the program, whether the program had an impact and the causal links between the program and its observed impact (Albright et al., 1998).

Ultimately, the study was conceived to discover whether the AHGP was feasible as a secondary prevention program to assist rural patients recover from MI in Tasmania. Perceptions from both patients and mentors might provide important insights regarding whether patients will use, complete and benefit from the home based CR program. The AHGP provided patients with resources and mentor support for about a six week duration. The program was evaluated by analysing data collected from patient telephone interviews, a mentor survey, the analysis of mentor clinical notes and self report patient questionnaires administered pre and post program. The AHGP was implemented as a pilot study project in Tasmanian public hospitals between 2008 and 2011.

# **Background of the study**

The study contributes to the evaluation of the AHGP as a home based model of CR for patients recovering from MI and live remotely in Tasmania. To do this, an overview of CHD is presented discussing the incidence, prevalence, impact and treatment of CHD and the importance of self management in terms of the patient recovery from MI. Following this, the aims of research, the significance of the study, and the structure of the thesis and a summary of chapter one is presented.

## Coronary heart disease

Despite medical advances in terms of treatment of CHD, it remains the number one cause of death globally and the World Health Organization predicts it will remain so until 2030 (WHO, 2015). Although death rates from CHD have fallen in Australia since the 1970's due to improvements in medical, surgical and emergency care (Briffa et al., 2009; Ford & Capewell, 2011), in 2013 CHD accounted for 19,766 deaths (ABS, 2015). CHD and associated comorbidity continue to contribute to poor health and mortality in Australia (AIHW, 2014d) with one Australian dying because of CHD every 37 minutes (ABS, 2015).

## Incidence, prevalence and trends of coronary heart disease

Currently there are no reliable national or jurisdictional registry data on the number of new cases (incidence) of CHD in Australia each year (AIHW, 2014e). However, the number of new cases of acute coronary events (heart attack and unstable angina) in 2012 was approximately 68,200 people aged 25 and over (AIHW, 2014e). The rate of acute coronary events was twice as high in men as in women [age-standardised rate of 558 and 266 per 100,000 persons respectively] (AIHW, 2014e). In 2009-2011, remote and very remote areas had the highest CHD death rate (101 deaths per 100,000 population), 1.3 times as high as that in major cities (80 deaths per 100,000) (AIHW, 2014d). Male and female CHD death rates in remote and very remote areas were 1.3 times and 1.2 times as high as in major cities (AIHW, 2014d). According to AIHW (2014d), higher CHD death rates in remote areas of Australia partly reflect the higher proportion of Indigenous Australians living in these areas, their

higher rates of CHD and the lack of accessible health care and socioeconomic disadvantages associated with living in remote areas services (AIHW, 2011).

The AIHW reported that, in 2011-2012 the prevalence of CHD to be an estimated 590,000 persons (3% of the adult population aged 18 or older) based on self-reported data (2014e). Of those with CHD, 277,000 persons experienced angina and 406,000 other forms of CHD (AIHW, 2014e). Australia has had success in treating and preventing CHD, however, the burden of this disease, in terms of prevalence, continues to grow due to unfavourable risk factor trends combined with an ageing population (AIHW, 2014d). For example, although smoking rates have continued to fall, increases in overweight and obesity, physical inactivity and in insufficient fruit and vegetable consumption suggest that the burden of CHD will increase in the future (AIHW, 2014d).

In Australia, trends in the rate of acute coronary events fell by 24% 2007-2012, from an age-standardised rate of 534 per 100,000 population in 2007 to 406 per 100,000 population in 2012 (AIHW, 2014d). According to Taylor and colleagues (2006) the decline in the rates of coronary events was similar for men (23%) and women (26%) and can be attributed to advances in coronary care including improvements in medical and surgical treatment, antithrombotic and other drugs used to lower high blood pressure and cholesterol and reductions in some risk factor levels (Nichols et al., 2016) rather than a reduction in the prevalence of CHD per se.

## Impact of coronary heart disease

In Australia, CHD affects over 590,000 people and contributes to significant illness, disability, poor QOLand premature mortality, and high health care costs (AIHW 2014e) despite it being a largely preventable disease. In 2013, 54,000 people suffered a heart attack and approximately 24 lives were lost per day (ABS, 2015). While CHD kills more Australians than any other disease, mortality rates alone do not reflect the true impact of CHD. People that survive an acute coronary illness may live with disability and its impact on their QOL for extended periods of time or even the remainder of their lives (Nichols et al., 2015). Negative outcomes from CHD and MI include, but are not limited to physical dysfunction, poorer QOL, delays in returning to work and financial costs (Murray et al., 2012). In terms of physical symptoms

experienced following MI, some patients encounter heart rhythm disturbances (palpitation), chest pain (including tightness and or discomfort in arms, shoulders, jaw, neck, epigastrium and back), dyspnoea, syncope or dizziness, gastrointestinal upset, fatigue, loss of energy and ability to exercise and in severe cases, the development of heart failure and cardiogenic shock (Haasenritter et al., 2012; Ayerbe et al., 2016).

In addition to physical symptoms, many patients suffer significant disturbances in their psychosocial health following MI (Glozier et al., 2013; Whalley, Thompson & Taylor, 2014; Richards et al., 2017). The landmark study, INTERHEART (Yusuf et al., 2004), demonstrated that compared with matched controls, a large proportion of the 12, 461 post MI patients surveyed, had episodes of or permanent periods of stress. Patients also reported examples of life changing events; financial problems and approximately one in four patients had felt depressed. Financial stress linked to health care costs, including medication use have been reported in many studies (Rahimi et al., 2007; Oberg, Fitzpatrick & LoGerfo, 2008). Patients sometimes report feelings of detachment in the acute phase of their care (Wingham et al., 2006) coupled with a loss of confidence or control in their abilities. The inability to make choices or decisions due to general feelings of uncertainty may be a contributing factor to the high levels of anxiety and depression often experienced by patients (Glozier, et al., 2013) especially when they learn they are experiencing or recovering from a heart attack.

The burden attributed to CHD equates to a significant cost to the individual, their family, community and the health care system. In 2010, CHD contributed to approximately 15% of the burden of disease in Australia based on years of life lost (Institute for Health Metrics and Evaluation, 2013). Even though CHD mortality rates have decreased over the last three decades, the burden of disease is not equally proportioned throughout the Australian population. The burden of CHD has a greater impact on people with low socioeconomic status, Aboriginal or Torres Strait Islander people, culturally diverse minorities and those who live remotely from health services. They have higher rates of cardiac related admissions to hospital and mortality from CHD compared with people living in urban Australia (AIHW, 2011).

## Risk factors of coronary heart disease

Risk factors are health related behaviours or conditions that predispose a person to developing an illness, condition or event and include behavioural and biomedical factors (AIHW, 2005b). CHD is potentially preventable with many of the risk factors associated with heart disease considered to be directly attributable to lifestyle choices. Behavioural risk factors which include smoking, physical inactivity, poor nutrition and excessive alcohol intake, may contribute to the development of biomedical risk factors. These include obesity, dyslipidaemia, high blood pressure and diabetes (AIHW, 2015). In Australia during the year 2011-12, individual risk factors of adults with CVD were as follows; 93% consumed an insufficient quantity of fruit and vegetables, 78% had dyslipidaemia, 75% were overweight or obese, 71% had high blood pressure, 61% were inactive, 18% exceeded the recommended alcohol intake, 10% smoked daily and 6% had impaired fasting glucose (AIHW, 2015). The risk of dying from coronary artery related events increase exponentially with the number of risk factors identified in an individual (Berry, 2010). In the year 2011-12, nearly all Australian adults with CVD had at least one of six risk factors (99.9%); 66% had three or four risks combined; 18% had five or six risk factors in combination, clearly underlying the need to provide disease management, education and monitoring for all persons with CVD (AIHW, 2015). With Australia's population growing and people living longer, the prevalence of risk factors need to be kept in check, otherwise the burden of CHD will continue to grow (AIHW, 2015). Interventions should be considered in conjunction with an individual's absolute cardiovascular risk score derived from the Australian Cardiovascular Risk Charts (NHF, 2011).

## Treatment of coronary heart disease

The aim of CHD treatment is to reduce the progression of the disease, saving lives and limiting injury. Optimal treatments combine the use of revascularization techniques, often in conjunction with pharmacotherapy and aggressive management of modifiable risk factors (Levine et al., 2016). Comprehensive ongoing prevention and CR services aim to provide patients with advice and support concerning the benefits of smoking cessation, good nutrition, alcohol intake moderation, regular physical activity and weight management (Smith et al., 2011). Some studies have emphasised that self

management and its related concepts, once practiced has the best chance of contributing to successful outcomes of patients with poor lifestyle behaviours (Adams, 2010). With such high numbers of people affected by CHD and spiralling health care costs, it is little wonder that in recent years a focus on promoting the virtues of self management has emerged (De Silva, 2011).

## **Dimensions of self management**

CHD is a complex chronic disease that requires monitoring and treatment of persons with CHD over many years. Chronic disease is expected to represent 80% of the burden of disease in Australia by 2020 (National Health Priority Council, 2005). There exists a plethora of information regarding the now popular term "self management." The term emerged in the 1960's when Thomas Creer first used it in the rehabilitation of children with asthma. Much of the early work on chronic disease management was based on the writings of Albert Bandura and Self-Efficacy Theory (Bandura, 1997). Self management is a broad concept and "involves (the person with the chronic disease) engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes" (Gruman and Van Korf, 1996, p.1).

Self management has been inextricably linked with the treatment of many chronic diseases including heart, diabetes, kidney, lung, mental illness and include musculoskeletal conditions such as arthritis (Australian Institute of Health and Welfare [AIHW], 2016). According to Curtin and colleagues (2005), self management identifies the patient as being the focus of management not the clinician or health service. Improved outcomes may be realised when the perspective of self management is divided into two chief domains:1) self management of health care, including components of self care, self-efficacy and self care activities, partnerships in care, communication; and 2) adherence and self management of everyday life through achievement and maintenance of "normality" (Redman, 2004; Curtin et al., 2005).

The Royal Australian College of General Practitioners [RACGP] (2010) conclude there are three main principles central to self management. First, a client or patient centred approach, central to all self management programs, explores the illness

experience as well as the disease and the person is understood as a whole person (RACGP, 2010). Common ground is discussed (including the problems faced, goals of treatment and the role and responsibilities of health provider and client) and opportunities to embrace health prevention and health promotion activities explored. Importantly, the development of a supportive and meaningful relationship between health carer and client must be realised. The second principle respects the client's right to make their own decisions about their health. Health care providers work with clients to establish realistic management plans to address their health needs (RACGP, 2010). The final principal involves motivation. Clients require motivation to successfully self manage their condition (Coventry et al., 2014; El Miedany et al., 2016). Many agree patient motivation or the desire to can be improved by enabling the development of a strong therapeutic relationship (RACGP, 2010).

Research findings have demonstrated chronic disease self management programs may improve the health behaviours of patients (Egger, Binns & Rossner, 2009; Ory et al., 2013; Davy et al., 2015). Although lay or peer led self management programs have been evaluated with conflicting results concerning improvements in symptomology (Coull et al., 2004; Chodish et al., 2005), some have demonstrated improvements to self management components such as self-efficacy and QOL (Foster et al., 2007; Parry & Watt-Watson, 2010). For patients to self manage effectively they need to acquire the knowledge and skills to do so and this can be achieved through health care support (Poureslami et al., 2017). Battersby and colleagues (2010) conducted an extensive review of the self management literature and suggested twelve guiding principles to support the development of self management programs in the clinical domain. Some examples of these guiding principles include, clinicians should use a non judgemental approach, engagement in collaborative goal setting and problem solving, enhance patient self-efficacy and ensure active follow-up.

Although the above principles are utilised in many CR programs in Australia, there remains a need to ensure clinicians receive training and ongoing support in chronic disease self management practices (Browning & Thomas, 2014). However, in Australia, it remains unknown how many health professionals undertake formal training in self management theory because, despite there being training programs, there is no national data of CR clinician training or qualifications. In terms of CR qualifications,

Woodruffe and colleagues (2015) advocate CR clinicians should undertake training relevant to their role. In situations where health care clinicians have been provided training or undertaken specific courses such as the Stanford program (Lorig et al., 2005), Model of Health Coaching for Chronic Condition Self Management (Gale, 2010), Chronic Care Model (Australian Institute for Primary Care, 2005), Flinders Model of Chronic Care Self Management (Battersby et al., 2008) and courses via the Australian Centre for Heart Health (2017) the principles of self management are likely to be reflected. The reality is that hospital and community based chronic disease self management programs vary in their scope and resources (Victorian Cardiac Care Network, 2014). CR programs are managed by varying numbers of health professionals from different vocational backgrounds (pharmacy, nursing, social work, physiotherapy, exercise physiology) and may not be specifically trained or practiced in the concepts of self management (Kennedy et al., 2013). Thus, the extent to which self management principles underpin Australian CR programs may be variable.

In summary, CHD is a common global chronic disease which may lead to disability and premature death if left unchecked. However, the disease process is largely preventable and can be managed by improving lifestyle behaviours and adhering to prescribed medical management. Today, CR reflects this move to self management to assist persons affected with heart disease by empowering them to adopt responsibility for their health and be active participants in their own care. Simply said, CR in relation to self management is about helping people with CHD help themselves (De Silva, 2011).

# Aims of research and research questions

The study aimed to evaluate the SPO of a home based CR program for patients recovering from MI and who live in rural areas of Tasmania. It used an explanatory, embedded single-case design in conjunction with the SPO framework of evaluating health care quality (Donabedian, 1966) to answer the research questions. An explanatory approach endeavours to explain causation, the linkages between the implementation of a new model of CR (AHGP) with the effects of that program. Understanding the SPO of the AHGP will provide evidence suggesting improvements to the program and its applicability as a new model of home based CR in Australia.

From this aim, several research questions were developed;

- 1. What are the structures of the AHGP, a home based CR program for patients recovering from MI as perceived by patients and mentors?
- 2. What are the processes of the AHGP, a home based CR program for patients recovering from MI as perceived by patients and mentors?
- 3. What are the outcomes of the AHGP, a home based CR program for patients recovering from MI as perceived by patients and mentors?

Currently, it is unknown whether the AHGP is feasible as a home based CR program and importantly, if patients will use and complete the program. As mentorship represents the cornerstone of the AHGP, the study also aims to provide an understanding of the SPO of mentoring and subsequently, explored the extent to which mentoring assisted patients to recover and improve their health outcomes. There is a paucity of published literature evaluating the facilitation of the Heart Manual (Lewin et al, 1992) and its franchises and limited information surrounds the value of mentoring patients with chronic disease. This research provides insights to CR stakeholders regarding the outcomes of the AHGP mentoring service, identifying limitations and possible improvements to the mentoring aspect of the program. A better understanding of mentoring and its significance in developing a collaborative partnership based on the concept of patient centred care (PCC) will inform clinicians concerning what aspects of their support assist or hinder each patient's individual journey following MI. Further, positive mentoring outcomes may also pave the way for mentoring to be applied to other similar chronic disease patient populations.

# Significance of the study

This study is significant for several reasons. First, evaluation of the AHGP will provide a beginning in terms of understanding how effective the AHGP is in improving the continuity of cardiac care and health outcomes for patients who cannot readily access hospital based CR programs. Continuity of care for patients is an important aspect of health care quality. Agency for Healthcare Research and Quality, 2013; Valaker et al., 2017). The complexity of health systems and multiple relations with various health professionals may lead to patients experiencing a poor transition in care

between hospital and primary health care. This in turn may influence patient mortality and morbidity negatively (McNaughton et al., 2015) and result in delays in patient care, patient and family dissatisfaction and an increased risk of rehospitalisation (King et al., 2013). The impoprtance of enhancing patient outcomes through the continuity of care has been reported in the literature (Giuliano et al., 2017). The AHGP has the potential to improve the continuity of care for patients leaving hospital and returning to their community. Patients commonly experience emotional distress and feel unprepared to leave hospital after surviving a serious cardiac event or illness (Moser et al., 2010). Mentors in this study have the potential to act as the seamless conduit between the hospital and the home in terms of providing ongoing biopsychosocial support and reduce gaps in health care continuity as outlined by others (Grace et al., 2006; Hadjistraropoulos et al., 2008). Knowledge gained from this case study has the potential of informing CR stakeholders concerning the suitability of the AHGP as a standalone home based CR program in areas of Australia that lack CR services.

Second, the study is important because if the evaluation of the AHGP is positive, wider implementation and a full scale evaluation study may be warranted involving multiple regional sites. Additionally, positive effects may also provide an impetus to make the AHGP accessible to patients residing in non regional areas who prefer not to access local CR programs. Providing choice for patients in terms of CR has been identified by others as critical in attracting patients with cardiac illness to CR programs (Madden, Furze & Lewin, 2010; Dalal, Doherty & Taylor, 2015). Positive outcomes from the implementation of the AHGP might lead to not only the provision of CR for rural patients, but significantly increase the overall utilization of CR services in Australia which for many decades has remained low.

In Tasmania, the burden of CHD is expected to increase as the population ages. The age standardised mortality rate for CHD in Tasmania between the years 2007-2010 was 105.3 deaths per 100,000 persons compared with the national average of 90.7 deaths per 100,000 persons (Department of Health and Human Services, Tasmania, 2013) despite medical advances in the treatment of CHD represents a significant health problem in Tasmania. With approximately 15 more Tasmanian's dying from CHD compared to mainland Australia clearly and most significantly, any CR program that has the potential to improve CHD outcomes will have benefits to both patients and

society, in terms of reducing the burden of disease on the community. In view of this, the evaluation of the AHGP will provide a beginning in terms of establishing an evidence base for a new home based CR program (the AHGP).

Third, the study is important because the AHGP may lead to changes in health care policy regarding CR in Australia. Exploring and understanding the implementation of the AHGP as a quality CR program using SPO methodology will provide research evidence for policy makers, health service leaders and CR clinicians. This information may be used to guide future clinical practice and influence CR policy. Recommendations from this study will inform clinicians regarding the implementation of the AHGP in terms of its feasibility to become a standalone home based CR program and its acceptability in meeting mentor and patient expectations. Put simply, the AHGP must be easy for mentors to use and patients must want to use it. The AHGP will also provide insight to clinicians concerning how individual patient assessment of their biopsychosocial needs can be formalised into appropriate patient centred goals and outcomes, inclusive of all diagnostic and population groups. As a potentially new model of service delivery, the AHGP should also demonstrate therapeutic outcomes that are patient focused and importantly, evidence based ensuring that best practice underpins patient safety, appropriate therapeutic interventions, advice and education provided.

Last, the study is important because insights from the programs evaluation will provide CR stakeholders and the wider health community with new knowledge concerning the mentorship component of the AHGP. Of interest will be the perceptions of nurse mentors and patients concerning the appropriateness and applicability of mentoring in assisting patients to realise their health expectations in terms of their rehabilitation. Further, insights from the mentor-patient relationship will inform relevant stakeholders concerning the way forward in terms of the future training of mentors, ways to improve the mentor service, funding arrangements, governance and support of future AHGP mentors in Australia.

#### Structure of the thesis

This thesis consists of seven chapters.

Chapter one has introduced the topic of the thesis and includes information concerning the background and significance of the research, the research problem, aims of the study and the structure of the dissertation. Chapter two provides an overview of the literature related to this study. Chapter three outlines the methods used to meet the research aims of this study. It includes a description of the SPO methodology used to conceptually underpin this study. The study design is presented detailing the sample, the CR studied, and the various instruments used to measure data. Following this, the collection, management and analysis of data and ethical considerations will be examined. Chapter four reports the thematic findings generated from the qualitative data derived from patient interviews and mentor specific data. Chapter five presents the quantitative results derived from AHGP. It incorporates information concerning sample recruitment and includes a description of the characteristics of the sample. Following this, the hypothesis testing results are reported. Chapter six provides a second level of analysis, interpreting the qualitative and quantitative data from this study, guided by the SPO framework. Chapter 7 presents a discussion of results of this study and their relationship with the current research literature and include recommendations for clinical practice, education and future research. Conclusions are drawn regarding this study including the context in which it contributes to new knowledge about home based CR in Australia.

# **Summary**

CR guidelines around the world contend that all patients should have access to CR services as part of their treatment and management after myocardial infarction. Unfortunately, CR services and resources are often not available to patients who are unable to attend hospital or out patient based CR services due to their rurality. Home based CR programs may improve access to CR services for persons affected with CHD and improve their health outcomes. This PhD research explores the SPO of a home based, mentor supported self help CR program for rural patients unable to access traditional CR services in regional Australia. A literature review was undertaken to provide insight concerning what is known about CR and mentoring, to inform the research methods and provide a context for the evaluation of the findings. This information is presented in chapter two.

# **Chapter 2: Literature Review**

## Introduction

A narrative review of the literature was undertaken to answer the following broad questions: What is CR? Why is it needed? How and by whom is it delivered? What is the evidence for its use? Who uses the service? It was undertaken to gain a general understanding about CR. The aim of this review was not to produce a systematic review of CR but to specifically examine its origins, effectiveness as a secondary prevention program, and identify its shortcomings such as issues with CR service delivery, poor CR attendance and completion by patients. First, a scoping strategy (i.e. a strategy aimed to identify or map existing research according to issues and themes of CR, to identify potential research gaps in the existing literature and to summarise this data to help plan and commission new research) was used to gather literature. Then, this literature was condensed. Throughout the review wherever possible, systematic reviews and meta-analyses and randomised controlled trials have been used to highlight quality evidence and discover what is known about the efficacy and effectiveness of CR. Qualitative research is included when focusing on patient's perception or experience of their illness and recovery.

Overall, this review of the literature indicates there has been prolific research undertaken globally to understand issues relation to the utilisation of cardiac rehabilitation. Patients who live rurally have been identified as one cohort that do not receive the benefits associated with completing a program. Alternative programs providing cardiac rehabilitation in the home by phone, internet or other media have been proposed and efficacy studies reported. Systematic reviews claim that home based are as effective as hospital based (face to face, group based programs).

There is also growing evidence to suggest home based programs meet the needs of patients, however, little is known about how these programs are operationalised and the role of the health workers that administer them. This narrative review therefore, moves from a very broad perspective of CR to a specific program and patient cohort used to provide home based education, support and care to a specific target population, namely rural patients.

This body of research suggests that innovative and alternative home based CR programs might be attractive to rural patients unable to attend hospital based CR due to distance. The adaptation of the AHGP to the Australian rural setting, transitioning from nursing expert to patient partner and mentor and utilising the concept of PCC to transform home based CR care will also be discussed in this chapter. The forementioned questions that guided the review resulted in the following sections in this chapter: Cardiac rehabilitation, Contemporary cardiac rehabilitation, Overview of cardiac rehabilitation programs, evidence base for cardiac rehabilitation programs, current issues in cardiac rehabilitation, the adaptation of the AHGP to the Australian rural setting, transitioning from nursing expert to nurse mentor, concept of patient centred care and the nurse-patient partnership.

# **Search strategy**

The literature review examined the broad topic of CR and necessitated the searching of several databases including PsycINFO, CINHAL, Cochrane Library, EBSCO, EMBASE, MEDLINE and PubMed. The search terms used included; "cardiac disease", "coronary heart disease", "atherosclerosis", "cardiac rehabilitation", "hospital based" and "home based cardiac rehabilitation", "secondary prevention programs", "myocardial infarction", "heart attack", "coronary care", "coronary care nurse", "cardiac rehabilitation nurse", "individualised care", "Heart Manual", "mentor", "mentoring", "nurse-patient partnership", "patient centred care", "self care", "self management." The inclusion criteria included original research published in English from 2000-2017, and hand searching of various national policy documents relating to population health and mortality, heart disease and CR guidelines was undertaken. Earlier papers were included if they were seminal works and considered relevant in providing perspective to this research study.

## Cardiac rehabilitation

The origins of CR can be traced historically back to the 1940's in the United States with the introduction of Work Evaluation units designed to test patient's physical and psychological capacity for work following the experience of cardiac related health problems (Certo, 1985). In the past, the mainstay of treatment MI was prolonged bed

rest, often lasting weeks which lead to decreases in functional capacity and the inability of many patients to return to employment (Certo, 1985). In 1958, Turell and Hellerstein proposed a comprehensive graded step program to be adopted by physicians treating cardiac patients (1958). This was followed by an era of research, which led to the discovery that physical exercise produced positive outcomes for patients recovering from MI (Certo, 1985).

In the 1960's inpatient CR programs in the United States became more formalised due to the collective efforts of Tobis and Zohman (1968) and Wenger (1969). CR programs progressed to include graded physical reconditioning, activities of daily living and education to enhance patient knowledge (Certo, 1985). Further developments led to the realisation that CR improved heart function and recovery time after MI, decreased hospital stay and enabled patients to return to work much more readily than compared with patients from earlier decades (Certo, 1985). Buoyed by the success of inpatient CR programs, and despite widespread criticism from his peers, Hellerstein sought to extend medically supervised CR services to outpatients (Certo, 1985). The continual development of inpatient and outpatient CR programs and subsequent research undertaken over the last 40 years have paved the way for the globally accepted CR programs patients attend today (ACRA, 2008; NICE, 2014).

In summary, prolonged bed rest was the mainstay of treatment ordered by physicians prior to the development of CR programs. In the 1950's, CR quickly evolved aiming to assist patients to return to work after a heart attack (Certo, 1985). Since then, CR guidelines have stated CR programs must be comprehensive, supporting both the physical and psychosocial needs of patients recovering from MI. Scientific statements about the treatment of cardiac illness and CR specific guidelines (American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR), 2016) have been developed and are regularly updated in many countries around the world (Balady et al., 2011; British Association for Cardiovascular Prevention and Rehabilitation (BACPR), 2012; NICE, 2014; Piepoli et al., 2016) with the aim of standardising the treatment and rehabilitation for many cardiac conditions.

# Contemporary cardiac rehabilitation

In Australia, CR is embodied as a process that seeks to provide a coordinated system of support that allows a person with cardiac disease to return to a satisfactory lifestyle and aims to prevent the recurrence of further cardiovascular events by improving self-efficacy and promoting favourable lifestyle behaviour change (ACRA, 2008). Contemporary definitions of CR have evolved from the traditional hospital bound models described by the World Health Organization (WHO) in the early 1960's where patients attend CR programs in person (Thomas et al., 2007). According to the WHO, the goal of CR is "to improve functional capacity, alleviate or lessen activity-related symptoms, reduce unwarranted invalidism, and enable the cardiac patient to return to a useful and personally satisfying role in society" (WHO, 1993, p.1). Modern definitions reinforce the importance of CR as an integral component of treatment following an acute coronary event and in terms of recovery management. Central to most contemporary definitions is the recognition that the patient plays a significant role in the successful outcome of CR (Thomas et al., 2007).

Secondary prevention refers to the various health care interventions implemented to prevent reoccurrence of cardiac events for patients diagnosed with CHD (AIHW, 2009). Interventions include medical care, education, vocational, support and lifestyle modification and can be delivered in different settings (ACRA, 2008). Thus, secondary intervention remains an integral part of the CR process, achieved by using various evidence based strategies designed to improve the health outcomes for persons with cardiac disease.

CR programs are highly recommended by peak cardiac professional groups worldwide. It is recommended that all patients be referred to a suitable CR program following a cardiac event (BACPR, 2012; NICE, 2014; Woodruffe et al., 2015; Piepoli et al., 2016). A comprehensive CR program should contain an exercise component (Anderson & Taylor, 2014), information and education (Brown et al., 2011), psychosocial counselling (Whalley et al., 2011; Richards et al., 2017), lifestyle modification advice to reduce cardiac risk (NICE, 2014; Heron et al., 2016), cardio protective therapies (Mastnak, 2015), measures to ensure long term self management

(Egger, Binns & Rossner, 2009; Toback & Clark, 2017), and finally, an audit and evaluation component (Woodruffe et al., 2015).

## Overview of cardiac rehabilitation programs

CR programs may be delivered to individuals or groups, in hospital or in people's homes and can vary in duration and intensity. CR can be delivered by trained health professionals (ACRA, 2008), peer or lay led (Kennedy et al., 2007; Wu, 2011) or delivered via emerging technologies (Frederix et al., 2017). These include telephone mediated (Gallagher, 2010; Jelinek et al., 2012; Varnfield et al., 2014) or internet based (Clark et al., 2015; Devi et al., 2015; Veen et al., 2017; Partridge et al., 2017). In Australia and the UK, patients may begin CR in hospital or in the community setting within one or two weeks of MI. Patients attend CR sessions weekly and programs typically provide education, graduated exercise and support to patients for approximately 6-8 weeks' duration (Dalal et al., 2015). In some European countries and the United States, hospital, out patient, community and residential based CR formats can be more intensive. Home based CR can last four to six weeks or longer and while out-patient CR can range from three to six months (Bjarnason-Wehrens et al., 2010; Menezes et al, 2014). Many countries offer both hospital and home based CR to cater for individual patient preferences in order to improve the uptake of CR (Dalal et al, 2015).

In Australia, hospital based CR dominates the availability of secondary prevention programs (Abell et al., 2016). With growing evidence suggesting that home based is comparable to hospital based CR (Kraal et al. 2013; Anderson et al., 2016) the availability of home base CR programs in Australia have increased since 2009 from four to fifteen percent (Abell et al., 2016). However, there is limited availability of research published on these programs, so it is unknown whether this trend will continue despite hospital based CR programs remaining costly to operate and sometimes difficult to access. Prior to the development of home based CR programs, other flexible models of secondary prevention programs such as Coaching Patients on Achieving Cardiovascular Health [COACH] (Vale et al., 2002), the Choice of Health Options in Prevention of Cardiovascular Events [CHOICE] (Redfern et al., 2009) and heart failure programs (Maru et al., 2015) have been available to provide patients with lifestyle

focussed education. Community based services also provide support in terms of smoking cessation programs, walking clubs and weight reduction programs. In addition, and more recently, the development of e-health programs have provided CR clinicians with a range of tools that can be successfully integrated in to existing CR programs to improve patient outcomes, particularly in the community setting (Chow et al., 2013; Redfern et al., 2014; Varnfield et al., 2014).

CR is commonly divided into three or four phases with phase one occurring in hospital, phase two occurring from discharge to when a patient's medical, physical and psychological status is stable and phase three and four usually represents an ongoing or maintenance period (ACRA, 2008). Advances in surgical interventions in the treatment of acute coronary syndrome (Andersen et al., 2015) has reduced the time patients stay in hospital and therefore, phase one CR, leading to the emergence of more flexible CR delivery systems that are comprehensive, culturally safe and integrated with each patient's primary health provider (Briffa et al., 2009).

## Evidence base for cardiac rehabilitation

Determining the effectivess of CR is a very complex issue because it:1) involves patients with different cardiac diagnoses and treatments (MI, angina, coronary artery bypass grafting [CABG] and heart failure); 2) provides a number of complex interventions (exercise, education, counselling, cognitive-behaviour therapy [CBT] and motivational interviewing strategies); and 3) often involves a number of health care professionals (cardiologist, nurses, physiotherapists, occupational therapists, psychologists, social workers and exercise physiologists) acting as a multidisciplinary team (Irish Association of Cardiac Rehabilitation, 2013). It may also occur in several different settings (in hospital, hospital and outpatient, community or home), be group based, delivered by telephone and or smartphone, via computer, facilitator, coach or peer/lay assisted. Depending upon which country, it may occur at differing time points;1) phase one (in hospital), 2) phase two (community setting, group based or individually home based), 3) phase three or four (long term community based maintenance programs or via interventions such as the National Heart Foundation of Australia's (NHFA) 'Heart Moves' program (Taylor & Jolly, 2007).

Several systematic reviews and meta-analyses were undertaken between 1980-1990 to determine the effectiveness of exercise based CR for patients with CHD (Oldridge et al., 1988; Bobbio, 1989; O'Connor et al., 1989., Jolliffe et al., 2000). Meta-analyses from this body of research yielded reductions in cardiac mortality between 20 and 32%. A review by Taylor and colleagues (2004), was undertaken to update the previous reviews and to examine whether exercise training alone, or exercise in combination with education and other psychosocial interventions compared to usual care, improved patient outcomes. Taylor and colleagues also believed there were some inconsistencies with the previous research. Some of the trials had small sample sizes, included mainly middle-aged men, low risk MI patients only and concern the benefits of exercise based CR may potentially have been overstated.

Taylor and colleagues (2004) systematic review investigating CR outcomes included a total of 48 randomised controlled trials (RCTs) totalling 8,940. Compared with controls, cardiac patients had reductions in all-cause mortality (odds ratio [OR] = 0.80; 95% confidence interval [CI]: 0.68 to 0.93) and total cardiac mortality (OR = 0.74; 95% CI: 0.61 to 0.96), total cholesterol (weighted mean difference, -0.37 mmol/L [-14.3 mg/dL]; smoking (OR 0.64; 95% CI: 0.50 to 0.83), systolic blood pressure (weighted mean difference, -3.20 mm Hg; 95% CI: -5.4 to -0.9 mm Hg), and improvements in HRQOL, though no meta-analysis was undertaken due to the range of outcome and reporting measures used in 12 trials (Taylor et al., 2004). Several other systematic reviews on CR effectiveness continued to find evidence of benefit, thus, CR is regarded an essential component of the health management of patients with CHD (Heran et al., 2011; Lawler et al., 2011, Anderson & Taylor, 2014).

The results of the RAMIT study by West and colleagues (2012) of 1813 patients (903 to CR and 910 to control) caused many to question the benefits of CR. West and colleagues reported that CR had no effect on mortality (at one, two and after seven to nine years), morbidity, risk factors or HRQOL. The results of their analysis resulted in tumultuous debate among CR clinicians. While null or negative results should be reported as evidence, some have refuted the results mainly on methodological grounds (Redfern et al., 2011). Namely, the RCT was stopped prematurely, and though a well designed study, underpowered with 1,813 patients included in one arm of the study when the sample size calculation was 8,000 patients to detect a 20% reduction in

relative risk indicated by earlier trials (Redfern et al., 2012; Berger, Brenneis & Hannes, 2012; Doherty & Lewin, 2012). Furthermore, 20% of the intervention arm did not complete the course of rehabilitation, further questioning the RAMIT study findings. Despite the outcomes of the RAMIT study, evidence continues to grow in support of CR effectiveness in reducing mortality and morbidity (Dalal, Doherty & Taylor, 2015), reducing the risk of hospital readmission and generally improving the QOLof those persons chronically affected with heart disease (Anderson et al., 2016).

In 2016, a systematic review reported the efficacy of CR could not be confirmed due to many of the trials having small samples and other methodological issues (Anderson et al., 2016). The review found CR did not reduce all cause mortality, but did reduce cardiac mortality, hospital readmissions and had a positive effect on patient QOL. Varied outcomes from many systematic reviews over the last twenty years has prompted speculation concerning the continued benefit of CR since the impact of statins, other medications and interventional strategies (Rauch et al., 2016). It has been suggested that changes in patient profiles, patient care and CR service delivery (Sumner, Harrison & Doherty, 2017) when grouped with older trials create challenges when interpreting data. A recent systematic review and meta-analysis of randomised and nonrandomised studies was undertaken to include data from actual clinical practice and mixed CHD populations (Rauch et al., 2016). Interestingly, it found CR participation reduced total mortality (Rauch et al., 2016). This finding was supported by a recent systematic review of non-randomised studies (Sumner, Harrison & Doherty, 2017). Observational evidence found CR reduced the risk of all-cause and cardiac mortality and re-hospitalisation.

CHD has been found to negatively impact on HRQOL (Bigger & Glassman, 2010; Moryś et al., 2016), thus CR programs which target the issues relative to poor HRQOL outcomes following MI, may be beneficial in promoting improvements to a patient's well being (Kang et al., 2016). In their Cochrane review, Rees and colleagues (2004) examined the effectiveness of psychological interventions used in the CR of patients with CHD versus normal care. They analysed 36 RCTs (including 12,841 patients) and reported outcomes on cardiac risk factors, psychological well being and HRQOL. This review updated two previous reviews (Dusseldorp et al., 1999; Linden, 2000) analysing the effectiveness of stress relieving therapies and effective coping skills

and other CR interventions to reduce psychological distress. Results from the trials contained in the reviews were mixed due to small samples and homogeneity amongst trials preventing the pooling of results. Rees and colleagues (2004) concluded it was not possible to generalise on the effects of psychological interventions on patient health outcomes experienced in patients completing CR because of the quality of trials that were reported. Interventions such as stress management appear to have small beneficial effects on HRQOL but no effect on cardiac mortality. Subsequent systematic reviews have reported similar outcomes to Rees et al, (2004) in terms of its effect on cardiac mortality, however, psychological interventions have recently been shown to reduce anxiety (standardised mean difference (SMD): -0.25 (95% CI -0.48 to -0.03) and depression (standardised mean difference (SMD): -0.21 (95% CI -0.35, -0.08) (Whalley, Thompson & Taylor, 2014), and improve patient QOL (Anderson et al., 2016; Moryś et al., 2016; Sumner, Harrison & Doherty, 2017). The most recent review (and update since Rees et al., 2004) of the evidence of psychological treatments for CHD found the methodological quality of conducted RCT's continued to impinge on the quality of evidence supporting the use of psychological interventions in CR (Richards et al., 2017). According to their Cochrane review, despite having no effect on total cardiac mortality or having another heart attack, participants reported reduced symptoms of stress, anxiety and depression (Richards et al., 2017). To improve the quality of evidence, they suggested future large scale effectiveness trials should test the impact of specific psychological interventions rather than multi faceted ones on different populations of CR patients (Richards et al., 2017). In order to improve the psychological outcomes for cardiac patients, many CR guidelines state that all patients should be offered psychological care based on cognitive behavioural principles (Scottish Intercollegiate Guidelines Network 150 [SIGN], 2017).

#### Current issues in cardiac rehabilitation

Patient under referral, poor attendance and completion of CR remain important issues today. Amidst the Australian context, there were 265 CR programs in all states and territories in 2001 (Bunker, 2001). This number has increased significantly over the last decade with ACRA currently reporting over 450 CR programs throughout Australia (ACRA, 2014). Despite the number of programs available and the substantial evidence

base supportive of their use (Clark, Redfern & Briffa, 2014), many patients with heart disease do not attend any form of CR in Australia (Walters et al., 2008; McDonall et al., 2013) with rates of CR attendance reported to be between 10 and 50% (Johnson et al., 2009; Jelinek et al., 2015). Globally, this trend of CR underutilisation occurs in many countries around the world with referral rates ranging from 20 to 50% (BACPR, 2012; Menezes et al., 2014).

Under or non referral of patients by CR clinicians has previously been linked to poor referral and communication practices (Karmali et al., 2014; Sumner, Harrison & Doherty, 2017). Under referral to CR is often a result of systems failure where patients are not referred due to poor hospital discharging practices (Hutchinson, Meyer & Marshall, 2014). The attitude of treating physicians towards CR (Ghisi et al., 2013; Beckstead et al., 2014) and poor discharge communication between hospital and the primary care physician (Kripalani et al., 2007; Falces et al., 2011) have been implicated. A lack of clinical awareness regarding CR program availability, the absence of key CR staff such as a designated CR service coordinator, insufficient time to arrange referral, limited program availability (Scott, Lindsay & Harden, 2003; Gaalema et al., 2017) and lack of perceived benefit (Grace et al., 2008, Arena et al., 2012) or patient knowledge of CR (Scott et al., 2013) all appear to impact on the utilisation of CR services. Automated referral systems (Mueller et al., 2009), multiple referral strategies and the inclusion of national CR guidelines (Woodruffe et al, 2015) have improved clinician CR referral initiatives (Gravely-Witte et al., 2010) without significantly impacting on rates of patient referral. Thus, there have been renewed calls to design and implement CR programs that cater for patient preferences (Wingham et al, 2006; Clark et al, 2015; Dalal, Doherty & Taylor, 2015). A variety of alternate CR formats have been proposed to compliment hospital based CR and improve CR choice for patients (Clark et al., 2013).

Explanations used to predict underutilisation are generally similar throughout the world. Predictors that demonstrate a higher likelihood of attending CR include a higher level of education (Audelin, Savage & Ades, 2008), program availability and accessibility (AIHW, 2012), CR programs that are flexible and individualised (Ades, 2007), those that provide lifestyle advice and are available in primary care settings

(Redfern, Briffa & Joshi, 2014). Other predictors include, strength of physician (Arena et al., 2012) and clinical referral (Gallagher et al., 2016), higher socioeconomic status (Dhaliwal et al., 2017) and finally, patients with higher levels of self efficacy (Dunlay et al., 2009) are more likely to attend CR post MI. Predictors of non attendance are vast in number and include older age (Suaya et al, 2009), the cost and availability of CR programs (AIHW, 2012), female gender (Grace et al., 2008; Beckie & Beckstead, 2011), living alone or in isolation with little social support or contact (Carroll & Rankin, 2005; Eichenauer et al., 2010) and the socio-economically disadvantaged (Scott, Lindsay & Harden, 2003). Other predictors include whether patients currently smoke (Allahyar, 2012), ethnicity (Bestwick et al., 2004), are anxious (Frasure-Smith & Lesperance, 2008; Roest et al., 2010) and or depressed (Thombs et al., 2006; Nicholson, Kuper & Hemingway, 2006) or possess significant co-morbidities (Brown et al., 2009). Patients who live rurally (Smith et al., 2008; Sangster et al., 2013) have work commitments or travel difficulties (Brual et al., 2010), or do not perceive the benefits of CR (Redfern et al., 2007; Johnson et al., 2009; Everett et al., 2009) are also less likely to participate in CR. While it remains important to address system failures resulting in poor referral, clearly the reasons why people, once referred do not attend, drop out or fail to complete CR programs also needs to be addressed by CR clinicians and peak professional bodies such as ACRA.

An important current issue evident in the research literature concerns how best to attract patients to CR services (Pack et al., 2013). Yet, there appears little understanding of how best to accomplish this task. In the past, CR clinicians have questioned whether the delivery and setting of CR has any impact on CR attendance. Home based CR was developed as an adjunct to hospital based services to improve access to CR for patients living rurally or remotely (Blair et al., 2011). Many have compared the two CR formats in terms of benefit to patients and health care costs and reported little difference in terms of acceptability, safety and cost (Clark et al., 2010; Taylor et al., 2015; Anderson et al., 2017). Despite both forms of CR assisting patients and improving accessibility and choice to utilise CR (Wingham et al., 2006), high numbers of patients who may benefit from CR choose not to attend programs (Clark, Redfern & Briffa, 2014). This remains a serious dilemma for clinicians both in terms of furthering our understanding concerning the underutilisation of CR (which may assist

clinicians to develop more appropriate CR delivery for these people) and the different recovery pathways people choose on there own volition.

Cardiac health practitioners are currently challenging conventional CR methods to provide patients with alternative models of care or CR service delivery (De Angelis, Bunker & Schoo, 2008, Clark et al., 2015). The aim of such programs is to reduce some of the known barriers patients face and to modify CR service delivery in conjunction with patient preferences (Dunlay et al., 2009; Neubeck et al., 2009; Huang et al., 2015). In addition, these programs need to be, highly individualised (patient focussed or centred), cost effective, culturally safe, multifaceted, and where possible integrated with the patients' usual primary care (Briffa et al., 2009). A recent systematic review by Karmali and colleagues (2014) reported on what type of inerventions improve CR uptake. In their review of 2,505 patients, CR programs that featured structured nurse or therapist contacts, were timely (implemented soon after hospital discharge), used motivational strategies, were flexible and individualistic and catered for women and older patients, were more successful in attracting patients and improving CR program adherence.

A further issue for cardiac rehabilitation lies in the recognition that no nation-wide minimum dataset collection is currently available for CR in Australia (National Health Data Committee, 2003). Despite peak health care bodies such as the HFA, ACRA and the AIHW confirming the need to develop a national strategy and registry to collect CR program statistics, only some CR data is collected by some Australian states (Zecchin et al., 2016). Due to funding issues, a similar CR outcomes register such as the National Audit for Cardiac Rehabilitation [NACR] implemented in the United Kingdom (Lewin, Thompson & Roebuck, 2004) and the Danish Cardiac Rehabilitation Database (Zwisler et al., 2016) has not been implemented nationally in Australia. Thus, it remains unknown how many patients in Australia are referred to, participate in or complete CR.

With CHD more prevalent in rural areas in Australia (AIHW, 2007; ABS, 2011), a final issue relates to how best to ensure that patients who cannot attend hospital or community based CR receive the support they require to self manage their cardiac condition. De Angelis and colleagues (2008) found that distance of travelling to established CR services was the single most significant factor in determining the uptake

of CR for rural based patients. Approximately 40% of patients surveyed were receptive to alternative methods of CR. These included home and general practitioner based programs, telephone based support and patient manuals or workbooks. Other researchers support the need to pilot test innovative home based CR programs, in order to improve CR accessibility for patients living in regional Australia (Dollard et al., 2004; Varnfield et al., 2011; Courtney-Pratt et al., 2012; Sangster et al., 2013;).

Innovations in CR service delivery include chronic disease based programs such as the Expert Patient Program [EPP] (Foster et al, 2007; Kennedy et al., 2007) and home based CR programs such as the Heart Manual in the UK (Lewin et al., 1992). There has also been numerous nurse led chronic heart failure programs and clinics implemented in many countries with favourable outcomes (Stewart & Horowitz, 2003; Taylor et al, 2005; Thompson, Roebuck & Stewart, 2005).

A review of literature conducted by Dollard and colleagues (2004) and updated by Neubeck et al (2009) identified several home based CR programs using various telehealth methods including telephone, home visits and multimedia technologies. Outcomes from these models demonstrated benefits comparable with traditional CR with improvements in patient knowledge of risk factors, risk factor profile, psychosocial functioning and a reduction in health service costs (Dinesen & Spindler., 2014; Clark et al., 2015). Other recent telehealth innovations include Coaching Patients on Achieving Cardiovascular Health [COACH] (Vale et al., 2002; Vale et al., 2003; Jelinek et al., 2009; Ski et al., 2015), Coaching Patients on Achieving Cardiovascular Health [CHOICE)] (Redfern et al., 2009), mobile phone-assisted CR (Mohan et al., 2008; Mattila et al., 2009; Walters et al., 2010; Varnfield et al., 2014) and various computer/internet-based CR secondary prevention programs (Brouwer et al., 2008; Vandelanotte et al., 2010; Varnfield et al., 2011). However, while many of these secondary prevention programs demonstrated improved outcomes for patients, not all can be considered as comprehensive as the AHGP in its content or delivery.

To date there has been limited evaluation of alternate forms of CR programs in Australia, and specifically, little evidence relating to the outcomes of patients or from nurses or others conducting such programs. Reporting the outcomes of the various small scale telehealth interventions used globally to manage a wide variety of chronic

diseases continues to be difficult. This is due to the many different interventions used and the heterogeneity of published research. This has cast some doubt on the effectiveness and sustainability of some of these programs (Wootton, 2012; Dinesen et al., 2016). New knowledge gained by exploring the AHGP may signal its acceptability by patients and nurses and feasibility in terms of a standalone telephone based CR program for patients recovering from MI in Australia.

## The adaptation of the AHGP to the Australian rural setting

The antecedent of the AHGP, "The Heart Manual" (Lewin et al., 1992; National Health Service (NHS) Lothian, 2016) was originally developed and trialled in the UK over two decades ago and has been successfully adapted in several countries throughout the world (Pedretti et al., 2006; Wang, 2007; Eadie & Tane, 2010). When the Heart Foundation of New Zealand piloted a similar version of "The Heart Manual," named Heart Guide Aotearoa, the investigators worked collaboratively with the Heart Manual authors to make the material culturally acceptable to the Maori population (Eadie & Tane, 2010). To be accepted by other populations and cultures, the original authors have on occasions given permission for pilot studies in other countries to make salient changes in relation to language, specificity of national CR guidelines and naming of pertinent resources. Currently, the Heart Manual continues to be recommended and implemented by various health services in the UK. Emerging research recently updated a Cochrane review confirming the Heart Manual's effectiveness when compared with hospital based CR programs (Anderson et al., 2017).

These changes do not usually encompass any specific changes to the cognitive-behavioural content or self management ideals of the CR program, thereby, allowing the program to be accepted by different counties, ethnicities and cultures (Wang et al., 2012). In Australia, ACRA convened a specialist group of experienced CR clinicians to overseer the cultural adaptation of the Heart Manual to ensure it met the country's current CR guidelines (ACRA, 2008a). Subsequent changes to the program's written resources (such as medical terminology, medications, emergency treatment of chest pain, exercise prescription and available contacts and resources, etc.) were agreed upon by group consensus of CR practitioners and then discussed with the Heart Manual

authors prior to the printing of written program resources. The subsequent program was then titled the AHGP.

The AHGP's audio visual and workbook proofs were then tested on a small number of lay subjects to test the resources for accuracy and readability. Once drafts were clarified the resources were then produced and packaged in readiness for the pilot study. This case study of the AHGP pilot study forms the foundation of the PhD research, which uses the SPO framework to explore the operationalisation of the program.

## Transitioning from nursing expert to patient mentor

Many nurses have adopted the traditional biomedical model of "health expert" where nurses provide patients with care, information and education based on their nursing knowledge and patients assume a passive role in their care. Recently, due to fragmentation of care experienced by many patients associated with reduced lengths of hospital stay, complex new technologies and multiple health professionals involved in their care (Wiggins, 2008), there have been calls to place the patient at the centre of their own care. (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2014). The premise is to move away from the notion that the nurse knows best to one of partnership (Wiggins, 2008) where the nurse and patient share knowledge, power and responsibility (Hook, 2006). According to Wiggins, key aspects of partnership include 'shared responsibility, information and decision making, which are supported by the attributes of communication, trust, respect and reciprocity' (2008, p 635). For nurses, the move away from tradition to one of partnership with the patient improves job satisfaction and a reduction in stress (Bidmead & Cowley, 2005) as they take on more of a supervisory role with less responsibility (Wiggins, 2008). Concept analyses relating to the nurse-patient partnership suggest many patient benefits. These include their ability to self manage, better utilise health care and improve their health outcomes (Hook, 2006). Gallant, Beaulieu and Carnevale (2002) suggest patients can develop a sense of control due to improvements in self-efficacy, knowledge and competence. Others suggest that partnership fosters patient empowerment which contributes to improvements in self esteem and feeling more capable and supported (Bidmead & Cowley, 2005).

The AHGP sets out to challenge nurse practices based on the biomedical model of health care by introducing them to the benefits of partnership to improve the health outcomes of patients. Shared decision making and providing one to one care by maintaining their role of mentor and partner remains a vast departure from the group work most clinicians undertake in hospital based CR (Elwyn et al., 2012). Thus, exploring nurse mentor perceptions may provide insights relating to this change in CR practice and be of clinical interest to other nurses thinking of implementing similar programs for patients experiencing other disease specific conditions such as diabetes, pulmonary disease and arthritis.

# Concept of patient centred care and the nurse-patient partnership

Researchers have also found that the patient centred care (PCC) approach promotes patient engagement and participation which may translate to improvements in health outcomes (Lusk & Fater, 2013). A recent concept analysis of PCC was undertaken to identify what key aspects of PCC are unique to nursing and to provide a nursing definition of PCC (Lusk & Fater, 2013). They found PCC was consistent with many nursing beliefs, attitudes and values with the ability of patients to engage and participate in their own care inextricably linked to the likelihood of positive patient health care outcomes (Lusk & Fater, 2013). Others have also highlighted the importance of patient participation in reducing stress, improving motivation and patient satisfaction with health care received and the important role nurses perform in encouraging and facilitating patient participation in their own care (Sahlsten et al., 2008).

Although research from Ekman and colleagues (2011) highlight the importance of improving the care experience of patients to provide quality health care, integrating patient preferences and changing traditional practice at the level of patient care is often difficult (Gillespie, Florin & Gillam, 2004; Groene et al., 2009). However, PCC is supported in Australia by the Australian Charter of Healthcare Rights (2008) and the Australian Commission on Safety and Quality in Healthcare (2011; 2014) and acknowledgement of its conceptual use in hospitals is becoming more widespread. Concepts such as respect for patient values and preferences, emotional support,

information, communication and education, continuity and transition, coordination of care, access to and coordination of care and involvement of family and friends care (Robb & Seddon, 2006; Slater, 2006; National Research Corporation (NRC) Picker, 2008) are core aspects of PCC. With respect to CR, of note is the recommendation of Australian CR guidelines advocating that CR programs be flexible and individualistic in their approach (ACRA, 2008; Woodruffe et al., 2015). However, while there is emphasis placed on empowering patients (Oudshoorn, 2005) to develop their self help strategies and having a individualistic approach to the provision of nursing care, there is no mention of PCC in the current CR guidelines. Thus, questions remain in terms of whether many CR nurses have received any relevant PCC training to date or possess the clinical time to operationalise PCC (Gillespie, Florin & Gillam, 2004) in their traditional CR programs, as many remain group based in their delivery and not stable in their funding arrangements (NHFA, 2014).

The concept of PCC represents a core competency for all health care providers in the context of providing excellence in quality health care (Sidani, 2008). In PCC, health providers respect individual patient differences, values, needs and preferences (Institute of Medicine, 2003). Specific attributes or themes associated with PCC include behaviours of developing a relationship or partnership (Munro et al., 2000; McCormack et al., 2010a) based on the patient narrative (Ekman et al., 2011), communication and listening (Sumison & Law, 2006), patient access to teaching and learning (Flach et al., 2004), respect and caring for the patient, and maximising family involvement (Meterko et al., 2010). Strategies such as attending to the individual physical and psychosocial preferences of patients, providing accessibility to care (Breen et al., 2009), and individualisation in terms of the planning of care are commonly used as reported in the literature (Robinson et al., 2008, Sidani, 2008).

Central to mentoring, shared decision making improves patient autonomy and makes patient empowerment more likely (Bastiaens et al., 2007, Muller-Engleman et al., 2011, Ekman et al., 2011). While not inherently specific to nursing, PCC behaviours are foundational in terms of nursing practice where a caring attitude, encouraging patient autonomy and the individualisation of care are key nursing constructs. PCC has been found to improve the perceived health care and satisfaction of patients (Olsson, Karlsson & Ekman, 2007; Ekman et al., 2012, Lusk & Fater, 2013)

and improve the discharge process (Ulin et al., 2015). Thus, the AHGP aims to use PCC as its foundation of providing care to patients recovering from MI.

## **Summary**

This chapter presented the research literature pertaining to CR as a secondary prevention intervention utilised to improve outcomes of patients with CHD. A definition of CR and its origins including its development and its effectiveness as a health management strategy was provided. Authors contend new CR programs must be developed to improve choice for patients and offer flexibility as well as meet their rehabilitative needs. CR programs also need to be available for patients who cannot access traditional programs due to their location or rurality. A description of the AHGP with its foundational use of PCC and the expected transition from nurse expert to patient partner and mentor concludes this chapter.

Chapter 3 outlines the methods used to meet the research aims of this study. It includes a description of the SPO methodology used to conceptually underpin this study. The study design is presented detailing the sample, the intervention studied, and the various instruments used to measure data. Following this, data collection, data management and analysis and ethical considerations are examined.

## **Chapter 3: Research Methods**

## Introduction

There is growing evidence that patients who complete CR following a MI have a reduction in all cause mortality (Heran et al, 2011; Lawler et al, 2011). Unfortunately, many patients choose not to attend hospital or community based CR programs despite having adverse risk factor profiles and limited understanding of heart disease. Many factors have been implicated in this lack of attendance, including program availability, suboptimal referral and a lack of understanding of the seriousness of the disease. Thus, new innovations aimed to attract participants to CR are still clearly warranted. This study aims to evaluate the structures, processes and outcomes (SPO) of a home based CR program for patients recovering from MI and who live in rural areas of Tasmania. It is envisaged that study outcomes will contribute to the evidence base concerning the effects of the AHGP, a home based CR program based on cognitive behavioural principles, PCC, secondary prevention guidelines and delivered in their own home.

The following section outlines the theoretical framework and methods used to meet the proposed research aims. The study design is presented followed by details relative to sample selection and the various instruments used to measure data of interest. Following this, the collection, management and analysis of data along with ethical considerations will be examined.

#### Theoretical framework

Donabedian's SPO framework of health care quality (1966) was the theoretical framework that underpinned this research with the intention of evaluating the impact the AHGP in terms of whether it met the expectations of patients recovering from MI as a standalone home based CR program. The Donabedian approach provides a framework for evaluating the quality of health care. Though Donabedian does not define quality as such, inferences pertaining to health care quality can be drawn by analysing the information contained within the concepts of structure, process and outcome.

According to Donabedian (1988), the concept of structure is the environment or setting in which health care occurs. It refers to the characteristics of care providers such as number of staff and qualifications and includes the tools and resources available to

provide care and the physical or organizational setting (Salzer et al., 1997). The concept of process demonstrates how the health care is provided in terms of giving and receiving care (Donabedian, 1988), and include factors such as the therapeutic relationship and rapport and the technical skill and knowledge utilized in the delivery of health services (Salzer et al., 1997). The concept of outcome helps define the effects of care on the health status of patients (Donabedian, 1988) and include categories such as patient attitudes toward treatment, improvements in health related knowledge and behaviours as well as improvements in symptoms and health functioning (Donebedian, 1988). In combination, these outcome categories signal patient satisfaction with care received. Figure 1 illustrates the conceptualisation of the SPO applied to the AHGP.

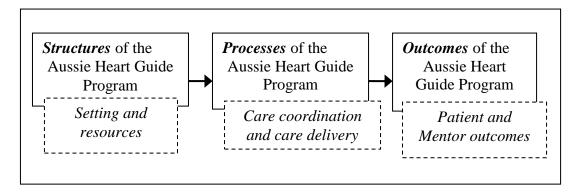


Figure 1. Conceptualisation of Donabedian's (1966) structures, process and outcomes framework applied to the Aussie Heart Guide Program.

According to Donabedian (1966), while each competent of SPO has the potential to influence the next, outcomes generally remain the ultimate validation in relation to the effectiveness and quality of medical care. The SPO framework of quality health care suggests improvements in care structures can lead to improvements in clinical processes which in turn may impact positively on patient outcomes (Rademakers, Delnoij & de Boer, 2010). Donabedian's SPO framework (1966) has been widely used by others in health care research with the broad aim of improving patient health care (Hoenig et al., 2002; Kunkel, Rosenqvist & Westerling, 2007; Schillinger et al., 2009; Chaboyer, McMurray & Wallis, 2010; Crilly et al., 2012; Nocella et al., 2015).

## Research aims and questions

The study aims to evaluate the structures, processes and outcomes (SPO) of the

AHGP for patients recovering from MI and who live in rural areas of Tasmania, Australia. It used an explanatory, embedded single-case design in conjunction with the SPO framework of evaluating health care quality (Donabedian, 1966) to answer the research questions. Evaluating the SPO of the AHGP will provide evidence suggesting improvements to the program and its applicability as a new model of home based CR in Australia.

As identified in chapter one, the three research questions were:

- 1. What are the structures of the AHGP, a home based CR program for patients recovering from MI as perceived by patients and mentors?
- 2. What are the processes of the AHGP, a home based CR program for patients recovering from MI as perceived by patients and mentors?
- 3. What are the outcomes of the AHGP, a home based CR program for patients recovering from MI as perceived by patients and mentors?

In terms of the research aims and questions concerning this study, several patient outcomes were identified and hypotheses generated.

#### Hypotheses include:

- 1. The AHGP will improve patient HRQOL following MI, evidenced by changes in the MacNew HRQOL scores.
- 2. The AHGP will reduce patient levels of anxiety and depression following MI, evidenced by changes in Hospital and Depression Scale (HADS) scores.
- 3. The AHGP will improve patient exercise levels following MI, evidenced by changes in the Short Measure of Physical Activity scores.
- 4. The AHGP will positively affect patient perceptions of their illness following MI, evidenced by changes in Revised Illness Perception Questionnaire (IPQ-R) scores.
- The AHGP will positively affect the self-management abilities of patients post MI, evidenced by changes in the Health Education Impact Questionnaire (heiQ) scores.

## Research design

## The case study

A case study method was chosen as an appropriate research design because it sets out to explain and understand a phenomenon, namely the AHGP, specifically because the AHGP is a specific case, with clear boundaries, which can be analysed to explain its structures, processes and outcomes and the relationships among them. According to Guba and Lincoln (1981), case studies can be evaluative, seeking to understand a phenomenon. Further, they can also be explanatory or seeking to explain a phenomenon in its real world context (Yin, 2009). Case studies can also provide an in depth analysis to show relationships between two subjects (nurse mentors and patients) that focus on a contemporary event such as the AHGP. Case studies can collect and analyse multiple sources of evidence (both quantitative and qualitative data) to develop new knowledge about a particular case or cases. According to Stake (1994), a case study should be defined by the case or cases, or phenomenon of interest, not by the method of enquiry used. The case study method was chosen in lieu of other research methods to provide new information about nurse mentors and their relationships with patients (as mentors) and extend knowledge concerning what is known about patients and home based cardiac rehabilitation programs previously. It was useful in terms of explaining rather than exploring the various "what" type of research questions arising from this research. The triangulation of both quantitative and qualitative case study data, new knowledge about the SPO of the AHGP will be clarified to examine whether the AHGP meets the expectations of patients and nurse mentors.

Case studies are robust, in-depth investigations of some single or multiple phenomena that may include an individual, group or organization (Schneider, Whitehead & Elliot, 2004). They can be used to develop theory, to evaluate programs, to assist researchers to develop new interventions and to inform clinical practice (Baxter & Jack, 2008). However, there remains confusion or debate concerning the categorisation of case study (Schneider, Whitehead & Elliot, 2004) and according to Stake (1994) researchers often fail to clarify, make explicit, describe or justify its use as a research method in their reports. Several different definitions and applications relating to case study are present in the research literature, including the case report,

case history, case summary and the case-control study (Minichiello et al., 2004). This may have contributed to making the meaning of case study in the past elusive.

The main proponents of the case study method are Stake (1995), Yin (2003) and Merriam (1998; 2009). While the perspectives of Yin (post-positivist), Stake (constructivist/interpretivist) and Merriam (constructivist) diverge from each other, they also share common assumptions about the case study method. Although Yin does not overtly disclose his philosophical orientation, others analysing his work have suggested a postpositivist orientation (Yazan, 2015). Positivism asserts that reality (natural and social worlds) can be objectively measured through science via experiments and observations (Polit & Beck, 2010). Postpositivists accept that theories, knowledge and values of the researcher can influence scientific outcomes (O'Leary, 2007). Essentially, postpositivists reject the notion that knowledge gained from experimentation is infallible (Harrison et al., 2017) because experimentation and observation are subject to error or bias. For Yin (2009), although case study research is an empirical inquiry, it must conform to a number of epistemological commitments (described later) in order presumably to open up alternate possibilities of knowing (O'Leary, 2007). Stake and Merriam's philosophical orientation stem from constructivist views suggesting we construct our view of reality or the world based on our perceptions of it (Yazan, 2015). For Stake, knowledge is constructed rather than discovered and qualitative case study researchers are interpreters of multiple perspectives or views about a case (Stake, 1995). Merriam appears to be more closely aligned with Stake's consructivist views suggesting that qualitative research should endeavour to understand the meaning of knowledge constructed by people (Merriam, 1998). Central to her consructivist views, Merriam considers a number of essential pragmatic structures imperative to help ensure case study research is manageable, rigorous, credible, and applicable (Harrison et al, 2017).

In their description of case study, Yin and Stake both share the view that the topic of interest must be well stated and fully explored. However, they use different criteria to explain their definitions and terminology. Both Yin and Stake base their case study teachings on a constructivist paradigm which is built upon recognising "the subjective human creation of meaning without ruling out objectivity" (Baxter & Jack, 2008, p.544). The constructivist paradigm, also values the close collaborative relationship

between researcher and study participant, where they can "describe their views based on their perceived reality" (Baxter & Jack, 2008, p.544).

Case study is often referred to as a method (Yin, 2009) while others view it as an approach or strategy (Walshe et al., 2004) possibly because many other research approaches contain elements of the case study design in terms of collecting, analysing and evaluating data. In comparison with other experimental and non-experimental research designs, the case study, according to Yin, "is an empirical inquiry that investigates a contemporary phenomenon in-depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident" (Yin, 2009, p. 18). Yin broadened this definition by applying a further set of assumptions, some of which are shared with other research designs, but in unison, differentiate the case study from other qualitative designs (Bergen & While, 2000). A case study design: 1) assumes an objective reality that can be examined using traditional rules of scientific enquiry, 2) may be used for theory building and theory testing, 3) considers the context as an essential element of the phenomenon being studied and 4) favours multiple data collection procedures and the type of data to be examined can be quantitative or qualitative (Yin, 1993). Yin's case study method was chosen over other research methods because the study sought to examine a phenomenon of a mentor led home based CR program within its 'real world delivery' and the regional setting (i.e. context), which impacts on the phenomenon itself. Yin's belief in the value of empirical enquiry and his postpositivist assumptions about the social world have led him to acknowledge the value of qualitative and quantitative research to both understand and measure socially constructed reality.

The case study method has been widely used in education (Stake, 1995; Yin, 2003), social psychology (Barlow & Hersen, 1984) and nursing research (Hellström, Nolan & Lundh, 2005; Chaboyer et al., 2005; Luck, Jackson & Usher, 2007). According to Polit and Beck (2004), the case study can be highly descriptive, examine trends over time and analyse and understand issues important to the case being studied. The case study may also be used to explore new phenomenon or issues, especially where little theory or measurement is available, to describe a process or effects of phenomenon, event or intervention or to explain a phenomenon's complexity (Kuhn, 1997). Yin (2009) suggests the explanatory purpose of the case study method is very

powerful in its ability to answer the "what," "how," and "why" type of research questions. Case study methodology is frequently applied to studies trying to determine the effectiveness of complex programs, services or interventions (Kuhn, 1997). In research studies designed to investigate complex issues or problem, case study methods can combine a mixture of data collection methods dependent on the nature of the problem and the questions to be asked (Kuhn, 1997).

Case studies can be prospective or retrospective and can be used inductively or deductively as a theoretical approach (Bitektine, 2008) to focus on a single case or multiple cases. This study used a deductive and inductive approach, being guided by the SPO framework by undertaking thematic analysis of data. A major attribute of the case study method is its flexibility and ability to examine complex relationships between data or interventions (Walshe et al, 2004). Unfortunately, in the past, the case study method has been unfairly scrutinised and undervalued when compared with various statistical methods (Hyett, Kenny & Dickson-Swift, 2014). Additionally, Yin (2003) suggests the case study method has been inappropriately compared with quantitative research designs such as the randomised controlled trial. A commonly held misconception is that case study methods are useful only to gain data in the exploratory phase of an investigation and that only experiments can explain phenomena and causal relationships (Yin, 2009). While some question the "generaliseability" argument (in terms of applying single case study findings to a wider population sample), Yin (2009) suggest that case studies "are generalizable to theoretical propositions" and not to populations or "statistical generalizations" (2009, p.15).

Another common misconception is that the case study method lacks rigour and trustworthiness compared with experimental methods. Proponents of the case study method agree that it is very important to follow established frameworks and guidelines to establish reliability, validity, transferability and confirmability (Russell et al., 2005; Baxter & Jack, 2008; Yin, 2009). A case study design that involves both qualitative and quantitative data offers the opportunity for the triangulation of data from multiple sources of evidence (Walshe et al., 2004). This has the advantage of enhancing rigour, especially construct validity (Yin, 2009) via the use of various data collecting strategies (including, but not limited to, field notes from observational data, open-ended interviews, structured surveys and archival documentation (Bergen & While, 2000). By

examining the cumulative view of data drawn from different contexts and interpreting where the data intersect or "triangulate," the reliability of using a single research method is strengthened (Silverman, 2010), a strategy now commonly adopted by many qualitative researchers. Methodological triangulation may be preferable in case study research where several research questions are to be explored or where mixed methods may help to corroborate similar findings (Mason, 1996) or contexts embedded in the data relative to the phenomena being explored.

In terms of designing a case study, Yin (2009) describes several steps to identify the case or cases to be studied and importantly, to establish the logic for conducting the study. One needs to consider; a) whether the case study method is appropriate for the research focus or question(s) being asked; b) the context, "case" or unit of analysis must be considered; c) have boundaries been placed on the case (time, place, context or activity) to determine the scope of the study (Yin, 2009) and d) the type of case study (guided by the study aim or purpose) should be stated. Yin and Stake use different terminology to describe case study type. Yin (2009) suggests that case studies are either exploratory (used to explore situations where a phenomenon being evaluated has no clear, single set of outcomes), explanatory (asking questions seeking to explain the presumed causal links in complex real-life interventions) or descriptive [used to describe a phenomenon and the real-life context in which it occurred] (Yin, 2003; Baxter & Jack, 2008). In contrast, Stake (1995) suggests a case can be intrinsic or instrumental. The intrinsic case study is preferred when the case is of genuine interest and the research is undertaken to understand the specifics of the case. Instrumental type of case study is used when researchers want to understand something other than the specific case being studied or understand an issue external or secondary to the case being studied (Baxter & Jack, 2008). Case studies can be single or multiple cases in design. Single case designs can be holistic (Yin, 2009), with a single unit of analysis or embedded, containing multiple units of analysis. In addition, theories, propositions or conceptual frameworks (Yin, 2009) may also be included in the case study design to anchor the study. However, theories may also be generated later from interpreting and analysing data derived from the case study (Yin, 2009).

A description of the steps involved in designing this case study follows. In terms of whether the case study method is appropriate for this research study, a case study

method asks "what" type of questions to explain certain phenomena. In this study, the SPO of the AHGP were examined to explain the extent to which the AHGP is a quality home based CR program. In terms of the context, "case" or unit of analysis, the case study used an embedded single case design with multiple units of analysis (encompassing both mentors and patients) to answer the research questions. This type of case study, was selected to allow an in depth evaluation of the AHGP and the mentoring role, using multiple sources of evidence (both quantitative and qualitative data). This was undertaken because there has been very little evaluation of the program to date.

In terms of the placement of boundaries on the case (time, place, context or activity), the case study was bound geographically in terms of participant residence, by data collection procedures and by time. The study occurred in regional areas of Tasmania, with the greatest number of patients using the AHGP in the south of the state. Only adult patients recovering from MI and who could not attend a hospital based CR program volunteered. Only registered nurses (who undertook specialist mentor training) took part in the AHGP. Data was collected from patients in hospital, via telephone interviews and by return mail during different time periods because of the geographical location of their residence (throughout Tasmania). Data from mentors was collected from their clinical patient records and via an internet based written survey. This method was chosen because mentors were a) placed in regional areas of Tasmania and face to face meetings were difficult to organise and b) mentors requested to be surveyed by email. The AHGP was also bound by time and place, with the study completed over a three year period, recruiting patients in Tasmania's public hospitals. Several forms of data collection were undertaken during the study to identify and understand the structures, processes and outcomes of the AHGP. These are highlighted in the data collection procedures section of this document. Quantitative data focussed mostly on patient and mentor perceived outcomes evidenced via self-report questionnaires and surveys. The analysis of mentor field notes and mentor survey provided qualitative data concerning the structures and processes relevant to the outcomes of the mentoring aspect of the program. In terms of the type of case study used (guided by the study aim or purpose), the study used an explanatory approach to understand the SPO of a new model of CR (the AHGP) and to link the implementation

of a program (AHGP) with program effects.

Case study research, according to Rosenberg and Yates (2007), can be conceptually and methodologically challenging to novice researchers. They advocate the use of schematics to provide the key steps necessary to promote rigour and the "procedural clarity" and "methodological integrity" required to conduct case study research (2007, p. 451). Figure 2, provides an eight step schematic representation of the procedural steps undertaken in this case study to provide conceptual and procedural clarity and promote methodological rigour (Rosenberg & Yates, 2007).

The case study method was chosen as an appropriate research methodology to build an explanation about the context of the study; the patients and mentors of the AHGP and the structures, processes and outcomes of the AHGP as perceived by patients and mentors. Building an explanation through pattern matching seeks to understand a phenomenon (the AHGP) and its value as a standalone CR program for rural patients recovering from MI.

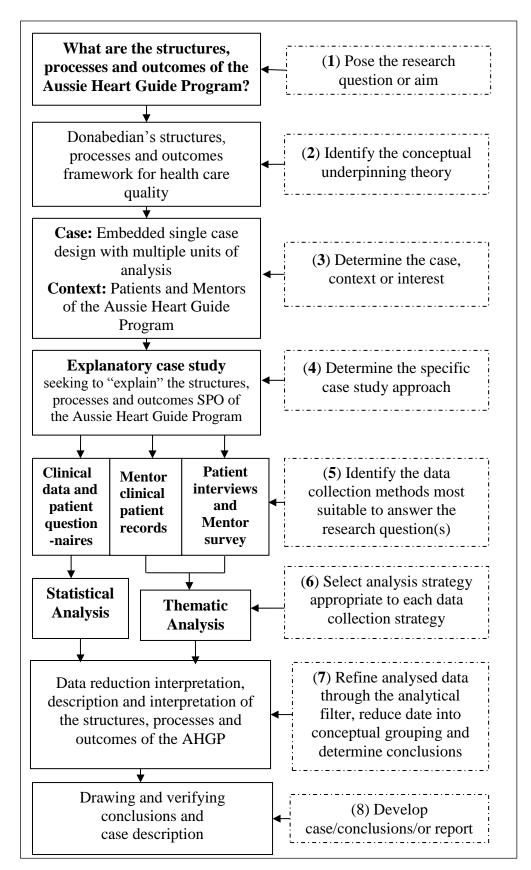


Figure 2. An eight step schematic of case study design applied to the Aussie Heart Guide Program [adapted from Rosenberg & Yates, 2007].

## Research methods

This section provides an overview of the sample used in this study. The setting, study participants, inclusion and exclusion criteria are described, followed by the recruitment strategy and the mentoring process. A detailed description of the collection, management and analysis of data, and steps taken to enhance study rigour of the research are detailed. The chapter finishes with the ethical considerations of this study.

## Setting

Participants in this study consisted of patients and mentors. Patients were recruited from patients admitted to the coronary care units (CCU) of three metropolitan hospitals in Tasmania. All patients in these hospitals were routinely offered CR as part of their treatment and convalescence. Currently in Tasmania, CR programs are hospital based and run as outpatient programs in four major metropolitan areas of the state. Mentors were coronary care and CR nurses who attended a training work shop about the AHGP and then agree to mentor patients in their homes. The study commenced in July 2008 and was completed in December 2011.

## Study participants

Study participants were patients and their mentors. Patient participants were those who agreed to participate in the AHGP and who met the following inclusion criteria; adults (18 years of age or older) and had suffered an MI. Patients with a previous history of MI were not excluded because all patients should have an opportunity to gain knowledge and on going support after cardiac illness. Diagnosis of MI was confirmed by each patient's consulting cardiologist. Proof of MI was deemed conclusive via the measurement of plasma cardiac Troponin I with an MI cut off of 0.120 ug/L (using the Vitros Troponin I ES Reagent on the Vitros ECi Immunodiagnostic System). Patients were identified for potential inclusion if they were unable (due to time, cost of travel, no transport, financial issues etc.) to access another form of CR, able to read and write in English and were not cognitively impaired. The ability to converse, read and write in English was justified because the AHGP is currently not available in other languages. In terms of cognitive impairment, participants needed to be able to comprehend the AHGP resources. Participants could join the program if they had family members or

significant others who could assist them with reading, writing and help complete questionnaires.

Adult participants admitted to coronary care units were excluded if they were clinically unstable (due to uncontrolled arrhythmia, unstable angina or heart failure [class 3 or 4]), had a history of major psychiatric illness (including dementia), possessed significant co-morbidities that may preclude the ability to exercise (severe osteoarthritis or rheumatoid arthritis, osteoporosis or back injury), or had severe eyesight or hearing impairment which would prevent the reading or listening to the AHGP resources.

The seven mentors who participated in this study were nurses specifically trained to deliver the AHGP. All mentors in the study were experienced nurses employed in coronary care units or outpatient CR programs in Tasmanian hospitals and were invited to register their interest in becoming an AHGP mentor in February 2008. After training, mentors used a checklist to check whether patients could be included or excluded from the study. Mentors, in conjunction with cardiology nurses, assessed patient eligibility.

## **Patient recruitment strategy**

All consecutive patients who met the inclusion criteria for the study were identified for potential study recruitment. The study aimed to invite 50 patient volunteers to participate in this multi-centred regional study. A limit was set due to the cost of audiovisual resources used in the program. Potential participants were initially identified on admission by coronary care nurses (or the CR nurse coordinator), if there was a strong likelihood that they had suffered an MI, lived in rural communities outside the reach of city or metropolitan hospital based CR programs.

When admitted patients were clinically stable, potential study participants were approached by coronary care nurses and introduced to the CR coordinator. No new processes were used to identify potential study participants. Patients who reside in geographically isolated areas, under normal circumstances are unlikely to travel long distances to attend hospital based CR programs. Thus, all study participants living remotely were given the opportunity to voluntarily participate in the AHGP. Each patient was informed about the study by CR nurse coordinators and given the Study

Participant Information Form (see Appendix 1) for perusal. After questions were answered to their satisfaction, patients interested in joining the study were advised of their right to refuse questions and withdraw from the study at any point without prejudice in relation to their treatment or ongoing care. At this point, patients were also advised that all their personal details and information would remain confidential with all personally identifying data removed from the study records after the completion of data analysis.

Patients wishing to participate in the study were asked to sign a duplicate consent form (one for participant to keep, one for study records) and then formally invited to join the program (see Appendix 2). In most cases, the attending CR nurse in each hospital became the assigned mentor for the patient and organised to meet with the patient and spouse, family or significant other at a mutually convenient time to formally begin the program. Patients who declined the opportunity to join the study received usual discharge care without prejudice. Participants were formally discharged from the study after they had completed 1) the six week AHGP, 2) completed the various evaluation questionnaires and 3) received a discharge letter from the study investigators.

Participants formally commenced the AHGP within one week of being discharged from hospital. Information regarding the AHGP was provided to patients prior to leaving hospital. Most patients met their nurse mentor for about an hour prior to leaving hospital. This interview was part of the AHGP in this pilot study research study. It was meant to formalise not only the mentor/patient relationship, building of trust and rapport but represented in most cases, the only time a formal face to face meeting occurred between mentors and patients, during the home based CR program. Ideally, all patients completed the interview with their mentor prior to discharge from hospital. However, on occasions, some patients were discharged from hospital within 48 hours of admission. In cases where participants wished to join the program but were to be discharged prior to the interview with their mentor, they were given the opportunity to join the program by arranging to meet with their mentor within one week of discharge from hospital. To ensure all aspects of discharge and features of the program were discussed, operational check lists were used to assist mentors to address all issues and processes pertinent to the AHGP.

## Mentor recruitment and training strategy

The recruitment of nurses to be trained as mentors occurred through hospital flyers, email contact between clinical wards and via a statewide CR interest group. To become a AHGP nurse mentor, individuals attended a specific training workshop designed and delivered in person by Professor Robert Lewin from York University, UK. This provided the framework for the specialist training of nurses in relation to the AHGP and the use of CBT principles and other strategies to assist mentors during the program. Once additional preparatory reading was completed, online and further training sessions were attended by mentors and interested nurses were invited to join the AHGP as mentors.

#### The AHGP

The AHGP was adapted from the United Kingdom's "Heart Manual" (Lewin et al., 1992) which was introduced to improve the uptake of CR for patients recovering from MI. As a home based CR program, the "heart manual" has been compared with other hospital based CR programs and found to be as effective (Dalal et al., 2007, Jolly et al., 2009; Taylor et al, 2015). In Australia, the AHGP was modified for the Australian setting in 2008 by the Australian Cardiovascular Health and Rehabilitation Association (ACRA) and Medical-Ed, Australia produced the audiovisual resources. It is a self help style CR program, patients recovering from cardiac illness can use in their own homes. It aims to assist recovery by providing continuity of care after discharge from hospital, disease specific information to aid in their understanding of their illness and by supporting patients practically and emotionally through the provision of specially trained nurse mentors. Essentially, the AHGP consists of several information and education based audio visual resources packaged in a self closing laminated plastic file (see Appendix 3) and the support and guidance of a nurse mentor for the duration of the AHGP. The resources included a) two workbooks for patients to read and follow recommendations, b) one workbook for spouses, partners and significant others to read, c) one patient pocket diary to record daily activities, use of medications, follow-up appointments and medical emergency prompts, (d) one relaxation compact disc or tape recording to help reduce stress and (e) one interactive educational CD-ROMs (compact disc read-only memory) specifically about heart health and (f) one patient diary to

record daily activities, use of medications, follow-up appointments and medical emergency prompts and 2) the support and guidance of a nurse mentor for the duration of the AHGP.

The first of two workbooks contain the most important information relative to recovery and is delivered in an easy to understand language often using a cartoon type format. While others have found the format not agreeable to everyone, due to the diversity of literacy and education in the population, extensive testing in other countries using similar formats found the cartoon format to be highly acceptable to most patients (Lewin et al., 1992; Pedretti et al., 2006; Eadie & Tane, 2010). workbook one's educational message commences with an introduction detailing the aims of the AHGP and some examples of what previous patient's thought of the similar h hospital. Most patients met their nurse mentor for about an hour prior to leaving hospital. This interview was part of the AHGP in this pilot study research study. It was meant to ome based CR programs.

Workbook one's introduction provides information regarding the program's aims and objectives, followed by a section where the patient can "sign up" declaring their interest and commitment to continue. Following this, an interactive section of the workbook introduces the reader to commonly held misconceptions about heart disease. This leads in to information about CHD, associated risk factors and the setting of goals to assist with recovery and maintenance of health. A case study titled "Julie's story" demonstrates to the reader how the planning of weekly targets, the use of a diary to guide recovery and help of a mentor or life coach assists recovery over time. The next section of the workbook deals with activity and relaxation. It encourages the use of the relaxation CR-ROM using guided imagery and breathing technique. The final page provides information relevant to patient safety and gives details about the symptoms of a heart attack and what to do if symptoms reoccur.

Workbook two contains an index and patients can read all or parts that are of interest to them. Mentors openly encourage patients to read through the entire booklet. However, the index system was introduced after field testing to prevent reader fatigue and assist those patients with cognitive issues such as poor concentration. The index page assists guide users to select headings they are interested in and then "tick" the

listings off, making it a relatively easy task of selecting other topics at different sittings. Some of the subject matter covered includes worries, sleep, sex, surgery, smoking, diabetes, medications, activity, heart problems in families and support resources available to them.

Workbook three is provided for partners and families. Many misconceptions surround how families should act around patients when they return home from hospital after a cardiac event. This aims to dispel some of these misconceptions, so family members can better understand the process of CR. It covers information concerned with providing support (emotional, physical and social) during their partner's recovery, issues concerned with physical intimacy and provides commonsense answers to many of the commonly held questions relating to heart disease and recovery.

The pocket diary is an important aspect of the AHGP intervention. It represents the daily and weekly goals or targets set by the patient in collaboration with their mentor. A degree of intrinsic reward is associated with goal setting. Practicing the skill then "ticking off" the goal (goal achievement) assists the user to move positively along the recovery pathway continuum. While patients were encouraged to choose their initial personal goals, mentors helped if requested to do so. Initially, mentors work closely with patients while in hospital to promote understanding of the lifestyle factors that may have contributed to their illness. From this point, patients select goals they wish to achieve over an agreed period. Mentors assist patients as necessary to ensure that behavioural goals are specific, measurable, achievable, rewarding and time bound. The diary is small enough to carry on their person or in a carry bag and contains relevant information concerning their recorded goals and progress, emergency phone contacts, doctor appointment times, risk factor measurements (such as blood pressure, smoking status, weight, girth size, activity, cholesterol and target checklists) and physical effort score when performing exercise or other activities. The program also offers a relaxation therapy CD for patients to use. For patients who do not have access to a CD player, a tape recording of relaxation techniques was supplied. A CD-Rom was also made available which contained heart health material and interactive diagrams of the circulatory system and information about risk factors of heart disease.

## **Mentoring processes**

Once patients had given consent and joined the AHGP, mentors organised a mutually agreeable time with patients to conduct an interview lasting approximately one hour. Mentors encouraged the patient's partner or significant other to be present at this interview to fully discuss the six week program. An information protocol (see Appendix 4) was designed to help guide the mentoring process. This was provided to mentors during one of the training sessions. One of the key elements of the mentor role was to support the patient through the transition from hospital to home. Apart from adequately preparing patients for discharge, some of the important goals of this meeting were to identify with the patient the supportive nature of the mentor role, to engage with and motivate the patient, check their level of confidence and establish a relationship based on mutual trust, collaboration and rapport (ie. PCC).

Much of the usual discharge planning to do with providing patients with information to allow them to make the safe transition from hospital to home was incorporated in to this meeting. Care of wounds, medication regimen, appropriate activity plans following MI and management plans incorporating the safe storage and usage of anti-anginal medications, and information relative tofollow-up medical appointments were routinely discussed at this point. The AHGP resources were explained at length by mentors and time given for patients to ask questions. Patients were asked to identify the lifestyle factors they thought may have contributed to their illness and what they considered they could do to lessen their risk. Mentors then reviewed the section of the AHGP workbook that deal specifically with commonly held cardiac misconceptions with the patient. This enabled misconceptions to be discussed and corrected prior to hospital discharge.

Other mentor-patient discussions during the hospital interview included the use of the pocket diary as a motivational tool and goal planning strategy. Potential problems or issues once identified were negotiated using SMART goals (setting goals that are specific, measurable, achievable, rewarding and timely) and an ongoing plan documented in the patient pocket diary. Activity goals for example, represented "targets" for the patients to practice every day for the following week. Progress was monitored via goal setting achievements and lifestyle behaviour outcome surveillance.

Mentors were encouraged to involve other health professionals or support services in the community tofollow-up on issues or problems that could not be readily improved without specialist health professional intervention.

Prior to hospital discharge, the patient completed the self report questionnaires which represent the baseline data. Upon returning home with their AHGP resources, patients work through their variousworkbooks including identifying their individualised health goals. Health goals include examples such as such as increasing their walking distance each day or practicing their breathing and relaxation exercises. Their effort or progress is recorded daily in their diary. The diary serves to provide an intrinsic reward for their daily effort in terms of practicing their goals. Mentors encouraged patients to take their diary with them when they visit their family doctor to help remind them of their progress or when telephone meetings were scheduled.

Mentors used a variety of strategies to assist patients in their health care decisions. Some of these strategies included CBT, motivational interviewing and specific goal setting. Mentors usually contacted their patients every week for six weeks following hospital discharge, but the amount of contact between mentor and patient remained negotiable with some patients requiring more contact and others less. Patients were encouraged to contact their mentor or student researcher any time during the program if important issues occurred out of pre-arranged contact times. The aim of weekly contact was to support patients and check their progress in terms of their goal achievement and to reinforce important aspects of their health care plan. If goals were met, mentors took appropriate steps to praise and encourage their effort and 'raise the bar' a little and discuss the addition of new goals or targets for the future.

Each consecutive weekly phone call by mentors followed essentially the same format of checking goals that were previously set, raising the baseline, checking for patiernt misconceptions, problem solving if required, review previous gains and reward positive progress through audit and feedback. In addition, mentors assisted patients with CBT strategies to rectify relapses in terms of their lifestyle behaviour change goals and advised patients concerning the availability of on going maintenance programs after completed the AHGP.

Although the student researcher knew some of the mentors professionally, an

invitation to participate in the study as nurse mentors was distributed through the health department usual communication networks and not directly by the student researcher. The relationship between student researcher and mentors was professional. No coercion was used to persuade mentors (or patients) to participate in the study. All data provided by mentors were provided freely. In terms of supporting mentors during the study, teleconferences were conducted during the first year of the study. Later, frequent contact was made via email. The student researcher provided feedback to mentors to problem solve any issues that may have arisen regarding the AHGP. These actions were undertaken prior to the commencement of and during the study to improve accuracy of data collection. The AHGP was implemented as a pilot project, and this case study was used to evaluate it.

## **Study instruments**

Several quantitative research instruments were used to collect data to measure patient outcomes in this study. Each of the instruments is outlined in Table 1. Following this, a description of each instruments reliability and validity is provided. Approval was sought from the various authors of the instruments used in the study. All instruments were given to participants in the form of self administered questionnaires. Justification for the selection of the study instruments is as follows.

The Hospital Anxiety and Depression Scale (HADS) was included as a study instrument because of its ease of use (for patients and scoring). It was widely used in previous comparable Heart Manual research studies. Thus, potentially, comparisons can be made from other previous research from the Heart Manual with the Aussie Heart Guide Program. There is growing evidence suggesting the importance of checking all cardiac patients for anxiety and depression because it negatively impacts patient outcomes. The Physical Activity instrument used in this study was selected also because of its simplicity in terms of its use which remains an important consideration for community based self report questionnaires. In relation to Illness perceptions, there is evidence to suggest patient patients privately construct their own representations or models which help them make sense of their experience and provide a basis for their own coping responses when they are facing a new illness. Previous research from several studies suggest that patients often have misconceptions regarding their illness

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(often about the disease itself) and these misconceptions if not corrected early may play a significant negative role in their recovery. In the United Kingdom, clinicians using the Heart Manual resources routinely check for patient misconceptions relating to their disease. Clinicians are also trained on how to check for possible misconceptions. Because the Heart Manual research is closely aligned with the AHGP, the IPQ-R was selected as an instrument in this study. Mentors could check patient responses about their illness and then correct any major misconceptions prior to commencing the program. The MACNEW health related quality of life (HRQOL) instrument was selected because it is one of only a small number of heart related HRQOL instruments available. It was chosen because it related directly to patients who have had a myocardial infarction (MI). The MACNEW relates directly with the AHGP intervention because patients in this study were all MI survivors. The Health Education Impact questionnaire was selected because it was originally designed to provide patient information relating to their satisfaction of a program or course in terms of its ability to convey health education and its impact on the patient's self management practices and the programs effect on their physical and mental behaviours.

Table 1: Summary of study instruments used to measure outcomes

Scale	Instrument: Construct/Subscale/ Dimension/Domain	Items #	Response options	Cronbach's alpha (previous)
HADS	2 Subscales			
	Anxiety	7	0= not at all 1= not often 2= sometimes 3= most of the time	.83
	Depression	7	As per Anxiety	.82
Physical Activity	5 Subscales		1	
	Type of activity	3	record numbe of times	
	Intensity of activity	3	<ul><li>a= often</li><li>b= sometimes</li><li>c= never/rarely</li></ul>	.74
	Duration of activity	1	Record number of minutes	.74
	Physical fitness	1	1= very heavy 2= heavy 3= moderate 4= light 5= very light	.74
	Daily activities	1	1=no difficulty 2=a little bit of difficulty 3=some difficulty 4=much difficulty 5=could not do	.74

IPQ-R	9 Constructs	84		
	Identity	14	Yes/no	N/A
	Timeline (Acute/Chronic)	6	1= strongly disagree 2= disagree 3= neither agree or disagree 4= agree	.89
	Consequences	6	5= strongly agree As per Timeline response	.84
	Personal control	6	As per Timeline response	.81
	Treatment control	5	As per Timeline response	.80
	Illness coherence	5	As per Timeline response	.87
	Timeline cyclical	4	As per Timeline response	.79
	Emotional representations	6	As per Timeline response	.88
	Causes	18	As per Timeline response	.86
MacNew HRQOL	3 Domains	27*		
	Physical domains	13	1=none of the time 2=a little of the time 3=some of the time 4=a good bit of the time 5=most of the time 6=almost all of the time 7=all of the time	.94
	Emotional domains	14	As per Physical domain	.92
heiQ	Social domains 8 Dimensions	13 42	As per Physical domain	.92
	Positive and Active Engagement in Life	5	1=Strongly disagree 2=Disagree 3=Neither agree or disagree	.86

		4=Agree	
		5=Strongly agree	
Health Directed Behaviour	4	As per Positive and Active engagement in life	.80
Skill and Technique Acquisition	5	As per Positive and Active engagement in life	.81
Constructive Attitudes and Approaches	5	As per Positive and Active engagement in life	.81
Self Monitoring and Insight	7	As per Positive and Active engagement in life	.70
Health Service Navigation	5	As per Positive and Active engagement in life	.82
Social Integration and Support	5	As per Positive and Active engagement in life	.86
Emotional Wellbeing (reversed scale)	6	As per Positive and Active engagement in life	.89

Scale - HADS (Hospital Anxiety and Depression Scale), Physical Activity (Short

Measure of Physical Activity) Questionnaire, IPQ-R (Revised Illness Perception Questionnaire), MacNEW

(MacNew Health Related Quality of Life Questionnaire), heiQ (Health Education Impact Questionnaire),

#- number if items, N/A (not applicable), \*some of the emotional and social domains share the same item number.

## Reliability and validity of study instruments

Reliability refers to how consistent results taken with a measure really are whereas validity refers to how well a test measures what it is meant to measure (Minichiello et al., 2004). Instruments used in the study were previously found to be reliable and valid by other researchers. An overview of each instrument is presented next. The 14 item HADS was used to measure levels of patient anxiety and depression in this study. The scale has been found to be easily administered taking between three and five minutes to complete, is available in several languages and has been found to be acceptable to a variety of patients from several clinical populations (Dawkins et al., 2006; Sultan et al., 2010). The HADS has been extensively researched over 20 years and consistently validated by several independent studies (Herrmann, 1997; Bjelland et al., 2002). Another large study found the basic psychometric properties of the HADS to be satisfactory in terms of its item factor structure, intercorrelation, homogeneity and internal consistency (Mykletun, Stordal, & Dahl, 2001). The various psychometric properties of the HADS including the internal consistency, test-retest reliability, factor analysis of the two sub scales (except for one item responsible for detecting depression) and concurrent validity used to measure the independent sub group correlations were found to be reliable and valid by Michopoulos and colleagues (2008).

The nine item Physical Activity (Short Measure of Physical Activity) questionnaire was used to measure the physical activity of patients at two differing time points, before and after program. The authors claim to have designed a simple method to assess the exercise behaviour of adults of both sexes in the community (Godin & Shephard, 1985). The instrument is self administered, takes little time to complete and discriminates between persons who exercise frequently as opposed to those who are sedentary (American College of Sport Medicine, 1997). The reliability and concurrent validity testing of the nine item questionnaire was found to be accurate in terms of discriminating between different time periods and levels of exercise intensity (Godin & Shephard, 1985). Others undertaking reliability and validation studies have found this simple questionnaire satisfactory in determining the exercise behaviour of individuals in the community setting (Sallis et al., 1993; Jacobs et al., 1993).

The 84 item IPQ-R was used to measure the illness perceptions of patients in this

study. It was administered prior to commencing the AHGP and after completion of the program. The IPQ-R version was undertaken by its authors (Moss-Morris et al., 2002) to improve the original version of the IPQ (Weinman et al., 1996). The IPQ-R aimed to modify some of the measurement properties and to improve the consistency of some of the items and to include another important theme consistent with the self-regulatory model, namely that of emotional representation (Moss-Morris et al., 2002). Subsequent testing of the IPQ-R found its psychometric properties to be improved. Analyses were conducted to test which questionnaire items best represent the original dimensions or categories. All the items and subscales were found to demonstrate internal reliability and validity and strong correlations were demonstrated when investigating the interrelationships between each of the dimensions (Moss-Morris et al., 2002). Test-retest reliability of the IPQ-R was conducted over a six month period by the authors to test the stability of the constructs over time and found their reliability to be consistent.

The 27 item MacNew (HRQOL) instrument was used to measure the HRQOL of patients in this study. The MacNew (HRQOL) was developed specifically for patients who have had a MI the psychometric properties of the instrument have been tested in several clinical studies and found to be satisfactory in the properties of reliability, validity, responsiveness and interpretability (Oldridge et al., 1998; Dixon, Lim & Oldridge, 2002; Höfer et al., 2004). The internal consistency of each of the three domains was found to be satisfactory and reproducibility standards confirmed via the test-retest correlations method on separate occasions (Hofer et al., 2004). In terms of validity, face and content validity was determined during the original testing of the instrument (Hillers et al., 1994) and construct-related validity to test the discriminatory properties of the instrument was also found to be satisfactory (Höfer et al., 2004; Maes et al., 2008). In relation to the instruments responsiveness (sensitivity to change) over time, it has been reported to be both responsive and sensitive (Maes et al., 2008) to changes in HRQOL. Others report similar results following treatment especially when the instrument was used as an outcome measure for CR (Gardner et al., 2003; Hofer et al., 2004).

The 42 item heiQ instrument was used to measure the benefits or impact of a broad range of patient education information contained in the AHGP. According to Osborne and colleagues (2007) the heiQ instrument has been extensively tested using

Structural Equation Modelling and Item Response Theory which demonstrated high construct validity as well as showing reliability when measuring a broad range of patient education program benefits. Further testing and feedback from subsequent trials has led to two further versions and refinements including, the translation of the heiQ into 9 different languages (Schuler et al., 2013), reducing the user response scale from 6 to 4 where two items were discarded from the instrument without compromising internal consistency or reliability (Osborne et al., 2007).

# The patient interviews

Qualitative data relating to patient outcomes was collected from patient interviews. Interviewed were conducted by the student researcher via telephone over a two week time period after the completion of the AHGP. The interviews were semi-structured, ranged between 10 and 30 minutes in duration and notes were written during patient responses and then typed on to a MS Word document. A core aspect of the AHGP was mentoring, which became one focus of the interview. The interview guide consisted of three broad questions: "What was your impression of the AHGP?" "What did having a nurse mentor mean to you during your recovery?" and "What was good or bad about the mentor?" Prompts were used to elicit more information from participants as required.

#### The mentor surveys

Qualitative data relating to the AHGP came from a mentor survey and mentor clinical notes. The SPO framework guided the development of questions for the mentor survey (see Table 2). Examples of structural questions were: 1) What knowledge and skills do you think you need to be a AHGP mentor? And 2) What did you find valuable about the mentor training? Suggest any changes that you believe would improve the mentor role. Examples of process questions were: 1) What were some of the major difficulties you experienced as a mentor? And 2) What barriers prevent you from incorporating the AHG in to your current practice? And 2) What were some of the major difficulties you experienced as a mentor? Examples of outcome questions were: 1) What personal/professional rewards (knowledge, skills or experiences) did you gain from being a mentor? And 2) What were the drawbacks associated with being a mentor? Drafts of these questions were piloted and slight modifications to wording were made

prior to the main survey being administered. All mentor clinical notes were collected and data analysed at the completion of the study.

Table 2: Mentor survey questions

#### Question

- 1. What knowledge and skills do you think you need to be an AHGP mentor?
- 2. What did you find valuable about the mentor training? Suggest any additional training that may have benefited the mentor role.
- 3. What barriers may have prevented you from incorporating the AHGP in to your current practice?
- 4. What were some of the difficulties you experienced as a mentor?
- 5. What aspects/jobs/activities do you think were most important in your role as a mentor?
- 6. What personal and/or professional rewards did you gain from being a mentor?
- 7. Were there any drawbacks associated with being a nurse mentor?
- 8. In your opinion, what are the strengths and weaknesses of the AHGP?
- 9. Is there anything else you would like to report about the AHGP?

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### **Data collection**

Data was collected from mentors and patients during the study. Quantitative data analysis compared the demographic and clinical characteristics of AHGP completers and partial completers using the Chi-square test analysis included demographic and clinical characteristic data from patients and specific patient outcome data. Qualitative data was collected from patient telephone interviews, a mentor survey and mentor clinical progress notes. There were six data collection points in this study which are presented in Figure 3. The first contact between the CR nurse coordinator and patients in hospital represents data collection point one. Demographic characteristics and other information such as medical history records, pathology and radiological results represent normal routine practice. This data was recorded in detail in the personal medical history of all patients admitted. Apart from normal demographic data, a

clinical medical history denoting risk factor or lifestyle risk was undertaken by the cardiology medical staff. Some of this data was included in the study's demographic data sheet as per Appendix 5.

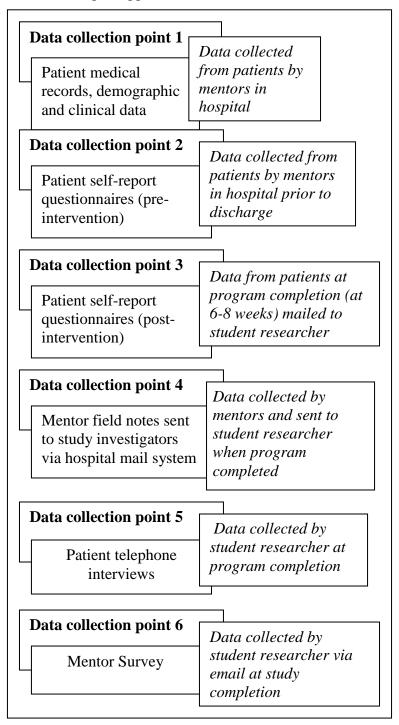


Figure 3. Data collection points from the study

Data collection point two occurred in hospital. Self report questionnaires were completed by the patient during the arranged mentor-patient interview prior to being discharged from hospital. Data collection point two represents the pre interventional data which was later analysed, and comparisons made with the post interventional data collected at the completion of the six week program. Once the patient and their family were satisfied with the proposed program, patients were discharged from hospital with mutually agreed follow-up phone meeting appointments with their assigned mentor.

The AHGP was deemed to be complete after approximately six to eight weeks duration subject to mentor and patient collaborative agreement. Mentors having patients with unresolved issues were encouraged to continue to mentor their patients until both parties were satisfied with outcomes. This enabled patients struggling with their recovery further support if needed. Mentors notified the chief investigator at this point to clarify that they had completed the program with their patient. Once notified, the study investigators mailed out identical self report questionnaires used prior to discharge (pre-intervention surveys) to each patient. Instructions explaining the purpose of the post intervention questionnaires accompanied the questionnaires. This represented data collection point three (post intervention surveys). Mentors contacted each patient's local doctor by letter to explain the objectives of the program and provided an update in relation to their patient's progress after completion of the program.

During the program, each mentor recorded field notes relative to their patient's week by week progress. As each patient completed the AHGP, mentors forwarded their field notes to the study investigators for analysis. These notes were kept securely in a locked filing cabinet. At the completion of the program these notes were mailed to the study investigators for de-identification, data analysis and safekeeping. This represented data collection point four. Patient telephone interviews were conducted by the student researcher following completion of the program. This represents data collection point five. The final data collection point (number six) occurred at study completion so mentors could reflect over the course of the study and consider the experiences gained from mentoring multiple numbers of patients. Mentors were all contacted, and an open ended email survey conducted to provide feedback concerning their mentor experiences. Additional information relative to the mentor survey was

introduced under the heading study instruments.

# Data analysis

Both quantitative and qualitative data analyses were used in this study. SPPS (version 19) software was used to perform the statistical tests required to analyse the quantitative data collected in this study. Statistical analysis included the use of descriptive and inferential statistics. Descriptive statistics were used to summarize the sample characteristics using frequencies and percentages for categorical data and means and standard deviations or median and IQR (interquartile range) for continuous data (for HADS, Physical Activity, IPQ-R, MacNew HRQOL and heiQ scores). A paired sample t-test was used to test the hypotheses that patient outcome variables changed over time (pre and post intervention). The level of significance was set at the conventional p < .05 and two tailed tests used.

Thematic analysis was used to analyse data from the patient telephone interviews, mentor field notes and the mentor survey. Thematic analysis, according to Braun and Clarke (2006) is a widely used qualitative research method. It offers a flexible and rigorous approach to construct meaning from diverse data by analysing data into patterns or themes. Thematic analysis may be applied across a range or theoretical approaches and probably stems from realist or experiential methodologies (Braun and Clarke, 2006). It also remains compatible with essentialist and constructionist psychological constructs and due to its theoretical freedom can provide flexibility as a research tool as well as provide a rich and detailed account of data (Braun & Clarke, 2006).

Thematic analysis can identify themes and patterns in two main ways; at the inductive level, whereby identified themes are inextricably linked to the data set or put simply, the thematic analysis is data driven or at the deductive level, where themes are analysed from a theoretical perspective or interest (Braun & Clarke, (2006). Deductive thematic analysis usually provides a less dense data set but a more detailed analysis of some aspect of the data. In this study, raw data from mentor surveys and field notes was first sorted deductively using Donebedian's SPO framework (1966) and then within this framework, data was coded inductively and sorted in to themes and sub-themes. Braun and Clarke (2006) conclude that the method of analysis chosen should be guided

by both the research question and the researcher's broader theoretical assumptions. Thematic analysis provides a flexible qualitative method across a range of epistemologies and research questions (Braun & Clarke, 2006).

Potential pitfalls such as failing to analyse the data at all (reporting a collection of extracts with out meaningful narrative), using questions set out in interviews or surveys as emerging themes, providing a weak or unfounded analysis where themes in the data and conclusions are mismatched, not supported or contradictory, can be avoided by following the step-by-step guidelines provided for novice researchers by Braun and Clarke (2006). They identify the following six phases as critical to this qualitative methods process. They include; familiarising oneself with the data (data transcription, reading and re-reading data, noting ideas from the data), generating initial codes (coding ideas systematically across the entire data set), searching for and collating themes, reviewing themes (checking themes against coded extracts in order to generate a thematic map), defining and naming themes (refining specifics of themes, generating definitions, names and the "story" behind the analysis), and producing a scholarly report of the analysis. Braun and Clarke (2006) also provide researchers with an invaluable 15 point checklist of criteria for helping to determine whether a good thematic analysis has been conducted in a robust and rigorous manner.

In this study, thematic analysis was used to analyse all collected qualitative data. This included data from the patient telephone interviews, the mentor survey and mentor clinical progress notes. Data from these three subsets of qualitative data were analysed separately. All narrative transcripts were read several times to understand meanings and gain an overall sense of the data. This helped achieve immersion and a sense of each participant's unique and complex perspective of two broad domains (the patient and mentoring eperience and the AHGP). Line by line coding of the data was conducted with similarities and differences observed. Codes were assigned to participants' verbatim statements. A code book and memos were written to document the analytic process including decisions about emerging sub-themes and final themes. After coding, key thoughts, patterns and conceptualisations emerged from the data inductively, leading to the grouping and labelling of sub-themes which were repeatedly rechecked and questioned by the research team and classified into a hierarchal set of overarching themes relative to each domain. Frequent recursive and iterative discussion occurred

among the research team until agreement concerning the emerging themes was forthcomimg. This ensured that the codes, sub-themes and emergent themes accurately reflected and encompassed the data.

In addition to the above, a further step of analysis was undertaken that focused on an explanation building strategy commonly used in case study research (Yin, 2009). Case study data were analysed across the three data sets together to better explain the potential causal linkages between the SPO of the AHGP. It entailed reviewing, refining and then grouping of all themes from the three individual data sets once again under the specific headings of the SPO framework. This secondary thematic analysis was undertaken to reveal consistent findings and potentially new themes relative to the AHGP.

# Rigour

An issue of trustworthiness of findings in qualitative data analysis is often considered in relation to credibility, dependability, transferability and confirmability (Lincoln & Cuba, 1985). In the current study, purposive sampling (Roberts & Burke, 1989) ensured a broad representation of patients. Nurse mentors were recruited from multiple hospital settings which also ensured a broad representation of survey responses. Analyst triangulation (Patton, 2001) occurred from regular meetings with the research team who ensured codes, sub-themes and final themes accurately reflected the data for transferability, credibility and confirmability. A code book and memos were written to document the analytic process including decisions about emerging subthemes and final themes. An audit trail (Lincoln & Cuba, 1985) of the analysis also enhanced confirmability. In addition, confirmability was facilitated by the research team adopting a reflexive approach (Barry et al. 1999) to find meaning from the research data. Direct quotations from the mentors enhanced the findings (Lincoln & Guba 1985). A case study design that involves both qualitative and quantitative data offers the opportunity for the methodological triangulation of data from multiple sources of evidence (Walshe et al., 2004). This has the advantage of enhancing rigour, especially construct validity (Yin, 2009) via the use of various data collecting strategies (Bergen & While, 2000).

## **Ethical considerations**

The research plan was carried out in accordance with the ethical principles identified for scientific research (National Health & Medical Research Council, 2007). Written ethical approvals to conduct this study (see Appendix 6 and 7) was provided by the Human Research Ethics Committee (Tasmania) Network (H0009996) and the Human Research Ethics Committee of Griffith University (NRS/02/10/HREC). Written consent was obtained from all participants. The study could have been terminated at any stage if for any reason the investigators believe that a continuation of the research was causing harm to any participant. Participants were excluded from the study if their illness or condition deteriorated markedly during the research project. The researcher respected everyone's right (whether a participant, health care worker or member of the research team) to self-determination (participants must not be involved in research with out asking them if they wish to participate), full disclosure (information must not be withheld from the participant), privacy and anonymity.

Patients were made aware that any refusal to participate in the study on their behalf would not have any effect on their treatment. Nurses participating in the study were advised thay could withdraw from the study at any time. Participants were also advised should a problem occur due to their participation in the study, the researcher will be available to enure all treatment is forthcoming andfollow-up assured. Each study participant gave informed consent after reading the information summary sheet outlining the study. They were encouraged to ask questions relating to the study and have these questions answered to their satisfaction. Bedside clinicians confirmed patient understanding had been achieved through questioning and revisiting critical aspects of the study as outlined in the information sheet given to all patients. The student researcher was available by telephone or email to answer queries or help mentors with problems should they arise from their participation in the study.

The AHGP nurse mentors assisted patients in terms of their informed consent and by explaining all relevant details about the AHGP to prospective participants. Risks were minimised by ensuring members of the health care team follow the agreed protocols established in the research plan for delivery of the AHGP and the collection of data. Study participants (nurses and patients) were advised that they could remove

themselves from the study at any point with out prejudice or penalty. Participants could also withdraw from the study if their condition deteriorated after leaving hospital.

In relation to data storage, all study materials in hard copy were secured in a locked filing cupboard. All databases were kept on file in the investigators password protected personal computer. All study materials after study completion once deidentified, have been at the University of Tasmania research study repository (located at the Launceston General Hospital). Data will be kept for six years as recommended by Human Research Ethics Committee (Tasmania) Network.

The AHGP is an education program designed to change patient perceptions about potential lifestyle behaviours that may be causing cardiac illness and demystify many of the potential misconceptions relevant to the causes, treatments and recovery of patients after a heart attack. It imparts knowledge and teaches participants, under the direction of a suitably qualified health practitioner, what things they can do for themselves to adopt healthier lifestyle practices and to lessen their risk of further heart illness. The program presents no appreciable risk to participants recovering from heart attack. Similar versions of home based CR programs are in use in several countries including the UK, Italy, Netherlands, New Zealand and Canada (NHS Lothian, 2016).

# **Summary**

This chapter has described the SPO framework of health care quality used to evaluate the AHGP. It has outlined the case study method used to meet the research aims of this study. Information relevant to study design included a description of the sample and the AHGP as an intervention. The instruments used to collect quantitative data including their reliability and validity was presented. In addition, the method of obtaining qualitative data was also described. Following this, the collection, management and analysis of data, rigour and ethical considerations were presented. The next chapter reports on the various themes that emerged from the analysis of qualitative data from the patient telephone interviews, the mentor field notes and the mentor survey.

# **Chapter 4: Thematic Findings**

## Introduction

The previous chapter described the theoretical framework and research method used to underpin this study. This chapter outlines the themes formulated through an in depth analysis of the qualitative data collected from the patient telephone interviews, the mentor survey and mentor clinical progress notes. Throughout the description of each **theme** and subsequent *sub-theme*, verbatim quotations from the participants are included to support and explain interpretation. As the study participants were either patients or nurse mentors, each quotation will be clarified accordingly, with a corresponding or number such as Patient #1 or Mentor #1.

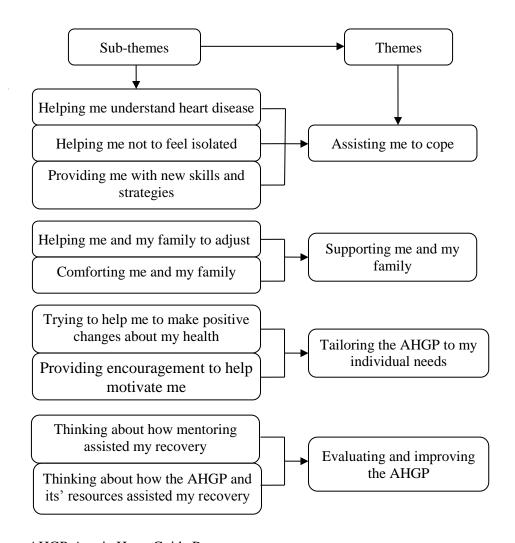
# The patient telephone interviews

CR patients enrolled in the study were interviewed by phone about their perceptions of the AHGP and their mentors. A total of 13 phone interviews were undertaken, comprising six females and seven male participants. Ages of the participants ranged from 46 to 69 years and most patients lived between 50 and 100 kilometres from the nearest hospital based CR program. Table 3 lists the characteristics of the patients who participated in the telephone interviews.

Table 3: Sample characteristics from the patient telephone interviews

Sample characteristic	Patients ( <i>n</i> =13) Frequency		
Marital Status			
Married/Partner	8		
Lives alone	3		
Employment			
Yes	8		
No	1		
Disability	2		
Retired	2		
Distance to Cardiac Rehabilitation			
<50 kilometres	4		
50-100 kilometres	7		
>100 kilometres	2		

The thematic analysis of the patient telephone interview data revealed four themes: (1) assisting me (the patient) to cope; (2) supporting me (the patient) and my family; (3) tailoring the AHGP to my (the patient) individual needs and (4) evaluating and improving the AHGP. Each theme is comprised of varying sub-themes. Quotations from patient interviews are provided under the description of themes and sub-themes to summarise the understandings constructed from the data. Figure 4 outlines these themes and sub-themes.



AHGP-Aussie Heart Guide Program

Figure 4. Themes and sub-themes from the patient telephone interviews

# Assisting me to cope

During the telephone semi-structured interview, the patients described how mentors assisted them to cope with the initial shock of having a heart attack and the period of adjustment following hospital discharge and returning home. Mentors helped patients by listening to their concerns, explaining hospital procedures, providing information about cardiac disease and treatment and practical support in terms of organising an individualised plan to follow after discharge from hospital. The data also identified that patients were appreciative when mentor support was empathic, recognized the patient as an individual, were treated with respect and afforded them

opportunities to gain control and make decisions about their care and future. The subthemes detailed in this theme include; *helping me to understand heart disease*, *helping me not to feel isolated and providing me with new skills and strategies*.

### Helping me to understand heart disease

The data showed it was common for patients to have little understanding of CHD in general and specifically, its cause, treatment and impact on their future. Patients suggested mentors were instrumental in providing the information they needed to understand the serious implications of heart disease, and what aspects of their lifestyle they need to change to reduce their risk of future cardiac events. Mentors assisted patient understanding by providing practical explanations, by using models and other media and by highlighting key aspects of the written program resources:

She told me what I needed to know and then it was up to me to do something about it. I do not think she could have done more. She explained everything in an easy way." (Patient # 11)

Patients also reflected that the acquisition of new knowledge about heart disease remained a critical factor in helping them to appreciate the need to follow medical management and after care advice and guidance:

The nurse spent quite some time explaining the program, preparing me for going home from hospital. She explained everything I needed to know very well and how she could help me get back to good health. (Patient # 13)

I think apart from giving me the facts about my heart problem, she settled me down, got me in to a routine [when at home]. She answered my questions about having a heart attack honestly and outlined the program and what I had to do when I went home." (Patient # 5)

### Helping me not to feel isolated

Many patients who lived alone or a long way from medical services expressed their mentors helped them overcome feelings of isolation. Feelings of isolation, according to some patients, were accentuated by the uncertainty that a similar episode may occur again, and that a further event may prove fatal. Patients with no immediate

family, who lived alone and resided in areas isolated from emergency health services, felt the most isolated:

I live a long way from the city and I live alone and do not drive, so it was very good to have someone to talk to and ring if I needed help. It was good for my peace of mind to have her number in case I got stuck." (Patient # 11)

Several patients reflected that while they preferred face to face contact with health professionals per se, in terms of living a distance from hospital services, they felt contact by telephone was much more beneficial than no contact:

I met her [the mentor] in hospital which was good because I could put a face to the voice on the phone. I found the phone calls to help somewhat. It was nice to get a phone call now and then to see how I was going. (Patient # 3)

Patients suggested that mentors screened them carefully prior to discharge to check whether they were at risk of feeling isolated and put in place solutions such as regular phone contact, community support networks and possible referrals to other community based health agencies:

I live alone, so the nurse mentor was vital for me I think in terms of my recovery. (Patient # 6)

#### Providing me with new skills and strategies

Patients reflected that while it was important to learn as much as they could about their disease or condition, they also needed practical support. Practical support could range from providing resources used for stress relief to developing specific skills such as learning how to set goals and record achievements in a personal diary. Patients also expressed that an established rapport with their mentor often meant that a collaborative approach was of benefit in terms of recovery. This was evident in patients who were encouraged to develop skills that would enhance their ability to self-manage in relation to long term goals:

Her phone contacts were greatly appreciated and I think kept me on track in terms of eating better and exercising each day. (Patient # 6)

## Supporting me and my family

Patients identified it was important to them that mentors included their family in discussions concerned with their discharge from hospital and specifically, aspects involved with their enrolment in the AHGP. In situations where patients and their families were emotionally overcome by the seriousness of their hospitalisation, it was hoped that mentors would provide the necessary information and support to promote acceptance of their heart condition and recovery. The sub-themes described within the theme providing support to me and my family include; *helping me and my family to adjust and comforting me and my family*.

## Helping me and my family to adjust

Many patients described feeling stressed when trying to come to terms with their illness and its effect on partners and family. Patients had an expectation that mentors would provide information and support to loved ones especially during their hospitalisation and include family members in terms of getting them prepared for returning home. Furthermore, patients hoped that mentors would support and reassure their loved ones by listening to concerns and clarifying issues during hospitalisation and in the weeks following discharge:

My partner was really upset and beside himself. He thought I could die at any moment. I had to send him home from the hospital because he was going to pieces. She [the nurse mentor] took him away and spent a good while with him discussing everything and going through the program and recovery. This action really turned things around for us. (Patient # 5)

I can't think of anything she could have done different. She was a "god send" for me and my wife who was very upset, especially in hospital. (Patient # 7)

## Comforting me and my family

Many patients felt that their mentor provided them with emotional support during their recovery. Support was forthcoming in several ways. Mentors who showed empathy were thought to embrace and understand some of the difficulties faced by many patients experiencing a life changing event. Mentors who listened and considered patient concerns, tailored a plan of care in conjunction with them and who gave

encouragement were identified as nurses keenly interested in them as a person. Mentors who were cheerful, friendly, hopeful and positive in terms of patient outlook appeared to encompass patient notions of support in the data:

I found the phone calls comforting and kept me on track, especially as I was trying to give up smoking and get in to exercise [which I am still doing]. (Patient # 1)

She made the whole experience bearable. I am quite elderly, and she was friendly, very caring, patient and understanding. (Patient #7)

## Tailoring the program to my individual needs

The collected data strongly reflected that many patients during their hospitalisation had little understanding about why they had a heart disease. Most found that their mentors were instrumental in providing them with the necessary information to make decisions about their after hospital care and build the necessary confidence to actively engage in their recovery.

In terms of its common usage today, "tailoring" in respect to individual needs, amounts to "making or adapting" to a particular purpose. Patients were found to be heterogeneous individuals of different age, gender, culture and social backgrounds. Their level of knowledge regarding the perceived threat of an illness and their emotional reaction to it was variable. The data reflected that patients responded positively to mentors who tailored their rehabilitation in consideration to their individual needs.

The sub-themes from the theme tailoring the AHGP to my individual needs include; trying to help me (the patient) to make positive changes about my health and providing encouragement to help motivate me (the patient).

#### Trying to help me (the patient) to make positive changes about my health

Some patients claimed making changes to their lifestyle difficult to realise despite being encouraged by mentors to improve their lifestyle. Ambivalence toward change may be characterised as a set of conflicted ideas or feelings about the need to make health changes. Despite the perceived benefits associated with adopting a healthy lifestyle, some patients interviewed chose not make changes. For some patients, the

consequences associated with making significant changes to their daily living were daunting. Alternatively, the timing in relation to giving up something they enjoyed was often not right for them:

I was really down in the dumps for about 3 months after my heart attack. I could not be bothered to do some of the things I had agreed to do. I'm not sure if it was because I went through a lot in hospital or because of my age. My mentor helped turn things around somewhat with her phone calls. (Patient # 13)

## Providing encouragement to help motivate me

Patients suggested that mentors played a central role in working together with patients to identify their personal risk factors and through collaboration, identify strategies to achieve predetermined health goals. Patients suggested that mentors used strategies of encouragement and other support networks to motivate them to complete the AHGP, especially when faced with feelings of low self-confidence to make positive changes in their health:

She encouraged us [patient and partner] to do the home rehab program together, to motivate us I think. She was big on having the desire to get up and get going again, and that is what we have done. (Patient # 5)

## **Evaluating and improving the AHGP**

During the telephone interviews, patients described their relationship with their mentors and the impact of the AHGP on their recovery. Specifically, patients were asked to reveal what was good or bad about their mentoring experience and more generally in terms of their perception of the AHGP resources. The data clearly indicated that patients thought that their mentors were an integral and important part of their recovery from MI. There were also favourable reports suggesting patients would recommend the AHGP resources to other patients, particularly those living alone or unable to access after hospital support. The sub-themes detailed in the theme evaluating and improving the AHGP include; thinking about how mentoring assisted my recovery and thinking about how the AHGP and its' resources assisted my recovery.

#### Thinking about how mentoring assisted my recovery

From the interview data, it appears patients were very satisfied with the level of assistance, care and support provided by their mentors during the six week program. Mentors appeared to adequately introduce the AHGP to patients while in hospital and then ensured patients were adequately prepared for discharge. One patient said, "my mentor was very important to me, she talked me through the whole program, I had some questions which she answered well and when I got home her phone calls were comforting and kept me on track" (Patient # 1). Positive patient comments suggest mentors might represent the conduit required to ensure a seamless transition from hospital to home for patients recovering from MI. Patients welcomed mentor efforts to regularly check their progress upon returning home, helping them to overcome potential barriers to recovery and encouraging them to meet their agreed health goals on a day by day, week to week basis:

The lady nurse mentor was excellent in all respects. She was able to keep me on task by phoning me regularly. She told me what I needed to know in an easy way and then it was up to me to do it. I do not think she could have done more. (Patient # 11)

In terms of mentoring, most patients thought the weekly contact time with nurse mentors for a period of six weeks was helpful:

I think the six week program was about right for me (Patient # 1)

The contacts with the mentor at home kept me focussed, settled me down and got me into a routine. The amount of contact with my mentor was about right. There were no bad points about the mentoring side of things. (Patient # 4).

# Thinking about how the AHGP and its' resources assisted my recovery.

Patients were satisfied with the resources used in the AHGP. The resources appeared to meet the informational needs of the patients and were simple to use:

I think the reading books [work books] should be made available to all patients having a heart attack. Having the books to keep means I can get them out from time to time to make sure I keep on track. (Patient # 1)

In terms of patient responses concerning the usefulness of the AHGP, patients appeared to be satisfied. Many patients stated enrolling in the AHGP, meeting their mentor while in hospital and having their mentor follow their progress at home, helped assist in their recovery from MI:

I am much relieved that I did the program, otherwise I am not sure how I would have gone in my recovery. I don't think anything has to be changed. (Patient # 5)

In contrast, two patients were unsure concerning the impact of the AHGP on their recovery, claiming they were motivated to improve their health, thus questioning the need to be in a CR program:

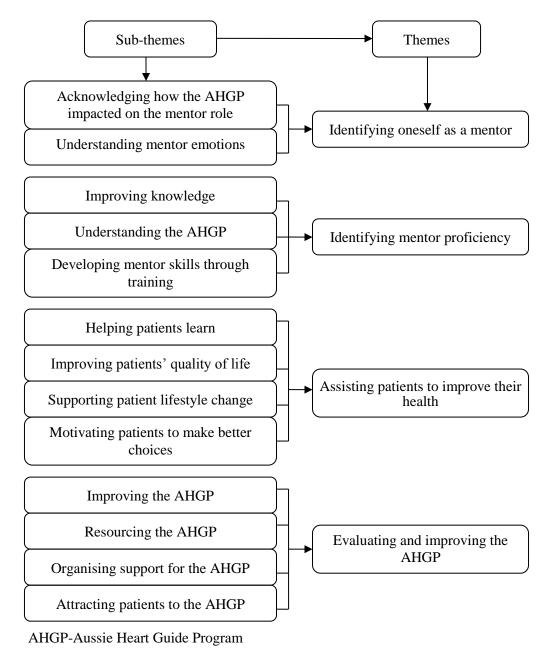
I would recommend the program to others even though I did not get a lot out of the books or phone calls. I can see how the program may help others that don't have much up and go or are not that interested in their health. (Patient # 4)

In summary, the patient telephone interviews were undertaken to enable patients enrolled in the AHGP to comment on aspects of the program and their relationship with their mentors. The analysis demonstrated that patients found that mentors were instrumental in assisting them to cope with their diagnosis, helping them to understand heart disease, to follow an organised plan, not feel isolated and providing practical support. Mentors not only provided comfort and support to patients but also their families and significant others. Patients also suggested that mentors ensured that the AHGP was tailored to their individual needs, providing encouragement to improve confidence and motivating patients to successfully engage in positive lifestyle behaviours. From this, it is apparent that the mentoring aspect of the AHGP is integral to the success of the program and importantly, mentoring assisted patients to recover their health after MI.

# The mentor survey

Mentors were surveyed about their experience of mentoring patients. A total of seven CR nurses (all female) participated, their ages ranged from 27 to 55 years of age. All mentors were experienced CR nurses with a minimum of five years clinical experience. Data transcripts from the mentor survey were revisited several times to verify meanings derived from the analysis. The data from the mentor interviews

revealed four themes: (1) identifying oneself as a mentor; (2) identifying mentor proficiency; (3) assisting patients to improve their health and (4) evaluating and improving the AHGP. Quotations from the participants are included to assist with interpretation. Figure 5 outlines the themes and sub-themes identified from the data relating to the mentor survey.



*Figure 5. Themes and sub-themes from the mentor survey* 

## Identifying oneself as a mentor

Mentoring patients to improve the transitional care for patients recovering from MI was a new concept for CR nurses in this study. The importance of improving the transitional care experience of patients leaving hospital and providing timely follow up has been reported previously (Berendsen et al., 2009; Prvu Bettger et al., 2012; Allen et al., 2014; Stamp, Machado & Allen, 2014; Braet et al., 2016). They were encouraged to reflect how mentoring might have changed their perception as nurses. Mentors said they brought a variety of knowledge, clinical experience, skills and personal attributes to their new role of supporting patients after hospital discharge. Mentors identified with the experience of assisting patients in their transition during their recovery fom hospital to home and through the mentoring experience, became more aware of the challenges patients face during their rehabilitative period. While depth of knowledge and clinical experience in CR was held in high regard by all mentors, many commented that the personal qualities of mentors could also be of great importance in determining positive outcomes for patients. Over and above the need to establish good rapport with patients, mentors thought that to be successful over time they needed to be extremely passionate about CR and have at their disposal a large "kit bag" of working knowledge about health psychology which would help them understand human behaviour. Mentors identified that the mentor role had the capacity to affect their emotions and that a link might be established between the difficulties some mentors experienced during the program and the recruitment of patients. Two sub-themes emerged under the theme of identifying oneself as a mentor; acknowledging how the AHGP impacted on the mentor role and understanding mentor emotions.

### Acknowledging how the AHGP impacted on the mentor role

Mentors suggested that while generalist nurses are qualified in their knowledge base to assist patients after MI, CR nurses who have undergone mentor training and develop their CBT skills, can provide a unique service to patients especially after hospital discharge:

I learned how to help clients to decide what it was they wanted to change and how they would do that within a set time frame. (Mentor # 4).

Mentors found that the AHGP positively impacted on their personal beliefs concerning their role as mentor. Mentors suggested that experiences gained from their time in the program, coupled with new skills they had acquired through the specific AHGP training, enhanced their previous level of knowledge and skills surrounding CR:

Encouraging people to set their own goals and acknowledging their progress and successes improved my CR skills. (Mentor # 2)

The program improved my communication skills and increased my understanding in relation to the journey patients often have to endure beyond the hospital door to successfully rehabilitate. (Mentor # 7).

#### Understanding mentor emotions

Some mentors were surprised to learn that the mentor role itself was quite demanding mentally and often left them experiencing feelings of frustration. Examples that negatively impacted on mentor emotions included time constraints, lack of patient motivation and trying to maintain good rapport with patients via phone:

A feeling of frustration and failure when the person involved was unable to successfully make changes to their lifestyle. I found the experience very emotionally draining at times. Mentors need regular holidays and a good support person. (Mentor # 5)

While some mentors acknowledged that the mentoring role was challenging and often exhausting, many reflected that the mentoring experience allowed them to revisit earlier held perceptions including their renewed sense of empathy for vulnerable patients:

Empathy (for the patient) is very important and an understanding of what it's like to experience a life-changing event. (Mentor #7)

While some mentors experienced negative emotions from the mentoring experience, most others found the experience professionally rewarding:

Satisfaction occurred when clients where able to make healthy choices and make changes to their life styles that they were able to commit to and maintain over time. (Mentor # 5)

One mentor also questioned why so many of the mentors who were initially trained failed to recruit patients and that intrinsic reward may not be enough to attract mentors to undertake a challenging role:

No financial reward exists for mentors to assist patients outside of work time may be a reason why so few mentors volunteered their time or tried to recruit patients. (Mentor # 5)

# **Mentor proficiency**

The data revealed that most mentors thought they needed to be highly proficient in carrying out of their mentor duties. Examples of mentor proficiency included a sound generalist nursing knowledge, knowledge about cardiac rehabilitation and the specific training required to understand the AHGP in terms of its applicability as a new form of service delivery and the practical skills required to assist patients with their recovery needs post hospitalisation. Mentors explained they required specific skill mastery in cognitive behavioural therapy and collaborative goal setting to assist most patients in their recovery and particularly, those patients with low levels of confidence in relation to their ability to change their lifestyle.

From the data, mentor proficiency encompasses the knowledge, skill set and clinical experience necessary to implement, coordinate and evaluate the AHGP. There were three sub-themes identified under the theme of mentor proficiency; *improving knowledge*, *understanding the AHGP and developing mentor skills through training*.

#### Improving knowledge

Mentors suggested they required a sound grounding in what they considered to be generalist nursing knowledge to be effective mentors. This included the knowledge acquired through nurse education, and then further developed over time with professional experience. Specifically, they referred to disease specific knowledge surrounding cardiac function and disease processes and subsequent management of heart related disorders, including, surgical and medical management and knowledge of risk factors:

Good understanding of anatomy and physiology but be able to apply it in a way that lay persons can understand. Knowledge of medications, treatment regimen and interventions, resources available to patients in and out of hospital and community support is needed to build from. (Mentor # 6)

Mentors suggested they also required specific knowledge and understanding of CR methods to be skilled in the execution of their CR duties. They asserted that knowledge regarding all aspects of CR was mandatory to compliment their new mentoring rolefor the role. This specific knowledge may be derived from academic nursing courses, ongoing professional development and hands-on supervised clinical training. It was apparent from the data that mentors considered their role to be unique requiring CR knowledge and clinical experience:

Knowing when and how to ask the right questions to elicit responses that will help patients understand cardiovascular disease and its impact, underlying causes or risks — will help set goals together to reduce ongoing risks, adverse outcomes, and to recover well with ongoing support to maintain lifestyle or behavioural changes in the long term. (Mentor # 2)

#### Understanding the AHGP

Mentors all agreed that they needed to understand the AHGP in depth to provide patients with the necessary guidance to help them acquire the skills needed to self-manage their cardiac health. Mentors felt that they needed to fully understand all aspects of the program and theories pertaining to cognitive behavioural therapy, motivational interviewing, collaborative goal setting and motivating patients with demonstrated ambivalence towards making changes to their lifestyle:

Know the AHGP resources in-depth and importantly, be able to apply the principles of CBT to practical situations. (Mentor # 2)

The mentor should have knowledge of behaviour change and behaviour change outcomes, the skill of SMART [specific, measurable, attainable, realistic and timely] goal setting and be familiar with relaxation techniques. (Mentor # 3)

#### Developing mentor skills through training

Developing mentor skills through training refers to the perceptions of mentors regarding the skills they learned during the AHGP training work shops. Mentors identified several program specific skills that improved their general knowledge and

experience specific to home based cardiac rehabilitation. These skills included examples such as collaborative goal setting, motivational interviewing technique and problem solving:

The AHGP training improved my role as a cardiac rehabilitation nurse. I had the opportunity to meet the mentor team members to review progress, discuss issues of concern and give others general support if needed. (Mentor # 2)

The training gave a good overview of the role of an AHGP mentor, including examples, suggestions and clarification of the pack and booklets to be used. The training covered important topics of rehabilitation, potential hurdles and strategies to overcome these. (Mentor # 7)

Further analysis identified that mentors thought that after completing the program training, certain skills must be obtained and practiced to competently assist and advise patients about the AHGP:

The program helped me develop telephone mentoring skills, communication skills, including active listening, open questioning, re-phrasing, positive feedback to patients, SMART goal setting and the use of diary to plan, monitor and evaluate patient goals, motivational interviewing and supporting clients to use various relaxation techniques. (Mentor # 3)

Apart from learning program specific skills such as interviewing patients, goal setting and the use of a diary to plan recovery, mentors considered it a priority to become familiar with the specific training manuals and the various patient resources. Subsequently, some mentors commented on how the applicability of resources assisted them as mentors:

The patient AHGP resources were user friendly and easy for patients to use. The mentor training manuals were easy to understand and work through and gave the reader examples of theory and practical applications through each phase of the AHGP. (Mentor # 3)

Notably, a small number of mentors felt that while the training covered their theoretical needs in terms of learning about a new program, it would have been

preferable to have follow-up workshops to practice skills relating to more practical aspects of the program such as patient interviewing, goal setting and telephony skills:

How the training was presented, led by an expert in behavioural medicine, group forum and participation was good but more practice sessions would have been an improvement. (Mentor # 1)

It would have been good to have someone to mentor us with the first patient interview to make sure we had all information and all necessary goals covered. (Mentor # 7)

Some mentors suggested certain aspects of mentor training, future resource development and the administration of the program could be improved:

Much more preparation and training is needed to adequately prepare mentors for the role. I think that is why some people dropped out being mentors after the training work shop. It was actually very hard work [mentoring] especially as you travel the highs and lows with patients as they recover. (Mentor # 6)

"Future training should provide more examples of different situations or scenarios and how to handle them. Include the rephrasing of negative patient's responses and how to paraphrase responses and reinforce effective/positive messages." (Mentor # 5)

## Assisting patients to improve their health

Analysis of the data strongly reflected the notion that CR involves the process of assisting patients to improve their QOL following a potentially life threatening illness. Achieving better outcomes for patients not only necessitated assisting patients through the recovery phase of their illness but also identifying possible contributing factors to heart disease and then working collaboratively with patients to promote positive lifestyle behaviours. Many mentors thought although their initial role was primarily one of support, due to patient vulnerability when faced with a potentially life threatening event, that role later transcended to one more aligned to promoting positive lifestyle behaviours.

Four sub-themes were identified from the theme, assisting patients to achieve better outcomes; *helping patients learn, improving patient quality of life, supporting patient lifestyle change and motivating patients to make better choices.* 

#### Helping patients learn

Mentors recognised that patients recovering from MI were often stunned and bewildered when faced with the prospects of uncertainty in terms of their long term prospects of survival. The data identified that mentors recognised they had a responsibility to assist patients by providing information to inform them about CHD.

To provide information for clients on health risk and health behaviour and to support the client to manage long term health outcomes. Helping clients to decide what it was they wanted to change and how they would do that within a set time frame. (Mentor # 4)

#### Improving patient quality of life

Mentors found education helped improve patient understanding. Patients who improved their levels of physical activity, sought supportive counselling and mastered skills such as deep breathing and relaxation, often improved their sense of wellbeing:

I found it interesting how vulnerable patients are in hospital but how quickly their confidence grows after a bit of education in hospital and after they gain a sense of control upon returning home." (Mentor # 5)

#### Supporting patient lifestyle change

Mentors suggested that one of their main roles was to support patients in their efforts to improve problematic lifestyle behaviours. They recognised that there were many barriers to patients not being able to change unhealthy behaviours or follow treatment plans. According to mentors, some patients were unable to see the long term benefits associated with lifestyle choices concerned with smoking cessation, improving diet and exercise:

Mentors need to know and understand the AHGP resource in-depth able to apply its CBT principles to each individual patient so that each patient will see the benefit of taking their medications and improving their health by learning to make positive lifestyle changes." (Mentor # 3)

Mentors suggested that one of their main roles was to support patients to adhere to their medical management or treatment plan. Mentors suggested that patients were more likely to reduce their risk of setbacks or adverse events if they not only followed prescribed drug regimens but actively sought to improve their health lifestyle outcomes. They recognised that there were many barriers attributed to patients not being able to follow treatment plans or the long term improvements associated with lifestyle choices concerned with smoking cessation, improving diet and exercise:

The mentor should have knowledge of behaviour change and behaviour change outcomes, the skill of SMART [specific, measurable, attainable, realistic and timely] goal setting and be familiar with relaxation techniques." (Mentor # 5)

### Motivating patients to make better choices

The data showed that poor motivation represented a major barrier to patients' ability to self manage their chronic condition and improve their QOL. Mentors found that building a good relationship or rapport with patients, motivating and encouraging them each week during phone contacts was central to assisting them through difficult times of low motivation:

Mentors can give patients hope and motivation to change poor lifestyle choices that may have impacted on their illness. (Mentor # 7)

Mentors need to be positive and motivating and able to build rapport with clients especially when they are in denial. (Mentor # 5)

However, most mentors agreed that motivating ambivalent patients was at times frustrating and emotionally tiring.

I found keeping some patients enthusiastic and motivated to achieve the goals they stated they wanted to achieve at times mentally exhausting. Patients were either very motivated to improve their situation, ambivalent or non-compliant. While many patients made gains, some just could not be bothered as time went on or they began to feel much better in themselves. (Mentor # 5)

Mentors identified that because poorly motivated patients were sometimes challenging, a need exists for mentors to be specifically trained so they themselves can cope with the negative consequences attributed to poor patient motivation.

The mentor's ability to cope with poorly motivated patients' needs to be strengthened. More practical training is needed to overcome negative responses from patients. (Mentor # 3)

In cases where mentors could successfully assist patients through phases of low confidence or hopelessness, mentors commented that the rewards of patient success were professionally very satisfying:

You need a lot of passion, skill and drive to assist unmotivated patients to achieve. The journey can be difficult but the intrinsic rewards high if mentors can get patients to trust and believe in them. (Mentor # 5)

## **Evaluating and improving the AHGP**

Mentors were given the opportunity to evaluate the AHGP through their learned experiences of the study. Mentors identified the strengths and limitations of the program as well as identifying areas for improvement. Mentors identified strengths and limitations of the AHGP and suggested ways to improve future training and expressed their views regarding the various audiovisual resources used in the AHGP., how the resources were appreciated by patients and thoughts concerning patient recruitment. In respect to evaluating the AHGP, four sub-themes were identified. They include; improving the AHGP, resourcing the AHGP, organising support for the AHGP and attracting patients to the AHGP.

#### Improving the AHGP

Through their contacts with patients, mentors identified the strengths and weaknesses associated with the AHGP. The strengths of the program included the acquisition of new skills for mentors such as CBT, motivational interviewing, reflective listening skills and an improvement in the progress and audit monitoring of the after hospital care of patients. From the data, it appeared the AHGP exhibited a number of positive effects on individual mentors such as enhancing their professional autonomy,

improving their CR skill set, provided insight concerning the development of the "mentor role" and the journey patients undertake following discharge from hospital:

The training and mentor experiences made me think and work more autonomously. At times, I had to deal with questions or issues without back up from doctors about side effects of drugs, missing medications, bleeding from angiography sites and the treatment of ongoing chest pain. Confronting problems prompted me to think outside the square. (Mentor # 7).

Weaknesses relating to the mentoring role included the realisation that the mentoring role was inherently quite different from normal CR nursing practice. Although mentors were generally satisfied with the initial AHGP training, some mentors suggested more intensive or follow-up training in the future would for example, foster the development of problem solving skills, how to rephrase negative patient responses and how to reinforce and or reward positive behaviours. Negative aspects concerned with training included issues such as the need to have more time allotted to practicing newly acquired skills in order to master them and specialised behavioural training to assist patients struggling with personal motivation:

I think people should know hard it is to be a mentor. Much more preparation and training needed to adequately prepare mentors for the role. (Mentor # 5)

Some mentors suggested that the AHGP has the potential to compliment hospital based CR in terms of its applicability and cost effectiveness compared with other models of CR:

The program is very cost effective because it is largely voluntary (mentoring aspect) and the patient resources are inexpensive compared with many hospital treatments. (Mentor # 2)

Mentors also believed the AHGP improved CR access for patients, especially those who live in regional areas and most notably, that the AHGP resources were valued by most patients. According to the mentor experience:

The one to one contact between the mentor and patient on an ongoing basis value adds to the treatment they have received in hospital. (Mentor # 3)

In terms of mentor beliefs concerning how the AHGP could be improved in the future, including the training of mentors, two mentors made the following observations:

Future training should provide more examples of different situations or scenarios and how to handle them. Include the re-phrasing of negative patient responses and how to paraphrase responses and reinforce positive messages. (Mentor # 5)

While mentor perceptions of the AHGP strengths outweighed identified limitations, several recommendations were forthcoming from them:

A potential weakness of the program is the expense to widen its use and future governance would need to be organised for future mentor preparation. (Mentor # 2)

### Resourcing the AHGP

The analysis of the data revealed that mentors thought the resources used in the AHGP were well designed and easy to understand. Mentors thought the written resources and other media were generally understood and valued by patients.

I thought the client resources were wonderful and easy to understand by patients. (Mentor # 1)

The patient AHGP resources were user friendly and easy for patients to use. The mentor training manuals were easy to understand and work through and gave examples of theory and practical applications applied to each phase of the AHGP. (Mentor # 3)

Some mentors suggested the need for some resources to be reviewed prior to a wider program implementation.

Relaxation CR-Rom was useful, query the value of CD ROM education package and I found some inaccuracies with written material with some information missing. (Mentor # 3)

#### Organising support for the AHGP

Generally, mentors found the AHGP to be poorly supported at an organisational level and by some health care clinicians. Mentors thought that poor support impacted

on their time spent with patients during face to face interviews and importantly, negatively impacted on the recruitment of patients in to the AHGP.

There was not much collaboration between mentors and other nursing staff. I think it was often easier to give patients a few brochures, an invitation to hospital rehab and send them on their way. (Mentor # 6)

Mentors were also concerned that some cardiology medical staff did not actively encourage the patients to enrol in the AHGP.

Doctors did not seem to support the program. Some commented that CR was a waste of time. That said, I hardly ever saw evidence of doctors explaining the positive effects of CR. It did not seem to enter the "medical" way of doing things. (Mentor # 6)

Some mentors believed some of the organisational issues could be improved by advertising the goals of the AHGP more widely within the hospital and in the community via General Practitioner networks.

More grounding work needs to be done to spread the word concerning the aims and resources of the program to doctor and other health professionals and in particular, practice nurses working in regional areas that work in conjunction with GP's. (Mentor # 6)

#### Attracting patients to the AHGP

The data revealed that mentors thought there were several barriers that significantly impacted on their ability to enrol patients into the AHGP. These barriers included issues with communication, time constraints and increased work loads:

Workloads, time limitations and the initial adjustment of introducing a new model of care negatively impacted on recruitment. (Mentor # 5)

Time was considered a major barrier in terms of implementing the AHGP especially in hospital. This issue was identified by a few mentor's due to a variety of interruptions in the clinical area, the amount of preparation and support required to

prepare patients for joining the AHGP and discharge due to the rapid turnover of patients.

I think patients generally accept that preparing them for discharge and enrolling in a newly implemented home based program is going to take a bit of extra time. A treatment plan, medication review, care of wounds, follow-up appointments, chest pain plan, activity plan, depression scale and QOL scale are all mandatory in countries that have good CR guidelines and CR indicators. (Mentor # 6)

Additionally, two mentors thought some aspects of the study's design may have negatively impacted on the recruitment of some patients.

From a patient perspective, the number of questionnaires which were needed to evaluate the study may have been a problem. Some patients would 'baulk' at the idea of so many. (Mentor # 4)

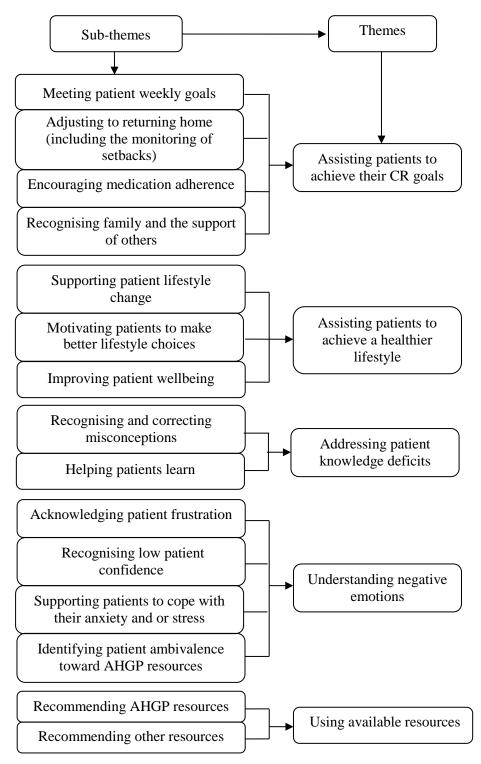
Time to interview and assist patients often remains a barrier because patients are not in hospital long and there is a lot of information to cover. The evaluation materials may have been possibly too expansive but probably necessary to tell the story in terms of the programs evaluation. (Mentor # 6)

In summary, the mentor survey was conducted to provide data concerning the perceptions of mentors supporting patients participating in the AHGP. From the data, mentors agreed that a high level of CR knowledge and proficiency was required to assist patients to improve their knowledge deficits, improve their lifestyle and reduce their risk of future cardiac illness. Along with understanding the core aspects of the AHGP and having experience in the CR, mentors acknowledged that specific mentoring skills could be improved with more specialised training in CBT and other similar strategies. Mentors also indicated that they believed the AHGP to be of great value to patients in terms of assisting their recovery provided suggestions concerning how the AHGP may be improved in terms of organisational governance, resources and patient recruitment. Mentors also provided insight concerning how the mentor-patient experience impacted on their emotions.

# The mentor clinical progress notes

The mentors who participated in the AHGP were experienced CR nurses working in each of Tasmania's major regional hospitals. Seven mentors, with a minimum of five years' experience, participated in the AHGP. Each mentor kept clinical progress notes to assist them to monitor their patient's progress during the AHGP. The clinical notes amount to a record that details each patient's progress from initial interviews in hospital to the completion of the six week program and mentor reflections concerning operational aspects of the program. Mentor hand written clinical notes were transcribed to a computer based format and de-identified. Data was revisited several times to verify meanings derived from the individual notations. Raw data was subsequently coded and organized by referring to the research question. Similarities and differences were observed and common ideas and patterns emerged from patient progress and mentor reflections.

The thematic analysis of the mentor clinical notes revealed five themes: (1) assisting patients to achieve their CR goals; (2) assisting patients to achieve a healthier lifestyle; (3) addressing patient knowledge deficits; (4) understanding negative emotions and (5) using available resources. Figure 6 outlines the themes and sub-themes that emerged from the analysis of mentor clinical note data.



CR-cardiac rehabilitation; AHGP-Aussie Heart Guide Program

Figure 6. Themes and sub-themes that emerged from the mentor clinical notes

## Assisting patients to achieve CR goals

Assisting patients with achieving CR goals or activities refers to the various educational elements, support and strategies mentors utilise to help patients recover from a potentially life threatening event and return to optimal health. Mentors assisted patients to recover from MI by providing a plan of care, which in conjunction with medical treatment, aims to help reduce their risk of further cardiac events. Mentors provide support and assistance during the patient's hospitalisation and in preparation of discharge.

Mentors assisted patients by working with them collaboratively to achieve the best CR outcomes possible. Mentors provided patients with information such as how to care for wounds, manage angina attacks, resume normal activities of daily living and other supportive strategies in case of setbacks. Patients were encouraged to choose which health goals they wished to accomplish and designed and implemented strategies in conjunction with their mentor to achieve positive outcomes. In practice, mentors routinely used the SMART mnemonic to support patients attain their goals, ensuring that chosen health goals were specific, measurable, attainable, realistic and time-bound.

Sub-themes identified under the theme of assisting patients to achieve their CR goals include; meeting patient weekly goals, adjusting to returning home (including the monitoring of setbacks), encouraging medication adherence and recognising family and the support of others.

#### Meeting patient weekly goals

The analysis of the mentor clinical notes gave examples of types of goals patients chose to work toward completing in the weeks following discharge from hospital. The mentor clinical notes also provided information relating to what type of goals patients could successfully meet and the circumstances surrounding why some patients found it difficult to attain their goals.

According to the mentor clinical notes, in terms of their CR experience, many patients had the expectation of simply wanting to return to their normal lives which included everyday activities such as cooking and cleaning, driving their car and returning to work. Mentors identified through their notes that patient recovery after MI

required a period of adjustment and this correlated strongly with being able to get back to their normal life. The notes also reflected that most patients understood the need to set daily and weekly goals to progress toward lifestyle change. Plans to stop smoking, increase their levels of exercise, initiate dietary changes and decrease stress in their lives were very common patient goals identified in the data:

He wants to eat less red meat (4x week only), decrease meal portion size, wishes to eat more fish (3x per week), eat less salt (not adding salt to cooking) and do relaxation exercises (15-20 min per day). (Mentor # 4)

Patient goals were revisited approximately every week by their mentor to check their progress and to determine whether their set goals had been met. Depending on the outcome, other strategies were often put in place to assist patients realize their goals prior to the next mentor-patient contact. Patients who could meet their weekly goals successfully were encouraged by their mentors to modify or set new goals:

The patient has used exercise bike for 10 mins 3-6 times per week. Walking 30 minutes per day. Plans to increase walking time to 40 minutes per day and increase speed. I have encouraged him to commence using arm weights, ½ kilogram, and each day for the first week. (Mentor # 5)

Some patients were not able to meet their desired goals each week. Mentors identified that they worked closely with patients to review their progress and develop strategies that patients could use to work towards positive health outcomes:

In terms of progress of health goals for this week, he has not limited meat in meals or reduced portion size. He has not used relaxation CD. I suggested that he try preparing meat in smaller portions then cooking it. He could talk to his local butcher about leaner cut of meat and small portion sizes. I reinforced the goal that he tries listening to the relaxation CD everyday. Unless CD tried, [we] won't know if it works or has benefit. (Mentor # 4)

#### Adjusting to returning home including the monitoring of setbacks

Mentors made notes and gave examples concerning many of the issues patients faced when returning home from hospital. In some cases, these issues led to patient

setbacks such as patients having to be readmitted to hospital or have their medical management altered. Patients that experienced setbacks often required to be closely monitored by their mentors to prevent further deterioration. The analysis confirmed that mentors routinely checked that patients experiencing setbacks understood the importance of visiting their family doctor expeditiously when confronted with symptoms or other troubling changes to their health status. The data showed that a great deal of mentor work involved supporting patients when frustrated with issues delaying their recovery by using positive encouragement and revisiting patient gains in terms of recovery steps made:

Not a good week. Re-admitted to hospital on Thursday. Medications recently changed. Patient collapsed after use of GTN spray after attempting to climb a flight of stairs. Reason? Reviewed activity projections and safety aspects of climbing stairs. (Mentor # 3).

#### Encouraging medication adherence

Mentors found that patients often required their medication regimens revisited to ensure prescribed medications were correctly administered. Some strategies were found to be successful in assisting patients to follow-up on their prescriptions. These included arranging medicine dispensing units such as Webster packs, medicine booklets containing drug information and checklists, checking patient knowledge regarding their various medications and routinely checking that patients had organised appointments to have their prescriptions reviewed and renewed:

A new goal is to keep medication taking in check [not a good record of med taking]. Now using pill-box as planned, and has two emergency books with meds written in them. One kept in his truck and one at home. (Mentor # 5)

#### Recognising family and the support of others

The data analysis found that mentors thought positive family support was very important in terms of assisting patients in their rehabilitation post MI. Positive support from family and friends was considered a valued adjunct to mentor care and support:

Establishing a plan with partner to exercise together and plan to eat healthier meals. Has returned to most previous activities and very well supported by work colleagues. (Mentor # 2)

Mentor clinical notes gave some examples in relation to how negative support structures impacted on patient outcomes. These ranged from family members being overly protective to little or no support received from family members. A few patients also reported support issues with employers or work colleagues:

Main issue is that the patient is feeling very down. Recommendation, talk to wife re support and see GP re referral to psychologist. Some issues with employment- "under the pump -it's only me", patient appears to be a high achiever, feeling as if he's let the team down. I feel he needs to be supported more during this time. (Mentor # 5)

## Assisting patients to achieve a healthier lifestyle

Mentors worked collaboratively with patients to identify the modifiable risk factors they could change to promote a healthier lifestyle and reduce their risk of future cardiac events. Once this was understood, mentors further supported patients by providing focus, concerning the possible strategies patients could adopt to successfully undergo lifestyle change. While mentors aim to support patients during this process, the attainment of patient lifestyle goals was dependent on many factors such as depth of patient knowledge, their confidence or willingness associated with making changes and their motivation to maintain the change once the goal was realised. Sub-themes identified under the theme of assisting patients to achieve a healthier lifestyle includes supporting patient lifestyle change, motivating patients to make better lifestyle choices and improving patient wellbeing.

#### Supporting patient lifestyle change

The analysis identified that a major aspect of mentor work in the AHGP revolved around supporting patient efforts to reduce their risk of future cardiac events through lifestyle modification. Examples of mentor support include building rapport and interest in the patient, listening to what is important to them, assessing their level of knowledge, involving them in setting their own achievable goals, rewarding their successes even if small and understanding their co-morbidities when attempting to correct modifiable risk factors. By processing the written evidence of their phone

conversations with patients, mentors could document the patient's journey over time. From this information, they acknowledged some of the difficulties patients encountered and provide examples of how some patients were successful in implementing implemented strategies to cease smoking, exercise more widely, reduce stress and improve their diet:

Encouraged to use [relaxation CD] more often if possible to cope with anxious thoughts - but pleasing that he used the resource (after encouragement last week). Suggested he uses the diary more and insert positive things after activities like "I feel better after I use the exercise walking machine or relaxation CD. (Mentor # 4)

#### Motivating patients to make better lifestyle choices

A great deal of mentor work concerned finding ways of improving patient confidence to assist them to make positive lifestyle changes. Mentors suggested that there was not a lot of innovation in respects to encouraging patients other than being overtly positive and reinforcing patient achievements. The analysis revealed that while some patients could modify or make changes, other patients made little gains in attaining lifestyle goals. Some of the reasons mentors attributed to this include ambivalence toward change, poor appreciation of the connection between heart disease and lifestyle risk, lack of incentive to give up something they enjoy (such as cigarette smoking) and the effect of co-morbidities interfering with such goals as increasing exercise:

He is planning a motor home trip next April. I suggested he use that exciting prospect as a primary motivator to get fit and healthy. (Mentor # 4)

#### Improving patient wellbeing

The data provided some insights in respects to how mentors considered patients improved their wellbeing through the attainment of personal goals and by reducing their lifestyle risk. Mentors identified that patients became "happier" when they felt they had made significant progress in terms of their rehabilitation or had managed to change lifestyle factors such as exercising more, losing weight or not smoking:

[The patient stated during the follow-up phone discussion] Everything is fine, feel I am back to good health. I want to continue to exercise, watch my diet and not smoke. I want to keep control of my life. (Mentor # 3)

## Addressing patient knowledge deficits

Mentors reflected on the need to educate patients appropriately, so they developed an understanding concerning any misconceptions they may have regarding the cause of their illness and generally, determine and explore any potential lifestyle factors that may predispose them to further risk of cardiac disease. Most mentors emphasised the need to frequently check for patient understanding in regards of their health perceptions, aspects of treatment and living with the chronic condition. By correcting misinformation, mentors continually reinforced important aspects of care relating to patient recovery after MI. The focus of ensuring patient understanding further complimented patient efforts to adopt changes to their lifestyle. Sub-themes identified under the theme of addressing patient knowledge deficits include; recognising and correcting misconceptions and helping patients learn.

#### Recognising and correcting misconceptions

Patients presenting with MI's may have little knowledge concerning their illness, however, they may still hold certain beliefs about what caused their illness. These beliefs may be influenced by social, cultural and personal factors. Mentors found that patients often held common misconceptions or wrong ideas about cardiac disease and what one should do when one has it. Patients who have misconceptions may avoid certain activities, prevent patients from returning to work, lead to poor coping behaviours and for some patients, promote further disability. Mentors thought patients were more likely to assume responsibility for their health once discharged from hospital if mentors took steps to routinely check for patient understanding of new information, skills and strategies learned:

Visited GP for new script. Doesn't feel comfortable about discussing medication changes. Has not reviewed his chest pain with GP. Walking 15-20 minutes occasionally. I suggested that chest pain is serious, needs to use medications safely. (Mentor # 5)

#### Helping patients learn

A large component of mentor work involved identifying each patient's depth of knowledge about CHD. Information could then be provided to patients to supplement or build on what they understood relating to the illness, specific treatment interventions and their recovery:

Mentors are required to provide information for clients on health risk and health behaviour and to support the client to manage their long term health outcomes. Helping patients understand the theories associated with rehabilitation and recovery and then help them move from theory to practice is needed. Mentors need plenty of life skills and a large kit bag of heart health knowledge to cater for individual patient differences. (Mentor # 7)

## **Understanding negative emotions**

Though many patients undertaking the AHGP were satisfied with their progress during their recovery and were encouraged when lifestyle goals were attained, a few patients experienced negative emotions. The most prevalent negative emotion experienced by patients was frustration. The source of frustration for some patients was linked to the experience of setbacks including ongoing episodes of chest pain, exertional dyspnoea and side effects associated with medications. Mentors also reported that patients became frustrated when they failed to meet their lifestyle goals such as the cessation of smoking, inability to reduce weight or increase their level of activity. In some cases, despite mentor efforts to motivate and implement strategies to support patients, patients found it difficult to believe and or accept that their illness was affected by their lifestyle choices.

Mentors also gave examples of incidents that led to episodes of professional frustration with some mentors experiencing anxiety when dealing with non-compliant patients. In part, this was due to a perception that even though some patients received a great deal of support and time invested in their recovery and attempts to improve lifestyle factors (such as cessation of smoking and diet modification), some patients were unable to meet their lifestyle goals. While some mentors became occasionally frustrated with patients, this did not deter their attempts to support and encourage patients. Mentors also felt that they possibly lacked specific strategies to cope with this

emotion and suggested that future training should endeavour to address this issue. Subthemes identified under the theme of understanding negative emotions include; acknowledging patient frustration, recognising low patient confidence, supporting patients to cope with their anxiety and or stress and identifying patient ambivalence toward the AHGP resources.

#### Acknowledging patient frustration

Some mentors found frustration had the potential to delay the recovery progress of patients. Patients reported to their mentors that they found aspects of their care to be frustrating. Patients were found to often lack decision making skills. For example, some patients suggested that they were too "stressed" to engage in attempts to meet goals. When mentors suggested that they practice positive self-talk or adopting a relaxation method outlined in the program, they lacked the motivation to try:

Feeling generally frustrated with progress but is experiencing some success with walking. Feels "useless and confined." Reinforced the need for positive thoughts re-small steps forward and just trying is a positive step. (Mentor # 5)

#### Recognising low patient confidence

Mentors found that a patient's level of confidence in terms of meeting their chosen goals affected their progress and recovery. Patients who had low levels of personal confidence were more likely not to undertake significant lifestyle change and were less likely to use the AHGP resources in a meaningful way:

Patient is still smoking. Patient at contemplation stage, he wants to give up, confidence 2/10, not able to identify what to do to get from 2-5/10 in terms of lifting his confidence rating. (Mentor # 3)

#### Supporting patients to cope with their anxiety and or stress

Mentors agreed that it was common for patients diagnosed with MI in hospital to experience anxiety or stress. Some women appeared to be more anxious in hospital and after discharge. However, they were more likely to try relaxation therapy methods than men and were generally, more successful at decreasing their levels of anxiety after education and appropriate support was given:

Patient is looking into ways of managing stress better-much of it comes from others. Strategies include – trying to say no to other people's demands more often, communicating needs to others, relaxation through bath, novel reading, and time out from busy schedules. (Mentor # 3)

Has not listened to relaxation tape yet, issues making time around wife and kids to practice. I reinforced the ideas behind using the relaxation tape. Could he explain to family the importance of this therapy in order to get further support? (Mentor # 5)

#### Identifying patient ambivalence toward AHGP resources

The mentor clinical note data provided many examples where patients set health goals in collaboration but failed to meet them. Patient ambivalence appeared to be linked to the unmet health goals of some patients. Despite encouragement from mentors, strategies that may have helped some patients meet their goals were not acted on. Some chose not to use some of the available AHGP resources such as the workbooks, diary and relaxation media. Mentors found experiences of ambivalence frustrating because they felt the resources were of good quality. Furthermore, patients did not offer reasons why they chose not to use the opportunities available to them:

Not achieving weekly goals. I suggested he write down 1 or 2 activities each day as a prompt in his diary. He says he does not want to make a plan or use a diary...cannot give a reason. (Mentor # 3)

## Using available resources

The mentor clinical notes provided examples where patients were encouraged to utilise the various AHGP resources. To improve outcomes for patients, mentors also utilised other health professionals, agencies or self help groups to supplement their mentoring role. Mentors also provided examples of patients who benefited from being directly referred to other health care professionals such as diabetic clinics, dietitians and psychologists. Sub-themes identified under the theme using available resources include recommending AHGP resources and recommending other resources.

#### Recommending AHGP resources

Through their clinical progress notes, mentors reflected which AHGP resources they considered patients used frequently or found the most helpful:

This week the patient has watched the interactive DVD and listened to the relaxation CD of 30 min duration, most days. (Mentor # 5)

Most patients used the interactive CD Rom, and found the resource very informative. (Mentor # 2)

#### Recommending other resources

Mentors gave examples of which resources or health professionals (other than those offered in the AHGP) they referred patients to:

Have given him "Heart Moves" contact information as alternative to joining a gym in the interim. (Mentor # 5) After my referral, the patient is reading supplied literature from diabetes support group, becoming more informed and more aware of the effects of insulin and the need for blood sugar monitoring. (Mentor # 3)

In summary, the analysis of the mentor field notes was undertaken to evaluate mentor perceptions regarding each patient's individual progress from hospital discharge to the completion of the AHGP. The analysis demonstrated that mentors used a common structure and process in assisting patients move from a position of patient dependence in hospital to accomplishing weekly goals. The analysis also highlighted how mentors assisted patients to achieve lifestyle goals such as smoking cessation, increasing exercise levels, adopting a heart friendly diet and reducing stress. Assistance from mentors included knowledge attainment, understanding and supporting patient emotions such as frustration, low confidence, lack of motivation or general ambivalence and coping with anxiety and stress.

# Summary

Overall, this chapter has described the findings from three data sources collected on three separate occasions; the patient telephone interview, the mentor survey and the analysis of mentor clinical notes. The analysis of the patient telephone interview revealed three themes; assisting me (the patient) to cope, supporting me and my family

and tailoring the AHGP to my (the patient) individual needs. The findings strongly suggest patients were very satisfied with the program and found their assigned mentors integral in providing support and helping them recover after MI.

The analysis of the mentor survey identified four themes; identifying oneself as a mentor, identifying mentor proficiency, assisting patients to improve their health and evaluating and improving the AHGP. The findings indicated that mentors require a high degree of proficiency in terms of their knowledge base and practical skills to help patients meet their desired health goals. Mentors also provided examples concerning what they believed to be attributes of the mentor role and which mentoring skills and strategies assist patients in their recovery from MI.

The mentor field notes described five themes; assisting patients to achieve their CR goals, assisting patients to achieve a healthier lifestyle, addressing patient knowledge deficits and understanding negative emotions and using available resources. The findings suggested that mentors thought that the AHGP positively assisted patients in their recovery after MI. The sub-themes also conveyed an appreciation of mentor work in terms of the skills and strategies used to assist patients in their recovery and efforts to adopt a healthier lifestyle. The following chapter presents the quantitative results relative to this study. It incorporates information concerning sample recruitment and includes a description of the characteristics of the sample. Following this, the hypothesis testing results are reported.

## **Chapter 5: Patient Outcomes**

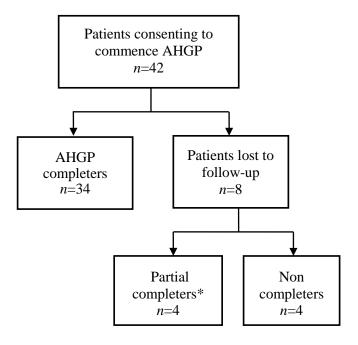
## Introduction

The purpose of this research was to evaluate the AHGP in regional Tasmania using Donabedian's structures, processes and outcomes framework for health care quality (1966). The study used a case study design to answer the various research questions. The previous chapter reported the findings derived from qualitative data collected during this study. This chapter presents the quantitative results from this case study and incorporates information concerning patient recruitment and a description of the characteristics of the sample. Quantitative patient outcome data were exploratory in nature, with the aim of identifying trends because the sample size was small. Several hypotheses relating to improvements in patient outcomes were detailed in the methods chapter. Five instruments (HADS, MacNew HRQOL, Physical activity score, IPQ-R and heiQ) were used in this study to collect patient outcome data over two time periods, at baseline (pre AHGP) and at the completion of the AHGP (at approximately six to eight weeks post hospital discharge).

# Recruitment of the sample

Quantitative data collection commenced in July 2008 and concluded in December 2011. Once their condition was stabilised, patients admitted to coronary care units in Tasmanian regional public hospitals, were approached by CR nurses to participate in the study. Recruitment for the quantitative component of the study is illustrated in Figure 7. Forty-two adult patients consented to join the study. The ability of CR nurses to recruit patients depended on several factors. Patients were identified as potential study participants if they were; (1) unable to attend existing hospital based CR programs; (2) nurse mentors were on duty during the patient's hospitalisation and (3) if patients could be screened for inclusion prior to hospital discharge. Of the 42 patients who were enrolled in the study, all patients received an appropriate introduction to the AHGP and its resources via the patient information sheet (see Appendix 3), and a face to face meeting with their nurse mentor prior to being discharged from hospital. Eight patients in total were lost tofollow-up. Four patients consented to participate in the AHGP but failed to complete the six week program (non completers) because of earlier than

expected discharge from hospital or were uncontactable post discharge from hospital. Four patients (partial completers) completed the pre program evaluation questionnaires but failed to return the post program evaluation after reminders from the research team. Thus, for the purposes of reporting the clinical characteristics of the sample, partial program completers refer to the four patients who completed the pre program evaluation only. A total of 34 patients completed the AHGP.



AHGP-Aussie Heart Guide Program, \*Partial completers (patients who completed Pre AHGP evaluation questionnaires but not the post AHGP evaluation questionnaires).

Figure 7. Flow chart of sample recruitment

# **Description of the sample**

Of the 34 patients who completed the study, 23 (68%) were males and 11 (32%) were females with a median age of 57 years (IQR 11.3; range 39-79). Table 4 lists the demographic characteristics of the sample.

Table 4: Demographic characteristics of the patient sample

	AHGP completers
Patient Characteristics	Frequency (%)
	n=34
Gender	
Male	23 (67.6)
Female	11 (32.4)
Marital Status	
Married	20 (58.8)
Partner	7 (20.6)
Single	6 (17.6)
Widow/er	1 (2.9)
Lives with	
Spouse	20 (58.8)
Partner	7 (20.6)
Carer	4 (11.8)
Alone	1 (2.9)
Occupation	, ,
Professional	4 (11.8)
Business/Retail	9 (26.5)
Labourer	12 (35.3)
Farming	3 (8.8)
Self employed	5 (14.7)
Disability	1 (2.9)
pensioner	-
Work status	-
Full time	11 (32.4)
Part time	8 (23.5)
Retired	8 (23.5)
Disability	6 (17.6)
Not known	1 (2.9)
Aboriginal	
Yes	3 (8.8)
No	31 (91.2)
Country of Birth	
Australia	31 (91.2)
Europe	2 (5.9)
Other	1 (2.9)

AHGP -Aussie Heart Guide Program.

Table 5 presents the clinical characteristics of the patient sample. Over 80% of completers received PCI and medication therapy as the mainstay of their medical treatment. In relation to their current admission to hospital, 70% (n=32) of completers had an admission diagnosis of ST segment elevated myocardial infarction (STEMI).

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In respect to cardiac related readmission to hospital within the 12 month period post AHGP, 79% (n=27) of completers remained admission free, with 20% (n=7) of completers reporting one or more readmissions to hospital for further cardiac management.

Table 5: Clinical characteristics of the Sample

Sample	AHGP completers
Characteristics	Frequency (%)
	n=34
Admission diagnosis	
STEMI	24 (70.6)
Non STEMI	8 (23.5)
ACS	2 (5.9)
Proximity to hospital based CRP	
(kms)	
<50	8 (23.5)
50 -100	20 (58.8)
>100	6 (17.6)
Reason for home based CR	
preference	
Distance from hospital	28 (82.4)
Difficulties with	1 (2.9)
transport	1 (2.9)
Self-employed and	
returning to work	4 (11.8)
Returning to work	
Previous cardiac history	
ACS	7 (20.6)
MI	11 (32.3)
CABG	3 (8.8)
Heart failure	1 (2.9)
Cardiac intervention	
PCI	28 (82.4)
Medications	
Apirin	34 (100.0)
Clopidogrel	29 (85.2)
Warfarin	3 (8.8)
Ace inhibitor	18 (52.9)
Betablocker	20 (58.8)
Statin	34 (100.0)
Carvedilol	1 (2.9)

AHGP - Aussie Heart Guide Program, STEMI - ST segment elevation myocardial infarction, Non-STEMI - Non ST segment elevation myocardial infarction, ACS - Acute coronary syndrome, CRP-cardiac rehabilitation program, CR- cardiac rehabilitation, CABG - Coronary artery bypass graft, PCI -Percutaneous coronary intervention, CRP - Cardiac rehabilitation program, kms – kilometres.

Table 6 presents the remaining clinical characteristics of the patient sample including height, weight, BMI scores and lipid profile.

Table 6: Clinical characteristics of the sample

Clinical Characteristics	AHGP completers $\overline{X}$ (SD) $n=34$		
Height (cms)	171.5 (8.59)		
Weight (Kg)	84.4 (16.54)		
BMI $(kg/M^2)$	28.6 (4.42)		
Lipid profile (mmol/l)			
Total(c)	5.5 (1.34)		
LDL(c)	3.8 (1.27)		
HDL(c)	1.0 (0.25)		
Triglycerides	2.1 (1.08)		

AHGP-Aussie Heart Guide Program,  $\overline{\mathbf{x}}$  -Mean score, SD-standard deviation, cms – centimetres, Kg - kilogram, BMI-Body mass index, mmol/l-milimolecules per litre, Total(c)-Total cholesterol, LDL(c)-Low density lipoprotein, HDL(c)-High density Lipoprotein.

Table 7 presents the specific cardiac risk factors of the patient sample. High cholesterol (82%), hypertension (65%) and smoking (50%) were the most prevalent cardiac risk factors for completers. All patients reported two or more cardiac risk factors with 29% (n=10) of all patients having six or more cardiac risk factors.

Table 7: Risk factors of the patient sample

Risk Factors for CHD	AHGP completers Frequency (%) n=34
Current smoker	17 (50.0)
High cholesterol	28 (82.4)
Sedentary	12 (35.3)
Hypertension	22 (64.7)
Family history	20 (35.3)
Obesity/overweight	20 (35.3)
Anxiety and/or	
Depression	14 (41.2)
Social isolation	13 (38.2)
Diabetes type I	-
Diabetes type II	10 (29.4)

CHD-Coronary heart disease, AHGP-Aussie Heart Guide Program.

# **Instrument reliability**

Table 8 reports the internal consistency and reliability of the various instruments measured using Cronbach's alpha coefficient. The HADS, MacNew HRQOL and heiQ demonstrated good internal consistency; however, the IPQ-R instrument had low alpha score possibly associated with the small sample size with some negative correlations interfering with the instruments reliability.

*Table 8: Instrument reliability* 

		Cronbach's	Cronbach's
Scale	Construct/Dimension/Subscales	Alpha	Alpha
		T1	T2
HADS			
	Anxiety	.82	.78
	Depression	.87	.89
IPQ-R			
	Timeline	.27	34*
	Consequences	.32	.32
	Personal Control	.33	.17
	Treatment Control	09*	.09
	Illness Coherence	.38	.63
	Timeline Cyclical	.80	.80
	Emotional Representations	.62	.73
MacNew			
HRQOL			
	Emotional	.94	.97
	Physical	.92	.93
	Social	.93	.94
	Global Score	.97	.98
heiQ			
	Health directed behaviour	.90	.89
	Positive and active engagement	.83	.87
	in life		
	Emotional distress	.82	.87
	Self-monitoring and insight	.57	.90
	Constructive attitudes and	.87	.85
	approaches		
	Skill and technique acquisition	.55	.90
	Social integration and support	.86	.87
	Health service navigation	.86	.84

HADS-Hospital Anxiety and Depression Scale, IPQ-R-Revised Illness Perception Questionnaire, MacNEW- MacNew Heart Related Quality of Life Questionnaire, heiQ-Health Education Impact Questionnaire, T1-time period one (administered prior to commencing the AHGP), T2-time period two (administered post AHGP). \*The Cronbach's Alpha result is negative due to a negative covariance shared by some of the items which interferes with any assumptions that may be made regarding the instrument's reliability.

# Hypothesis testing results

It was hypothesised the AHGP effect on patient outcomes would demonstrate improvements in levels of anxiety and depression, level of exercise, illness perception, QOL and improve patient's ability to self manage their chronic disease.

Table 9 presents the anxiety and depression outcomes for patients completing the AHGP. Paired-samples t-tests were used to compare the means of patients before and after participating in the AHGP. Patient anxiety but not depression significantly improved (anxiety with a decrease in mean scores of 2.6 [CI95% 1.3-3.8] and depression; a difference in the mean scores of 1.5 [CI95% 0.66-2.45]).

Table 9: Patient outcomes for anxiety and depression

Scale	Pre AHGP $(T1)$ $\overline{X}$ (SD) $n=34$	Post AHGP $(T2)$ $\overline{X}$ (SD) $n=34$	Paired <i>t</i> -test	<i>p</i> -value
HADS Anxiety	7.6 (4.27)	5.3 (4.44)	t=3.70	<.001
Depression	5.0 (3.95)	3.7 (4.15)	df=32 t=2.78 df=32	.09

HADS-Hospital Anxiety and Depression Scale, AHGP-Aussie Heart Guide Program, T1-time period one (scale administered prior to commencing the AHGP), T2-time period two (scale administered post AHGP), SD-standard deviation, df-Degrees of freedom.

Table 10 reports patient outcomes in relation to the modified physical activity scale. The patients' ability to improve their tolerance for moderate exercise after MI improved post AHGP, but no other statistically significant changes were seen, possibly due to the small sample size. This represents a mixed result, showing only a small improvement in patients undertaking exercise after completing the AHGP.

Table 10: Patient outcomes for physical activity

Scale	Pre AHGP (T1)	Post AHGP (T2)	Paired	р
	$\overline{X}$ (SD) $n=34$	$\overline{X}$ (SD) $n=34$	t-test	value
Modified Physical Activity Scale				
Strenuous exercise	0.9 (2.14)	1.1 (2.65)	t=46 df =33	.64
Moderate exercise	2.5 (2.65)	3.7 (3.66)	t=-2.21 df=33	.03
Mild exercise	4.4 (0.77)	5.5 (0.60)	t=-1.19 df=33	.18
Exercise or activity that increased heart rate	2.0 (0.13)	1.8 (0.12)	t=1.31 df=33	.19
Exercise for a minimum of 30 minutes per day	1.4 (0.11)	1.3 (0.09)	t=.94 df=33	.35
Exercise intensity	3.2 (0.20)	3.2 (0.17)	t=19 df=33	.90
Self-rated difficulty related to exercise/activity	2.1 (0.19)	1.8 (0.17)	t=1.27 df=33	.90

AHGP-Aussie Heart Guide Program, T1-time period one (scale administered prior to commencing the AHGP), T2-time period two (scale administered post AHGP), SD-standard deviation; df-Degrees of freedom.

In respects to the IPQ-R outcomes, Table 11 reports the various identity dimension related symptoms experienced by patients. Patients were asked to consider the type of symptoms as part of (the IPQ-R Identity Dimension) they experienced after diagnosis of MI (in hospital) and following completion of the AHGP. Loss of strength, fatigue, sore eyes and wheeziness were common symptoms reported by patients before and after the AHGP.

Table 11: Identity dimension symptoms (IPQ-R) experienced by patients

Scale	Pre AHGP	Post AHGP	CI.	1
	(T1)	(T2)	Chi-	p value
	Frequency(%)	Frequency(%)	square $^{\Delta$ , a	
	n=34	n=34		
IPQ-R				
Identity Dimension-				
"Symptoms experienced				
since my illness"				
Breathlessness	21 (61.8)	16 (47.1)	2.49	.28
Pain	19 (55.9)	15 (44.1)	4.75	.09
Dizziness	19 (55.9)	10 (29.4)	1.20	.23
Loss of strength	17 (50.0)	13 (38.2)	10.1	.01
Sleep difficulties	17 (50.0)	11 (32.4)	1.20	.23
Fatigue	16 (47.1)	19 (55.9)	6.33	.01
Stiff joints	15 (44.1)	19 (55.9)	0.88	.64
Headaches	13 (38.2)	9 (26.5)	1.55	.19
Sore eyes	10 (29.4)	9 (26.5)	5.48	.04
Nausea	9 (26.4)	4 (11.8)	1.99	.36
Upset stomach	6 (17.6)	4 (11.8)	3.26	.13
Wheeziness	5 (14.7)	7 (20.6)	5.56	.04
Weight loss	5 (14.7)	8 (23.5)	4.33	.07
Sore throat	4 (11.8)	4 (11.8)	0.00	1.00

AHGP-Aussie Heart Guide Program, T1-time period one (questionnaire administered prior to commencing the AHGP), T2-time period two (questionnaire administered post AHGP), <sup>,Δ</sup>-Analysis performed using Chi-square test to assess the existence of a relationship between individual patient symptoms over time <sup>a</sup> Chi-square test may be inaccurate because greater than 33% of the cells had expected values of less than 5.

Table 12 lists the symptoms patients perceived were related to their illness pre and post AHGP. Apart from experiencing stiff joints, no other statistical differences were detected in relation to patient perceptions concerning identity dimensions relating to their illness pre and post AHGP. However, it is possible that patient perceptions relating to their illness may have demonstrated statistical differences had the sample been larger.

Table 12: Identity dimension symptoms (IPQ-R) relating to the patient's illness

Scale	Pre AHGP (T1)	Post AHGP (T2)	Chi-	p value
	Frequency (%) <i>n</i> =34	Frequency (%) <i>n</i> =34	square <sup>Δ, a</sup>	
IPQ-R				
Identity Dimension -				
"Symptoms related				
to my illness"				
Breathlessness	19 (55.9)	15 (44.1)	1.87	.39
Pain	19 (55.9)	11 (32.4)	2.06	.35
Fatigue	16 (47.1)	13 (38.2)	2.59	.10
Loss of strength	16 (47.1)	12 (35.5)	3.09	.21
Dizziness	14 (41.2)	6 (17.6)	2.26	.32
Sleep difficulties	10 (29.4)	10 (29.4)	.88	.64
Headaches	9 (26.5)	5 (14.7)	.12	.60
Nausea	8 (23.5)	3 (8.80)	1.01	.43
Wheeziness	5 (14.7)	4 (11.8)	.78	.51
Stiff joints	5 (15.2)	4 (12.1)	6.66	.03
Sore eyes	4 (11.8)	2 (5.9)	2.99	.22
Upset stomach	4 (11.8)	1 (2.9)	.13	.88
Sore throat	4 (11.8)	3 (8.8)	.76	.40
Weight loss	3 (8.8)	5 (14.7)	.91	.38

AHGP-Aussie Heart Guide Program, T1-time period one (questionnaire administered prior to commencing the AHGP), T2-time period two (questionnaire administered post AHGP), <sup>A</sup>Analysis performed using Chi-square test to assess the existence of a relationship between individual patient symptoms over time. Chi-square test may be inaccurate because greater than 33% of the cells had expected values of less than 5.

Patients completing the IPQ-R questionnaire were also asked to consider the cause of their illness (another variant of the IPQ-R dimensions). Patients were asked to choose from a list of possible causes using a five point Likert response to agree or disagree with each of the listed causes. Table 13 reports patient perceptions concerning the cause of their illness before and after the AHGP. Patients reported a strong association with smoking, pollution in the environment and a weaker association with stress and worry in terms of what they believed caused their illness.

Table 13: Patient perceptions concerning the causes of their illness

Scale	Pre AHGP $(T1)$ $\overline{X}$ (SD) $n=34$	Post AHGP $(T2)$ $\overline{X}$ (SD) $n=34$	Paired <i>t</i> -test	<i>p</i> -value
IPQ-R Possible causes of their illness <sup>a</sup>				
Stress or worry	3.2 (1.15)	3.7 (1.14)	t=-1.93 df=33	.06
Hereditary	3.5 (1.13)	3.6 (1.18)	t=000 df=33	1.00
Germ or virus	2.2 (.93)	1.9 (.83)	t=1.72 df=33	.09
Diet or eating habits	3.4 (1.15)	3.3 (1.12)	t=.66 df=33	.51
Chance or bad luck	2.5 (1.10)	2.7 (1.14)	t=39 df=33	.69
Poor medical care	2.5 (1.08)	2.4 (.95)	t=.54 df=33	.58
Pollution in the environment	2.4 (1.02)	2.1 (.96)	t=1.97 df=33	.05
My own behaviour	3.3 (1.22)	3.1 (1.20)	t=1.40 df=33	.16
My mental attitude	2.4 (1.07)	2.0 (.91)	t=1.83 df=33	.07
Family problems	2.5 (.92)	2.4 (1.13)	t=.31 df=33	.75
Overwork	2.4 (1.0)	2.3 (.91)	t=.79 df=33	.43
My emotional state	2.5 (1.15)	2.6 (1.09)	t=.45 df=33	.65
Ageing	3.1 (1.24)	3.9 (1.07)	t=.98 df=33	.33
Alcohol	2.0 (.86)	2.1 (.84)	t=.51 df=33	.60
Smoking	3.0 (1.41)	3.4 (1.33)	t=-2.17 df=33	.03
Accident or injury	1.9 (.79)	1.7 (.66)	t=1.48	.14
My personality	2.0 (.73)	2.1 (.95)	df=33 t=.28	.77
Altered immunity	1.9 (.75)	1.9 (.86)	df=33 t=.000 df=33	1.00

IPQ-R-Revised Illness Perception Questionnaire, AHGP-Aussie Heart Guide Program, T1-time period one (administered prior to commencing the AHGP), T2-time period two (administered post AHGP),  $\overline{X}$ -Mean score, SD-standard deviation, df-Degrees of

freedom, a rank ordering of the three most important factors patients believed caused their illness.

IPQ-R Dimensions relative to patient understanding of their illness pre and post the AHGP are reported in Table 14. No statistical differences were noted between the various dimensions. As stated previously, the small sample size in this study may have impacted on these results.

Table 14: IPQ-R Dimensions relating to patient understanding of their illness

Scale	Pre AHGP	Post AHGP	Daimad	n volue
	$\overline{X}$ (SD)	$\overline{X}$ (SD)	Paired <i>t</i> -test	p value
	n=34	n=34	i test	
IPQ-R Dimension*	<i>N</i> =3 1	70-31		
Personal control	20.1 (2.57)	20.3 (2.53)	t=38 df=33	.34
Timeline	18.9 (2.98)	19.6 (2.34)	t=-1.19 df=33	.24
Consequences	18.8 (2.07)	18.5 (2.59)	t=.56 df=33	.70
Treatment control	15.4 (2.03)	14.9 (1.97)	t=.96 df=33	.12
Illness coherence	13.5 (2.93)	12.5 (3.06)	t=1.58 df=33	.62
Timeline cyclical	10.7 (3.19)	19.6 (2.34)	t=.49 df=33	.23
Emotional representations	16.9 (4.23)	16.1 (4.33)	t=1.20 df=33	.24

<sup>\*</sup>IPQ-R Dimension relating to patient understanding of their illness, AHGP-Aussie Heart Guide Program, T1-time period one (questionnaire administered prior to commencing the AHGP), T2-time period two (questionnaire administered post AHGP),  $\overline{X}$ -Mean score, SD-standard deviation, df-Degrees of freedom, IPQ-R-Revised Illness Perception Questionnaire.

The last section of the IPQ-R questionnaire encourages patients to rank the three most important factors they felt contributed to their illness. Out of 18 possible causes, patients identified the following causes as the most prevalent; hereditary factors 29% (n=10), smoking 26% (n=9), stress 17% (n=6), and eating habits 14% (n=5). Groupings of causal beliefs could not be ascertained once again due to the small sample size. A

factor analysis could have been used to identify groups of beliefs if the sample numbered more than 85 patients (Weinman et al, 2000; Moss-Morris et al, 2002).

The Mac New HRQOL questionnaire was used in this study to measure patient's QoL prior to and after completion of the AHGP. Table 15 reports patient outcomes in relation to the MacNew HRQOL questionnaire. Significant positive improvements were made by patients in their emotional, physical, social and global domain scores after completion of the AHGP. An increase in mean scores across all domains at AHGP completion suggested patient HRQOL improved following completion of the program.

Table 15: Patient MacNew HRQOL outcomes

Scale	Pre AHGP (T1)	Post AHGP (T2)	Paired	<i>p</i> -value
	$\overline{X}$ (SD)	$\overline{X}$ (SD)	t-test	•
	n=34	n=34		
MacNew HRQOL				
Emotional domain	71.6 (18.41)	78.4 (18.6)	t = -3.1	.004
			df=32	
Physical domain	67.5 (16.31)	75.0 (14.62)	t = -3.4	.002
			df=32	
Social domain	70.2 (17.40)	76.3 (15.21)	t = -2.6	.012
			df=32	
Global HRQOL Score	209.4 (50.33)	229.9 (47.52)	t = -3.1	.003
			df=32	

AHGP-Aussie Heart Guide Program, T1-time period one (questionnaire administered pre AHGP), T2-time period two (questionnaire administered post AHGP),  $\overline{X}$ -Mean score, SD-standard deviation, MacNew HRQoL-MacNew Heart Related Quality of Life Questionnaire, df-Degrees of freedom.

Table 16 reports the patient outcomes relating to the heiQ that was used to measure improvements in a patient's ability to self manage. No differences were detected between the mean scores pre and post AHGP intervention. The small sample size in this study may have impacted on the heiQ results.

Table 16: Patient heiQ outcomes for patients

Scale	Pre AHGP	Post AHGP		
	(T1)	(T2)	Paired	<i>p</i> -value
	$\overline{X}$ (SD)	$\overline{X}$ (SD)	sample	
	n=34	n=34	t-test	
heiQ Domains				
Health directed behaviour	11.8 (2.90)	11.6 (3.26)	t=.26 df=32	.79
Positive and active engagement in life	14.9 (2.96)	14.1 (3.52)	t=1.26 df=32	.26
Emotional distress	13.3 (3.98)	13.7 (4.50)	t=25 df=32	.80
Self-monitoring and insight	17.4 (2.62)	17.6 (4.35)	t=.85 df=32	.39
Constructive attitudes and approaches	15.4 (2.66)	14.8 (3.16)	t=.22 df=32	.82
Skill and technique acquisition	11.5 (2.20)	14.8 (3.16)	t=.85 df=32	.55
Social integration and support	14.8 (2.77)	14.4 (3.50)	t=.85 df=32	.89
Health service navigation	15.0 (2.44)	15.1 (3.36)	t=.85 df=32	.58

AHGP-Aussie Heart Guide Program, T1-time period one (questionnaire administered pre AHGP), T2-time period two (questionnaire administered post AHGP),  $\overline{X}$  -mean score, SD-standard deviation, df-Degrees of freedom, heiQ-Health Education Impact Questionnaire.

# **Summary**

This chapter reported the quantitative results of this study and incorporated information concerning patient recruitment, a description of the characteristics of the sample and the patient outcome results. This chapter firstly reported the clinical characteristics of the sample and demonstrated no meaningful differences between AHGP completers and partial completers. However, small patient numbers may have influenced the results. Five instruments were used to collect data over two different time periods; at baseline (pre AHGP) and at the completion of the AHGP (approximately six to eight weeks post hospital discharge). All instruments except IPQ-R had good internal consistency and reliability and demonstrated improvements in anxiety (but not depression), moderate exercise and HRQOL. The IPQ-R provided

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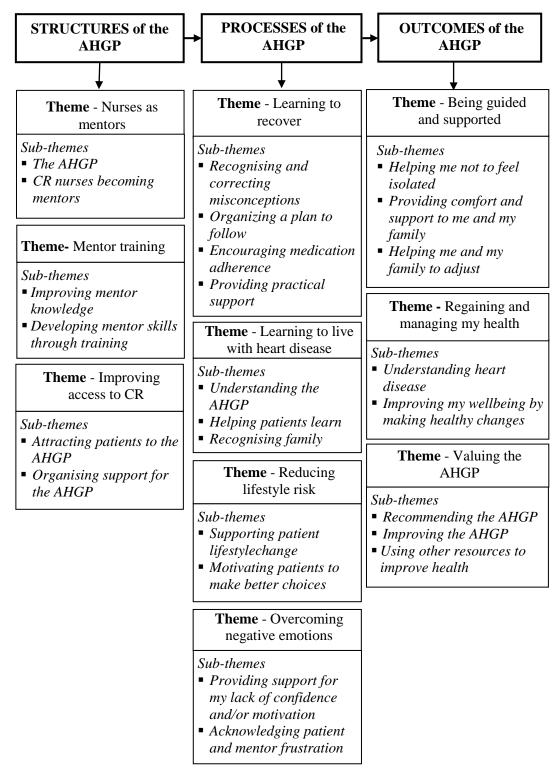
limited information because of its poor reliability, relating to the perceptions of patients relating to symptoms of their illness and the possible causes of their illness. The heiQ showed no significant improvements in patient outcomes after patients have completed the AHGP. A detailed discussion of these results will be presented in Chapter 7.

# Chapter 6: Understanding the structures, processes and outcomes of the AHGP

# Introduction

The previous chapter presented the results from a quantitative analysis. This chapter provides the findings from an explanation building analysis (Yin, 2009) guided by Donabedian's SPO framework (1966). In this study, data analysis followed a twostep process. The first step entailed a thematic analysis of three separate sets of data (patient interviews, mentor surveys and mentor clinical patient notes). Step two focused on an explanation building strategy commonly used in case study research (Yin, 2009). Case study data were analysed across the three data sets together to better explain the potential causal linkages between the SPO of the AHGP. It entailed reviewing, refining and then grouping all themes from the three individual data sets together under the specific headings of the SPO framework. Throughout the analysis, the emerging findings including the themes and their relationship to the data were reviewed and refined, aided by regular meetings among the research team. Patient and nurse mentor qualitative data was considered in relation to three main elements: (1) the setting for the service, health personnel and resources (structure); (2) services provided by mentors and patient interactions (process) and (3) the effect of this mentoring service on patients (outcome). Broadly, the SPO framework suggests improvements in care structures may lead to improvements in clinical processes which inturn may impact positively on patient outcomes (Rademakers, Delnoij & de Boer, 2010).

The grouping of themes and sub-themes emerging from the second step of qualitative analysis and applied to the specific headings of the SPO framework is provided in Figure 8. The findings from this additional analysis is described next and interpreted in more detail revealing new themes and some consistent findings with previously identified themes. Quotations from patients and mentors are provided in support of the various interpretations arising from the analysis of data.



AHGP - Aussie Heart Guide Program, CR - Cardiac rehabilitation

Figure 8. Themes and sub-themes emerging from the second step analysis of data and grouped under SPO

#### **Structures**

Three structural themes emerged from the second level step in the analytic process: (1) nurses as mentors; (2) mentor training; and (3) improving access to CR.

#### **Nurses as mentors**

The first structural theme, nurses as mentors, provided mentor insights concerning what impact the AHGP had on them as CR nurses and their new role as patient mentors providing patient centred care after hospital discharge. It encompassed the following sub-themes *the AHGP and CR nurses becoming mentors*.

#### The AHGP

Mentors welcomed the opportunity to trial a new model of CR care that had to potential of delivering ongoing care to cardiac patients in their homes. Mentors expressed confidence in the new program:

It's an evidence based, validated program from overseas that was updated to make it relevant for Australian patients. This format has been well received in other countries, is very cost effective because it is largely voluntary (mentoring aspect) and the patient resources are relatively inexpensive compared with hospital treatments. (Mentor # 1)

How the AHGP was presented to them as a model of CR also impressed some mentors. One mentor wrote "The training was well presented, led by an expert in behavioural medicine and the group participation was good. The training allowed all mentors to be "on the same page" with resources and the aims of the program." (Mentor #5) Most mentors found the AHGP provided them with new skills and experiences. Some liked the freedom a new program gave patients in terms of "having a choice" of program instead of usual care if they could not attend a group based CR program. Other mentors simply saw the new program as "new skills" to be learned. One mentor said "The AHGP introduced CBT which was completely new for me. I also had to learn to communicate more effectively over the phone which is a new skill in itself. "I have now a better understanding of peoples needs." (Mentor #4)

#### CR nurses becoming mentors

From the findings, it was apparent that mentors developed some insight about their new role by reflecting on their relationships with their patients during their recovery. Initially mentors believed that mentoring was simply an extension of what they already did as CR nurses in hospital. However, in time mentors found they had moved away from their normal work culture of presenting information and education to patients. Previously in their roles as CR nurses, it was then up to patients to "do the right thing" if they wanted to recover. The experience of relationship building with patients and the satisfaction of observing them making their own decisions about their care and meeting their health goals in their own homes, provided new meaning for mentors. One mentor wrote on the mentoring role:

Being friendly rather than overtly professional, like the us and them approach was different for me. Operating on their [the patient] level, but with professional advice and courtesy was important. When giving professional advice and support you have to gain people's trust. Showing patient's they matter, their concerns are important and that you are there for them after they leave hospital really helps. (Mentor # 6)

The findings confirmed that mentors not only believed in the development of their new role, they valued the new skills that came with learning to be a mentor. One mentor wrote "Initially the new model of care [AHGP] was a bit of a barrier. However, as a practitioner it was important to commit to making the program work. The benefits of this model are important to patients and CR practice." (Mentor #2)

In terms of how mentors believed their new role of mentor had changed or supplemented their previously existing nursing practice, there were a variety of responses, including the development of new skills associated with mentoring, increased autonomy and recognition of the issues patient face when transitioning to after hospital care:

The new role was about supporting clients who were unable to attend or not interested in attending a group setting for cardiac rehab. Being a mentor improved my ability to project and remain a positive role model when patients relapse and to keep trying to motivate them. (Mentor # 5)

The implementation of the AHGP signalled a departure from normal nursing practice for all mentors but also provided new knowledge for in terms of the mentoring role. One mentor said:

The mentoring process made me work more autonomously with patients. It made me think outside the square and at times I felt vulnerable because while you are wanting to help patients make decisions and solve problems themselves, it's hard not to jump in and say Mr X, you need to do this or this might keep happening. (Mentor #6)

Although some mentors found their new autonomous role as mentors difficult at first, due to work load constraints and sometimes a lack of perceived support at an organisational level, most mentors agreed that it was rewarding to help patients recover in their own homes:

It was nice to see how happy they were at having someone interested in their welfare post discharge. The experience of mentoring has widened my knowledge and the new skills I have learned will now also be used with the wider community of hospital patients. (Mentor #1)

### **Mentor training**

The second structural theme, mentor training, acknowledged the specific training CR nurses undertook to deliver the six-week program to patients and develop understanding about the theoretical and practical aspects of the home based CR program. The provision of training was included in the program to improve mentor knowledge about CR, the AHGP, PCC and discussion relating to developing the role of mentor. Mentors suggested a strong knowledge base of cardiac anatomy and physiology, cardiac disease processes, risk factor analysis and experience in all aspects of cardio-rehabilitative care was needed to deliver the program to patients. Mentors believed the additional AHGP training provided them with the skills needed to provide information, support and guidance to patients recovering from MI. Mentors acknowledged the contribution of additional AHGP training and mentoring experiences made in expanding and complimenting their basic knowledge of CR. The AHGP training provided new insights regarding the importance of working collaboratively with patients to improve their heart health through lifestyle behaviour modification.

Some mentors found the mentoring role difficult to engage with at first because PCC and CBT which underpin the AHGP represented a new approach requiring a change in work culture. The theme mentor training, encompassed the following sub-themes improving mentor knowledge and developing mentor skills through training.

#### Improving mentor knowledge

Most mentors thought the specific training associated with the AHGP expanded their CR knowledge and adequately prepared them to implement the AHGP. One mentor said:

The training demonstrated a new pathway from hospital to home and beyond. It showed mentors what to do, how to do it and the teaching resources available. Having someone to ask questions and get help with problems was good. (Mentor #2)

Although mentors participating in the study were experienced CR nurses many agreed that the AHGP training and mentor-patient experience enhanced their learning in several important ways. For example, it provided them with new knowledge about CBT and program specific strategies that could be implemented to assist patients to achieve their health goals. This included information relating to the importance of correcting patient misconceptions regarding heart disease, promoting patient coping actions and strategies to engage patients with low confidence in the program by rewarding positive lifestyle behaviours, and developing motivational interviewing and collaborative goal setting skills. Mentors gained valuable insights specific to how the mentor role differed from their normal duties as a CR nurse.

It was important for mentors to suggest ways the mentor training and adaptation to the new role could be improved. With some mentors finding the rigours of mentorship exhausting at times, more in-depth training in the future was advocated. According to mentors, more theory and practice sessions concerning CBT and ongoing mentor support for less experienced CR practitioners may equate to improvements in new recruitment and the retention of others. Future training should involve current mentors who would be well placed to provide accounts of their experiences gained through the mentor-patient relationship concerning "the journey" patients undertake when transitioning from hospital to home; "Future improvements should include the

opportunity for trained mentors to meet and discuss implementation, use and techniques to improve skills at one month after workshop." (Mentor #3)

#### Developing skills through training

From the data, most mentors were satisfied with the level of training provided for the implementation of the AHGP with one mentor suggesting; "the training was strength of the program." (Mentor #1) However, though the majority of mentors found their prior CR knowledge, experience and AHGP training prepared them for their new role as mentors, some found aspects of some of the training inadequate. There was general agreement among mentors suggesting that in terms of developing the mentor role, follow-up support for mentors to discuss mentoring aspects of the AHGP would have been welcomed. One mentor suggested; "Future improvements should include the opportunity for trained mentors to meet and discuss implementation, use and techniques to improve skills at one month after workshop." (Mentor #3) This suggests that mentors may have developed ideas about the mentoring role during the program and as they became more experienced as mentors wanted to discuss their findings further. More indepth training in CBT, interactive role playing sessions (preferably with patient volunteers), telephony skills and the provision of continuing mentor support for less experienced CR practitioners was recommended by mentors:

...more preparation and training may be needed to adequately prepare mentors for the role. It was actually very hard work especially as you travel the highs and lows with patients as they recover. (Mentor # 6)

Although a small number of mentors did not think their new skills provided through training adequately prepared them for their new role, this was not reflected from patient descriptions where patients commonly indicated a high level of satisfaction in terms of mentor knowledge about the AHGP, treatment and CR care. One patient commented; "she [the mentor] settled me down, got me in to a routine when at home. She answered my questions honestly and outlined the program and what I had to do when I went home." (Patient #2)

## Improving access to CR

The third structural theme, improving access to CR, suggests the AHGP was a viable option to access CR for patients who live remotely from hospital based CR services. Despite both patients and mentors believing the AHGP improved access to CR, several important organisational issues appear to have impacted on recruiting patients to the AHGP and therefore, may also impact on the future availability of the AHGP. Two sub-themes concerning improving patient accessibility to CR emerged from the data, attracting patients to the AHGP and organising support for the AHGP.

#### Attracting patients to the AHGP

In terms of CR service provision, both patients and mentors believed the AHGP improved access to CR. Most patients were aware that in Tasmania, CR services were previously only available as outpatient programs and welcomed the opportunity to receive CR in their homes if they were unable to commit to a hospital based CR program:

I think the whole program helped me a lot as I would not have gone back to hospital for rehab. (Patient #1)

Mentors also believed the AHGP improved CR access for Tasmanian patients, especially those living in regional areas because patients used and completed the AHGP. This suggests mentors thought if patients like a program and it meets their expectations they are more likely to want to use access it.

Patients enrolled in the program were able to avoid long travel times. It was good that patients could choose this program over the normal information given out at discharge. (Mentor #1)

Some mentors believed that the AHGP lacked support in the clinical domain despite hospital management approving the program's use in the clinical area. Collaboration between mentors and other health care professionals including other nurses was found to be at times lacking and this may have directly impacted on some patients enrolling in the program. According to mentors, there were occasions when cardiology staff did not actively encourage patients to join the AHGP and this may have impacted of attracting some patients to the program. One mentor said "some doctors did

not seem to support the program. I hardly ever saw evidence of doctors explaining the positive effects of CR to patients." (Mentor #6)

## Organising support for the AHGP

According to mentors, communicating the aims and benefits of the AHGP to all relevant stakeholders prior to the program's implementation may have improved cooperation between various stakeholders and general support for the program. Promotional efforts may have enhanced participant recruitment. One mentor said, "a need exists to advertise the program more widely for health practitioners to gain a better understanding of the goals of the program." (Mentor #2) Mentors also described occasions when they felt they were too time poor to conduct lengthy patient interviews because of their other roles and priorities and the early discharge of patients following coronary interventional procedures. Some suggested that because mentors felt unsupported at times, some mentors may not have been as motivated to recruit patients into the AHGP, especially when faced with heavy work schedules. One mentor stated "Workloads, time limitations and the initial adjustment of introducing a new model of care sometimes impacted negatively on recruitment." (Mentor #5)

Mentors were also concerned that future AHGP availability could be adversely affected by governance and resource issues. These include the administration of the program, the development of a competency based mentor program (to train future mentors) and develop funding strategies to pay for the audiovisual resources sed in the AHGP. In recognition of these issues one mentor said, "A potential weakness of the program is the expense to widen its use and future governance would need to be organised for future mentor preparation" (Mentor #2). Some patients also stated they hoped the AHGP would continue to be available for patients who live remotely from hospital. One patient stated "My mentor was important to me as she was a good listener. I hope that the program is able to continue." (Patient #2)

## **Processes**

Four process elements emerged from the findings following a second level analysis of the data: (1) learning to recover; (2) learning to live with heart disease; (3) reducing lifestyle risk; and (4) overcoming negative emotions.

## Learning to recover

Learning to recover represented a common thread for many patients diagnosed with MI. Patients experienced a wide variation of emotions when admitted to hospital following a MI and this theme signifies the point in time where they realise they had survived a critical event and needed to think about their future. Learning to recover appeared to signal the belief by patients that survival from serious illness was possible. Four sub-themes; recognising and correcting misconceptions, organising a plan to follow, encouraging medication adherence and providing practical support occurred collectively during hospitalisation and after discharge and signal the foundation of the mentor-patient interaction.

## Recognising and correcting misconceptions

Mentors found misinformation surrounding the causes and treatment of MI often befuddled patient perceptions, potentially impacting on recovery. In the hospital setting mentors routinely checked for patient understanding concerning the risk factors known to contribute to CHD. One mentor commented:

A patient's understanding deficit on what has occurred needs to be acknowledged early while in hospital as they often have misinformation concerning the causes attributable to heart disease. Misconceptions need to be corrected before patients can learn to move forward and adopt the central role in their own health. (Mentor # 7)

To promote patient understanding of CHD, its treatment and management, mentors routinely assessed patient knowledge about CHD and corrected misconceptions to prevent further disability or delay recovery. From this point mentors worked with patients to design and implement a recovery program for patients.

#### Organising a plan to follow

Mentors suggested that it was important as CR nurses to develop a recovery plan to provide patients with structure and direction in readiness to transition from hospital patient to undertaking self care in their homes. According to the patient data, it was common for many of them to be overwhelmed by the hospital environment and some found it difficult to comprehend what they need to do to in terms of their recovery. One patient said about their time in hospital:

I felt safe in hospital though everything was a bit of a mystery to me. Everything was very rushed and I just did what I was told. Doctors told me 'this is what we are going to do, do you understand, sign this, see you later' type of stuff from them did not help much. (Patient #3)

Mentors thought hospitalisation was stressful for most patients they encounted. Mentors believed a highly individualised plan, designed in collaboration with the specific needs of the patient, often helped reduce the high level of stress encounted and improve health outcomes for patients. Providing a continuum of care for patients recovering from MI was a priority for mentors; "I think being available to them, especially in the first week or two post discharge is really important. This reduces anxiety and helps them get on with recovery." (Mentor #6) Supporting their transition from hospital to home was also important to patients:

She helped me get ready to leave the hospital and told me what I had to do to get better, and what to do each day. She put stuff in my diary so I would not forget what I to do. I'm getting on a bit and I forget things." (Patient # 8)

#### Encouraging medication adherence

Mentors identified the importance of encouraging patients to adhere to their medication regimens during their recovery. Mentors ensured that the correct use of medication was a priority in the patient's plan of care. One patient said, "She [the mentor] organised my medications so I knew what to take when I got home." (Patient #10) According to mentors, failure to take prescribed medications could potentially lead to the development of dysrhythmias, thrombosis of implanted stents and heart failure and severely delay patient recovery. Mentors ensured that patients understood their medications, why it was necessary to take them, how to safely store medications and how to treat symptoms with medications safely. Mentors also found some patients had misconceptions regarding the importance of medication taking that needed to be corrected to promote compliance. One mentor recorded the following observation about medications in her clinical notes:

He mentioned that he has been getting some discomfort in the chest and also that he has been having regular headaches since leaving hospital. He thinks Imdur causes headaches and has stopped taking it. I suggested he contact his doctor urgently to get further advice as he may be getting chest pain from not taking the drug. (Mentor # 5)

#### Providing practical support

Responses embedded in the data suggested patients wanted to know what they had to do to get better and welcomed mentor efforts to help organise a plan of care for them in terms of their recovery. Several patients stated they valued the practical support provided by their mentors in terms of their suggestions concerning their activities of daily living as well as the psychosocial support to combat patient feelings of anxiety and fatigue. One patient said "...my mentor cared about me and said if I worked hard at improving some things like regular walking, giving up the fags etc and looking after myself better, that I should have a full recovery." (Patient #3) Knowing that their mentor was available to assist them especially after discharge from hospital, helped many patients transition successfully from hospital to home. One patient said:

...the contacts with the mentor at home kept me on track...when I got home I was 'down in the dumps' a bit. I think apart from giving me the facts about what I needed to know and do, she settled me down and got me in to a routine. (Patient # 4)

## Learning to live with heart disease

The second process theme, learning to live with heart disease, appeared an essential component of patient recovery. Mentors found patients commonly perceived MI to be an acute event rather than a chronic disease. Patients and mentors both agreed that understanding the chronicity of CHD assisted patients to adhere to their recovery plans, medical treatment and take a greater responsibility concerning managing their care. The data suggested that mentors thought a major function of the AHGP involved the provision of education and self help strategies to enable patients to lean to live with the chronicity of CHD and improve their health through lifestyle modification. The theme learning to live with heart disease encompassed the sub-themes of *understanding the AHGP*, *helping patients learn* and *recognising family and the support of others*.

#### Understanding the AHGP

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Patients suggested mentors ensured they understood the aims of the six-week home based CR program and their responsibility in terms of reading the workbooks and using the diary, relaxation and other educational materials. Most patients found the program resources easy to understand and could ask questions relating to the materials as needed with their mentors:

I found the books really good to read. I had some questions after reading the books and my mentor was able to answer those questions when we spoke on the phone. I have the books and can get them out from time to time to make sure I am on track. (Patient # 2)

Data from the patient interviews and mentor clinical notes indicated that family members who did read the AHGP resources found them beneficial in terms of clarifying how they could provide patient support. One mentor wrote in the clinical notes "...used the interactive CD Rom and read through some of the workbooks with partner. Found the resources very informative, establishing a plan to exercise together and eat healthier meals." (Mentor #2) While a number of patient's families took time to read the programs resources, some spouses failed to do so even after encouragement from mentors "...partner discussed some issues with me as she is anxious about him doing too much. I encouraged her to read the workbook specially designed to help family." (Mentor #7)

Mentors indicated that central to the role of mentor was the need for them to deeply understand all aspects of the AHGP including the various cognitive behavioural techniques that underlie the program. In consideration of learning about the AHGP one mentor wrote:

It was important to know the program and resources in-depth and to be able to apply the principles of CBT to patient behaviour under practical situations. Apart from understanding about CHD, the program is about changing lifestyle behaviours (Mentor # 6)

The data also suggested that program knowledge gained from understanding the operationalisation of the AHGP allowed mentors to check for patient understanding after reading the resources and helped mentors to gauge patient progress when contacted by telephone. Most patients found the written and audiovisual resources helpful. One patient stated:

I found the books really good to read. I had some questions after reading the books and my mentor was able to answer those questions when we spoke on the phone. I also think the reading books should be made available to all patients having a heart attack. I have the books to keep and can get them out from time to time to make sure I am on track. (Patient # 1)

In common with patient responses about the program resources, mentors believed patients thought the resources were easy to understand:

The program resources represented a useful format for certain patients as the resource was largely pictorial, aimed with a sense of humour, but contained all the need to know messages about their cardiac health. (Mentor # 4)

#### Helping patients learn

Helping patients to learn about CHD and its ongoing management remained an important function for mentors even though the program's audiovisual resources provided patients with education. According to one mentor "...being able to adapt the program to suit the individual person, and tailor it to suit the habits and interests of the individual" (Mentor #7) was an important factor in helping patients want to engage with the program and their prospects for recovery. Mentors regularly checked for patient understanding concerning the resources used in the program by asking relevant questions about their care and week by week progress. Working collaboratively within a PCC framework meant that mentors could assist patients with day to day strategies to help them solve problems or issues relating to their recovery.

#### Recognising family and the support of others

From the data, patients thought it was important for mentors to not only care for them but also support their immediate family. Some patients found their family were often overwhelmed by the "busyness" hospital environment and the distress associated with having a seriously ill partner or family member in hospital. One patient said about the impact of her mentor on her partner:

My partner was really upset. He thought I could die at any moment. I had to send him home because he was going to pieces. Seeing this stress and how my partner was basically ignored by the doctors,

she [mentor] took him away and spent a good while with him discussing everything and going through the program and recovery with him. This really turned things around for us. He is not really a worrier, it was just the shock of maybe me dying at 45, I think. (Patient # 5)

Mentor data from surveys and their clinical notes acknowledged the importance of support networks for patients during their hospital stay and after discharge from hospital. They included when possible spouses or partners in patient education and the planning of care post discharge. Mentors were particularly mindful when patients lived alone or were isolated from community and tried to find ways to support patients especially after normal working hours. One mentor wrote in the clinical notes:

A friend is helping him cut wood for his fire and has had some visitors this week. Good for his social interaction as he lives alone and cannot drive the car yet. (Mentor # 2)

## Reducing lifestyle risk

The third process theme, reducing lifestyle risk, identified the importance of patients understanding which lifestyle behaviours may have contributed to their CHD. Some risk factors attributed to heart disease are modifiable and mentors assisted patients in hospital to identify which risk factors they could modify and to develop lifestyle strategies to reduce their risk of future events. The theme was considered important by both patients and mentors. However, some patients found it inherently difficult to change some lifestyle behaviours. Two sub-themes were central to the theme reducing lifestyle risk; *supporting patient lifestyle change* and *motivating patients to make better choices*.

#### Supporting patient lifestyle change

Mentors believed supporting patient efforts to change lifestyle behaviours that may have impacted on their development of CHD to reduce their risk of future cardiac events was an integral component of their role as mentors. Mentors believed some patients thought they had recovered well from MI if they could regain their previous health. Thus, recovery for these patients could be achieved independent of whether they had made changes to their lifestyle. Other patients understood the rationale for reducing

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modifiable risk factors associated with CHD. One mentor wrote about her patient's goal of reducing stress:

Patient is looking in to ways of managing stress better. She says much of it comes from others. Strategies include – trying to say no to other people's demands more often, communicating needs to others, relaxation through deep breathing, bathing, novel reading and time out from busy schedules. (Mentor # 3)

Despite educational messages from the AHGP resources and mentor encouragement concerning cardiac risk factor reduction, a small number of patients found it difficult to comprehend the need to make lifestyle changes. One patient said:

"...because I am my wife's carer so I did not really have a lot of time to do any rehab. I basically just did what I normally do and gradually became more confident to do more. She [the mentor] did ring to check up on how I was doing which was thoughtful. (Patient # 9)

According to mentor clinical notes, supporting patient efforts to undergo lifestyle change to reduce the risks of future cardiac events contributed to a large proportion of their work.

#### Motivating patients to make better choices

Mentors appeared to support the suggestion that CHD is largely a preventable disease due to its link with risk factors such as sedentary lifestyle, smoking and poor dietary habits. Helping motivate patients to make better lifestyle choices was important to mentors. One patient said about her mentor's influence "She said if I worked hard at improving some things like regular walking, giving up the fags etc and looking after myself better, that I should have a full recovery." (Patient #3) Once prevention strategies were developed in conjunction with patient expectations, a critical part of the mentor role was to support patients by sharing their knowledge, closely monitoring patient progress and providing patients with encouragement and positive reinforcement. Mentors recognised that motivated patients were generally easier to support than others in terms of making healthier choices in relation to their lifestyle:

When giving professional advice you have to gain people's trust. Showing patients they matter, their concerns are important and

that you are there for them really helps with getting them motivated to try and change unhealthy habits. (Mentor # 6)

## Overcoming negative emotions

The fourth process theme, overcoming negative emotions, suggests that some patients and mentors experienced negative emotions during the AHGP. From the data, it appeared that a small number of patients experienced emotions of ambivalence towards having to make changes in their lives, anger, frustration and some lacked motivation. Mentors considered these emotions had the capacity to negatively impact on the recovery of some patients. Mentors also found assisting patients with negative emotions at times challenging and frustrating mainly because they felt unprepared in terms of their training to assist patients overcome emotions such as ambivalence or frustration. The theme overcoming negative emotions encompassed two sub-themes; providing support for my lack of confidence and/or motivation and acknowledging patient and or mentor frustration.

## Providing support for my lack of confidence and/or motivation

Some patients found their confidence was continually challenged during their recovery. The data revealed that unmotivated patients often found their recovery to resemble a two-step forward and one-step backward pattern. Patients who made health gains one week could relapse the following week due to any number of differing reasons. Thus, some patients became anxious, frustrated and less confident in their ability to meet their week to week rehabilitative goals or make lifestyle specific changes over time. One mentor wrote in her patient's clinical record:

He [the patient] is trying really hard to reach his goal. Have had many setbacks physically and emotionally. Increasing back pain, limiting his walking time and frequency. Encouraged him to keep going with his plan because he has had some success in meeting some of his goals. (Mentor # 4)

A small number of patients struggling with low motivation during their recovery noted mentors trying to help them. One patient said "she [the mentor] encouraged us [patient and spouse] to do the rehab program together, to motivate me I think." (Patient #2) Monitoring patient confidence and level of motivation remained an important consideration for mentors working with the AHGP. One mentor suggested "patients

themselves can be the greatest barrier to their rehabilitation with the level of patient motivation absolutely critical to success." (Mentor #7) Mentors acknowledged the task of supporting poorly motivated patients was at times challenging. Lack of motivation, according to mentors, could be linked to patient perceptions of "failure" if they thought they had not met their weekly goals or expectations. One mentor stated "I felt a feeling of frustration and failure when the person involved was unable to successfully make changes to their lifestyle. I found the experience very emotionally draining at times." (Mentor #5)

Mentors found that to promote success, in terms of assisting patients to help realise their recovery goals (such as smoking cessation, symptom relief and improving level of exercise), steps had to be taken to improve low patient confidence and motivation from the outset of the AHGP. Strategies implemented by mentors were largely determined on an individual basis in conjunction with patient identified health goals. Importantly, the goals had to be realistic in terms of being achievable and reasonably attainable on a day to day basis. One mentor wrote "in terms of this week's dietary goal, he wants to eat less red meat, decrease meal portion size by 20 %, eat more fish, consume 5 serves of vegetables per day and use less salt." (Mentor #4) Mentors referred to this process as patients "taking small steps" day by day to achieve their goals. Thus, small positive gains in goal attainment, with success being positively reinforced through mentor encouragement, in many cases led to improvement in patient confidence.

#### Acknowledging patient and mentor frustration

Data from the patient telephone interviews and mentor clinical notes identified a small number of patients became frustrated if they perceived they could not meet their health goals. One mentor wrote in her clinical notes; "[the patient] said they are feeling frustrated but is having some success with walking. She feels 'useless and confined.' I reinforced the need for positive thoughts in terms of small steps forward etc. Just 'trying' is a positive step." (Mentor #3) According to mentors, frustrated ambivalent patients commonly preferred to do things their way and in their own time. Some of these patients suggested the health benefits gained by changing certain behaviours (such as cigarette smoking and poor dietary choices) did not necessarily outweigh the personal satisfaction or enjoyment of continuing the behaviour.

Some mentors felt unprepared when faced with the prospect of mentoring frustrated, ambivalent or poorly motivated patients. Mentor anxiety concerned with not being able to assist some patients to achieve their health goals led to a small number of mentors becoming frustrated. One mentor wrote in her clinical notes; "A feeling of frustration and failure occurred when the person involved was unable to successfully make changes to their lifestyle." (Mentor #6) From the data, mentors used a variety of interventions such as providing patients with positive reinforcement, emphasising achievements and by setting realistic health goals, to help alleviate transient episodes of patient frustration. One mentor wrote:

Won't walk to improve her exercise even though she agreed to try. Says it does not interest her. I suggested some different activities she could incorporate in to her daily activities. Gave encouragement regarding her previous success in meeting some of her other goals. (Mentor # 4)

Helping patients to overcome negative emotions ultimately helped improve mentor frustration. Unfortunately, despite mentors reinforcing the benefits associated toward improving poor lifestyle behaviours, a few patients demonstrated ambivalence toward the program and made little attempt to change or modify their potentially heart disease contributing lifestyle behaviours:

Apart from becoming frustrated with a small number of patients, mentor frustration appeared to stem from two other sources. As mentioned previously, some mentors perceived that they were not supported by their organisation and some doctors appeared to show a disinterest concerning the benefits of CR and the patients themselves. Frustration also occurred for a small number of mentors because they felt professionally unprepared to cope with negative emotions during telephone meetings with patients. One mentor wrote "...talking over the phone as apposed to face to face was quite difficult. At times, I felt I could not verbalise my thoughts as effectively or with as much conviction." (Mentor #4) Mentors suggested improving support to mentors and offering advanced training in techniques and strategies used by professionals working in the field of health psychology would better prepare mentors to support patients with negative emotions.

## **Outcomes**

Four themes relating to outcomes emerged from the second level analysis of the data; (1) being guided and supported; (2) regaining and managing my health; (3) valuing the AHGP and 4) valuing the mentoring role.

## Being guided and supported

The first outcome theme, being guided and supported, reflected patient thoughts concerning the level of care provided by mentors during their recovery. From the data, many patients claimed their relationship with their mentor to be the most integral component in their recovery. They commonly described the experience of isolation and fear associated with being in hospital and how it was comforting to meet their mentor in hospital and receive their support while in hospital and after discharge. The theme outlines patient perceptions in terms of the guiding and supporting role of their mentors in assisting them to meet their rehabilitative and health needs. This theme encompassed the following sub-themes; helping me not to feel isolated, providing comfort and support to me and my family and helping me and my family to adjust.

#### Helping me not to feel isolated

Many patients described the isolation and fear they felt in hospital bought about by the uncertainty of their future, the prospects of returning home, and how they and their families might react once discharged from hospital. For these patients, it was comforting and reassuring to meet their mentor in hospital to have their questions answered about their illness and prospects for recovery. Having a mentor available to them by telephone was highly valued by patients who lived alone or had little family support.

I had several set backs and I live a long way from the city and I live alone and do not drive, so it was very good to have someone to talk to and ring if I needed help with something. It takes a week to get in to the local doctor or locum doctor, so, it was again good for my peace and mind to have her number in case I got stuck. (Patient # 11)

#### Providing comfort and support to me and my family

Data from patient interviews provided many examples of patients feeling comforted and supported by their mentors in hospital and upon returning home. One patient said "She made the whole experience bearable. I am quite elderly, and she was friendly, very caring, patient and understanding." (Patient #7) In terms of providing supportive care to patients living remotely from hospital by telephone, some patients said that while speaking over the phone was not always ideal, it was very comforting to hear a reassuring voice in the weeks following their discharge. One patient stated, "I live alone, so the nurse mentor was vital for me I think in terms of my recovery." (Patient #6) Patients also stated that mentors provided them and their families with support in terms of answering questions, checking progress, rewarding positive behaviours and encouraging patients to keep trying to achieve their health goals. Some patients commented that support from their mentor was like being coached and welcomed the encouragement from mentors to help them stay motivated after returning home. One patient said during her phone interview; "she kept me on track, especially as I was trying to give up smoking and get in to exercise which I am still doing." (Patient #1) Patients also found the concept of "working with" their mentor to overcome problems a novel and largely unexpected experience. Some patients admitted that while it was good to have a mentor to help, they realised that it was their responsibility to take action in terms of their recovery:

We talked about what I had to do to get better and then it was up to me to do it. I do not think she [the mentor] could have done more. She kept me on task and I think all I needed was the will power to make some changes. (Patient # 10)

Encouraging patients to take a central role in their health was also important to mentors "as mentors, our new role moves away from the didactic model of educating patients so clients can manage themselves and take responsibility for their own health." (Mentor #6)

Patients thought their mentors demonstrated a level of empathy necessary to understand their experience as patients and provide support. Empathy was considered an important factor by patients in developing a mutual and respectful relationship with their mentors. One patient remarked "She seemed to be interested in me as a person,

not just a job to do, if you know what I mean." (Patient #7) Holistic thoughts about their patients were also reciprocated by mentors who identified compassion, respect and empathy to be important components of establishing a trusting collaborative partnership with patients. One mentor said "empathy [for the patient] is very important and an understanding of what it's like for patients to experience a life-changing event." (Mentor #7)

## Helping me and my family to adjust

Most patients described some level of anxiety about leaving the perceived safety of hospital and returning home. Patients reflected that having a mentor available soon after discharge from hospital helped them and their family's progress through a period of emotional adjustment "The mentor helped me cope with my stress after being discharged from hospital." (Patient #2) Patients believed providing mentor support to patients soon after leaving hospital reduced feelings associated with stress and anxiety:

I felt pretty isolated after returning home from hospital. I felt safe in hospital though everything was a bit of a mystery to me. ...She got me ready for going home again. She promised to contact me in a few days of getting home to check up on me. I found that helpful because it calmed by nerves a bit. (Patient # 3)

Several patients said they felt their mentor lessened their stress prior to returning home by explaining the AHGP in detail, providing them with a plan of care to help provide some clarity and structure during their recovery, and mentors being available to them by telephone if significant issues arose outside structured weekly contact times. Included in the plan of care were strategies patients could use to monitor for setbacks (ie. what to do if they experience chest pain or other symptoms, care of wounds, graduated exercise scoring, correct storage of medicines).

# Regaining and managing my health

The second outcome theme, regaining and managing my health, highlights how the AHGP assisted patients to regain their ability to make decisions during their recovery and about their longer-term health. Many patients felt vulnerable and overwhelmed after being admitted to hospital. Apart from learning they had survived an acute life threatening event; patients commonly experienced a loss of personal

control related to them losing the ability to make decisions about their health. Two subthemes; *understanding heart disease and improving wellbeing by making healthy changes*, further reveal how patient transition to improved health occurred.

#### Understanding heart disease

Data from patients and mentors acknowledged the important role education plays in patient recovery from illness. The data established patients who understood their illness and treatment were more likely to be motivated to help themselves in terms of their recovery. One patient concluded the following after reading the AHGP workbooks "I know I have to take charge in making myself healthier. I think the heart attack was a big shock. I think you can only do so much for people, they have to get off their bum and do stuff for themselves." (Patient #13) Mentors suggested that through understanding the risks associated with heart disease, patients are better equipped to adjust to changes in their lives and this should translate in to improving their ability to self-manage their health and improve their sense of wellbeing. This included supporting patients with decision making and health goal setting to build confidence, change associated risk behaviours, self-monitor to prevent relapses and enable coping skills. Mentors further identified that by working closely with patients to develop these self-management skills, patients could improve their intrinsic motivation and potentially improve their QOL. One mentor wrote in the clinical notes about their patient's progress; "Everything is fine, feel I am back to good health. I want to continue to exercise, watch diet and not smoke. I want to keep control of my life." (Mentor #2)

#### Improving wellbeing by making healthy changes

Data from the patient interviews suggested most patients improved their sense of wellbeing during their recovery. Wellbeing appeared to be aligned with recovery from illness and for some patients making changes to their lifestyle. One patient said in relation to making positive changes:

In terms of eating better and exercising each day, I was able to lose some weight which gave me more energy to do things. After the shock of having a heart attack I am much happier now. (Patient # 6)

Although some patients were not able to meet all their heath goals, they still derived benefits such as learning about CHD and improving their coping and self

management skills after MI. Some patients said they were just happy to survive a "heart attack" and recover their previous health. Others were satisfied that the program and mentor improved their wellbeing by reducing their anxiety and stress associated with MI. One patient said, "My mentor was important to me as she was a good listener and taking the stress out of things has made me a lot happier." (Patient #13). Other patients thought the AHGP improved their wellbeing by improving their knowledge of CHD, including understanding the disease process, treatments involved and how they might take steps to self-manage their health care needs in the future. One patient suggested "the books made me realise that I should try and keep as fit as I can with lots of walking and watch what I eat etc. which is essential for general health, not just heart health." (Patient #6)

## Valuing the AHGP

The third outcome theme was valuing the AHGP. The theme was derived from mentor and patient perceptions relating to the effects of the AHGP in terms of assisting patients to recover from MI and reducing the modifiable risk factors associated with CHD. Mentor perceptions related to the impact of the AHGP on patients and their new role as mentors. The theme valuing the AHGP encompassed three sub-themes; recommending the AHGP, improving the AHGP and using other resources to improve health.

#### Recommending the AHGP

Findings from the data reflected both patient and mentor support for the AHGP. Patients were satisfied with the AHGP resources in terms of their learning and informational needs. The resources provided easy to understand explanations about CHD, its treatment and management and provided patients with examples of strategies they could use to improve their self care.

I found the books really good to read. I had some questions after reading the books and my mentor was able to answer those questions when we spoke on the phone. I also think the reading I have the books to keep and can get them out from time to time to make sure I am on track. (Patient # 1)

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While the AHGP resources helped patients understand more about CHD, most patients thought mentors were an integral component in terms of the program and their recovery from MI. Guidance, support and comfort provided by mentors during the program were welcomed by most patients:

The lady rehab nurse became my mentor and she was excellent in all aspects. She was very understanding and patient. (Patient # 10)

She [mentor] answered questions honestly and was pretty straight forward…like professional but also listened to me. (Patient # 5)

Most patients said the program helped them and they would recommend it to others. One patient stated "I am glad I was able to use it. I would recommend the program to others who live a long way from hospital." (Patient #3) One patient was unsure about the impact of the AHGP on his recovery "I am not sure how much the program helped me. I think it would help a lot of people after a heart attack. Maybe the program is not for everyone. I am not sure." (Patient #13)

Mentors were also satisfied with the resources of the AHGP and would refer the AHGP to future patients requiring CR if it was available. One mentor wrote:

I though it was a great resource for rural patients. I hope the patients felt more valued because of the one to one contact and the friendly phone calls to check how they were going after leaving hospital. A major strength of the program is that patients do not waste time or money travelling in their cars to a hospital based rehab. Also, what were patients getting prior to this model? Most patients would get no rehab, maybe a brochure and a check up with their local doctor. Some patients do not like group based rehab and this program would suit them better. (Mentor # 1)

Mentors believed the flexibility of the AHGP and its availability in terms of offering patients a choice in CR service suggested the AHGP could improve the CR access for patients who live in regional areas. One mentor wrote about the programs applicability; "Excellent for those who do not like group work or for those with disabilities. It was especially useful for those suffering depression." (Mentor #3) Mentors also identified some potential issues concerning the governance of the AHGP if it was to be offered in the future and in other states of Australia. These include the

administration of the program, the development of a competency based mentor training program and the cost of associated with running the program and its resources. One mentor considered "From where would a future program be administered and funded and how future mentors are to be trained, face to face or via the internet? The program could be expensive to introduce more widely." (Mentor # 2)

#### Improving the AHGP

Data from the patient interviews revealed that patients could not offer any major suggestions in relation to improving the AHGP. Most patients claimed they were satisfied with the AHGP including the audiovisual resources and their mentors. One interviewed patient said "I cannot think of any changes or improvements to the service. It was great and much needed especially by older people who live alone out of the city. (Patient #11) Most patients were willing to enrol in the AHGP and complete it. This demonstrated its potential to mentors as a standalone home based CR program. Mentors and patients appeared to agree on the timeline of the program, suggesting six to eight-week duration was about right.

Although mentors believed that not much needed to be done to improve the physical resources of the program they were concerned about some of the resources not being used by some patients. They found the AHGP easy to use and the incorporated checklists and standardised discharge planning procedures ensured that treatment plans were developed and implemented for all patients according to their health needs. Although all patients completed the program, a small number of patients chose not to use some of the components (such as the relaxation resources or diaries) despite being encouraged to do so by mentors. Reasons for not using some of the resources include patient scepticism regarding the benefits of relaxation or the use of diaries or a preference for "managing" their own recovery at their own pace.

Mentors found a few patients required a great deal of encouragement to use the relaxation resources on a regular basis. Invariably, some patients found the relaxation media useful where as for others, it was not for them. Similarly, with the patient diaries, some patients refused to use the diary to plan their activities other patients found the diaries helped. Some mentors acknowledged that it was difficult to assist patients with these two resources as nearly all patient contact was via the telephone and not in person. Mentors were not forthcoming with suggestions on how the resources might be

improved over and above encouraging patients to at the very least try the resources. There was a suggestion that the workbook set aside for family information was not used much. Mentors believed the resource was well received by those family members who chose to read it. They also acknowledged that greater encouragement should be provided while family members visited during the patients' hospitalisation for family members to appreciate the importance of reading the information.

In terms of improving the AHGP, mentors suggested that steps be taken to openly encourage the support of the program at an organisational level with the aim of improving collaboration between all health stakeholders. Training of future mentors was also considered by mentors to be important in terms of future program improvement. One mentor believed "It was probably too much to expect mentors to become proficient in their skills after one workshop. Follow-up sessions would have had benefits especially for mentors who may have been struggling or had ongoing issues." (Mentor #6) Mentors suggested future training should also include ongoing support using teleconferencing if face to face meetings are not possible for all mentors involved with the program.

## Using other resources to improve health

The data found mentors used a variety of resources other than the AHGP to assist patients with their recovery during the six-week program. Mentors were proactive in referring patients with complex care issues to other health care professionals. Mentors interacted with their patient's family doctor and cardiologists as needed during the program and by providing an end of AHGP description of patient outcomes. Patients with issues pertaining to their medication regimen or recurring symptomology were encouraged to seek clarification from doctors. The mentor notes provided many examples of mentors checking appointment schedules for patients and seeking updates concerning changes in their management; "Discussed weight gain with patient and he has agreed to be referred to his doctor for ongoing weight management via the program summary." (Mentor #3) Common examples of mentor referral include diabetic educators and or clinics, dietitians, physiotherapists, occupational therapists and seeking referral for psychology under GP arranged clinical care plans.

Mentors sought expertise from other health professionals if the patient was very isolated from medical services and could not travel to gain access to health services.

Patients were particularly at risk if they lived alone or without family or other social support. Under these circumstances, mentors were especially vigilant in regularly following up patients each week or more often if required. Mentors networked with local voluntary groups to arrangefollow-up after hospital care in terms of home visits and transport to health services. They also referred patients wanting to continue with a structured exercise program to walking groups and health gyms:

Patient's blood sugar level not stabilising possibly due to anxiety about using needles. Arranging a visit from diabetes support group with his permission." (Mentor # 2)

Walking with exertion scale set at 6. Wants to go to local Gym but waiting for clearance from his doctor. Have given him 'Heart moves' information as alternative to joining gym in the interim. (Mentor # 3)

## Valuing the mentoring role

The fourth outcome theme was valuing the mentoring role. It emerged from the mentor surveys and mentor clinical notes and describes the various mentor perceptions relating to AHGP outcomes and their role in the delivery of the AHGP. Insights from this theme help build a representation of how mentors perceived their work and change in work culture. Valuing the mentoring role encompassed two sub-themes; *mentor outcomes relating to the AHGP and developing the mentoring role*.

#### Mentor outcomes relating to the AHGP

Findings from the data suggested the AHGP had a major impact on the development of nurses as mentors. Mentors suggested they knew little about mentoring prior to participating in the AHGP. Although there was some discussion about mentoring during the training, mentors believed they developed their own ideas from the experience of developing collaborative relationships with patients. There were several mentor outcomes relating to the impact of the AHGP on patients and on them as nurse mentors. One mentor said about their mentoring experience "Being able to provide honest and accurate answers to questions and adapt the program to suit the individual person, and tailor it to suit the habits, interests and needs of the individual." (Mentor #3)

They were also satisfied as health practitioners when patients could implement strategies to maximise their health outcomes. One mentor believed; "Satisfaction occurred when clients where able to make healthy choices and make changes to their life styles that they were able to commit to and maintain." (Mentor #6) Findings from the data indicated that developing the mentor role helped nurses understand more completely the patient experience of hospitalisation and their transition to home and subsequent recovery from illness.

#### Developing the mentor role

Data from mentors provided new insights concerning how their role as mentors evolved during the AHGP and their interactions with patients. From the findings, developing the mentor role improved the level of nursing autonomy concerning the after-hospital care of cardiac patients. Positive feedback from patients and mentors provide some evidence to suggest the viability of mentoring not only for home based CR but possibly in terms of other similar chronic disease management systems.

Mentors described attributes they thought were important for their role as mentor.

Mentors believed their previous knowledge and experience of CR, understanding of risk factor management and developing a meaningful therapeutic relationship with patients was essential to develop and engage with the mentoring role. In terms of care provision, mentors thought having a real interest and passion in helping patients was important to gain trust and respect in developing patient rapport. Being a good communicator, positive in outlook and encouraging in manner, motivating, empathetic and supportive in terms of acknowledging patient progress and success during their recovery were also considered important attributes of being a mentor:

Knowledge of adult learning principles, cardiac rehabilitation knowledge and experience and knowledge of the program. Having lots of examples of things people can do to help themselves. You need a large kit bag of ideas. (Mentor # 6)

You need really good communication skills. Showing patients they matter; their concerns are important and that you are there for them really helps. (Mentor # 1)

The AHGP appeared to help develop mentor perceptions about their new role as mentors. From the findings, the experience of mentoring appeared to improve mentor communication skills and their knowledge and skills concerning the benefits of CBT and using the PCC model to underpin their nursing care. One mentor suggested that an essential part of their role was "...to be comfortable enough with the program, to move away from the didactic model of educating patients so clients can manage themselves and take responsibility for their own health" (Mentor #6). Mentor surveys and clinical field notes identified that while mentoring could be mentally taxing, there were intrinsic rewards associated with the experience of mentoring patients. Generally, most mentors expressed satisfaction when they felt they had contributed to their patient's health outcomes:

The mentoring aspect has the potential to be rewarding professionally. (Mentor # 3)

Satisfaction for me occurred when patients expressed their appreciation. (Mentor # 4)

Mentors concluded the mentor role changed their normal work culture of education and information provision to a role more closely aligned with assisting and providing support for patients recovering post MI beyond the hospital door. Assisting patients to regain their physical and psychosocial functioning after discharge from hospital and then to monitor and support patients in their efforts to achieve lifestyle behaviour change was important to mentors. Evaluating their care in terms of the successful recovery of patients during their post hospital care and modification of unhealthy lifestyle behaviours was also seen as a departure in terms of hospital work and their development as mentors. The data revealed that providing rehabilitative care to patients was probably easier for mentors than supporting patients in their efforts to improve their health (and reduce their risk of further events) by changing lifestyle behaviours that may have contributed to CHD:

With mentoring, you travel the highs and lows with patients as they recover. Keeping some patients enthusiastic and motivated to achieve their goals they stated they wanted to achieve was actually hard work. (Mentor # 6)

Mentors provided suggestions concerning what they considered to be positive and negative aspects of the mentoring role. Most mentors believed the AHGP and the development of the mentoring role improved their knowledge and skill set as CR nurses and their ability to work autonomously as health care professionals:

Mentoring helped me develop telephone mentoring skills, including active listening, open questioning, re-phrasing, positive feedback to patients, SMART goal setting, the use of diary to plan, monitor and evaluate patient goals and motivational interviewing. (Mentor # 4)

The mentor role enabled nurses to develop new experiences in terms of assisting patients transitioning from hospital to home. One mentor said about adopting the mentor role "The program helped me develop some new skills. It introduced me to CBT. It helped me understand the patient "journey" beyond the hospital door." (Mentor #1) Other mentors suggested that mentoring made them more aware of the issues that impact significantly on patient progress during their recovery. Working closely with patients to identify problems and assisting them to overcome them in practice was viewed as a positive outcome of the mentoring role. In terms of negative aspects attributed to mentoring, some mentors perceived a lack of support in terms of what they were attempting to achieve at an organisational level and about supporting each other clinically. Most mentors also thought time constraints were a barrier and may have impacted on the delivery of the AHGP. Mentors believed more specialised training and organisational support was warranted in terms of improving the home based CR service.

It would have been helpful to have provided more support for the mentors. (Mentor # 3)

I needed more time to become proficient with the program, more patients to work with and have the hospital support at an organisational level. (Mentor # 4)

# **Summary**

This chapter provided the findings from an explanation building analysis of case study data guided by the SPO framework of health care quality. Thematic analysis was undertaken across three sets of data including, patient telephone interviews, mentor surveys and the mentor clinical (patient) notes to provide insights in relation to the evaluation of the AHGP as a home based CR program for rural patients. New elements associated with the framework have been described in association with the themes and sub-themes derived from the data. In terms of structures, three elements were identified; nurses as mentors, mentor training and improving accessibility to CR. Processes identified from a second level analysis identified four elements, learning to

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recover, learning to live with heart disease, reducing lifestyle risk and overcoming negative emotions. In terms of outcomes, four elements were identified; being guided and supported, regaining and managing my health, valuing the AHGP and developing the mentor role. This second level step in analysing the qualitative data from this study has identified mentor data to be richer especially in relation to the structure and process elements compared with outcome elements that were dominated by patient data.

The findings suggest that both structures and processes were important in determining patient outcomes and the applicability of the AHGP as a potentially viable home based CR program for rurally located patients recovering from MI. The findings also provided some explanations concerning the impact of the AHGP had on the development of the mentor role used to deliver the program. Although patients and mentors generally valued the AHGP, mentors were concerned that some structural issues need to be reconciled prior to further development of the AHGP. The findings from this second step of a two part qualitative analysis plus the statistical improvements reported in the patient outcomes chapter suggest the AHGP has the potential to meet the expectations of patients and mentors using the program.

Chapter 7 presents a discussion of the findings of this study including their relationship with the current research literature. It includes the limitations of research and recommendations for clinical practice, education and future research. Conclusions are drawn regarding this study including the context in which it contributes to new knowledge about home based CR in Australia.

# **Chapter 7: Discussion and Conclusions**

## Introduction

In global terms, more people die from CVD than any other condition (WHO, 2015) and in Australia, CHD remains the leading cause of death with 13.6% of all registered deaths in 2012 (ABS, 2015). The elderly (Lavie et al., 2011), women (Grace et al., 2016), people from rural and remote areas, from an ethnocultural background (Findlay, Oh & Grace, 2017) or with low socioeconomic status (ABS, 2011; Graversen et al., 2017) are less likely to attend than other groups. Distance and cost of travel make it difficult for some patients to attend CR programs (Van Engen-Verheul et al., 2013), so telehealth and other innovations such as home based CR programs (Clark et al., 2015) have been developed to improve patient CR participation (Ski et al., 2015; Gallagher & Neubeck, 2016). The purpose of this research was to evaluate a home based, mentor supported CR program in regional Tasmania, using the Donabedian SPO framework for health care quality (Donabedian, 1966). This chapter discusses the study findings using the SPO framework and provides an update on the AHGP. Following this, the limitations of this study, the implications and recommendations for nursing practice and future research are discussed.

## **AHGP Structures**

In SPO, the term 'structures' refers specifically to the setting in which care takes place and include material, human and organisational resources (Donabedian, 1988). In this study, the three prominent structural components were the AHGP, nurses as mentors, and organisational infrastructure and support for the AHGP. Each of these structural components are discussed.

# The Aussie heart guide program

Though home based CR remains underutilised in many other countries (Mampuya, 2012; Shanmagasegaram, 2013), it has been found to be an attractive option for some patients who cannot travel to attend a hospital based CR program but still wish to access (Grace et al., 2008) and complete a CR program (Clark et al, 2015). Patients in this study believed they would not have completed any form of CR if they had not been offered a choice to undertake the AHGP. Other research has discovered that women,

older patients, those with significant comorbities, come from low socioeconomic backgrounds, live rurally or in social isolation are more likely to die within five years of MI (Roger et al., 2011). The study demonstrated that if the AHGP had not been available to them, patients would not have accessed a CR program. As a new model of home based CR, the AHGP clearly improved the uptake of patients usually not able to access CR due to their distance from hospital based CR services.

Patients were very satisfied with the resources used in the program. This finding compares favourably with other research using home based CR resources where written self-help resources provided patients with explicit guidance in terms of their rehabilitation post discharge (Lewin et al., 1992; Linden, 1995; Lacey et al., 2004; Jones, Greenfield & Jolly, 2009). Patients suggested the AHGP was of personal value to them because the audiovisual resources helped them to understand the benefits associated with completing a CR program. In keeping with established Australian CR guidelines (Woodruffe et al, 2015), the AHGP provides patients with information about their cardiac illness, psychosocial and vocational counselling, treatment of symptoms, activity prescription and risk factor analysis and lifestyle behaviour modification.

Although patients and mentors were satisfied with the AHGP resources in general, a small number of negative aspects were reported in the findings. A few patients said listening to relaxation resources was not for them and suggested the need for further exploration in terms of alternative resources to promote relaxation. Mentors found that some patient's spouses/carers were not interested in the workbook specifically designed to inform, educate and encouraging family involvement. This contrasts with other research highlighting the importance of spousal and other support networks in patient recovery (Pryor et al, 2014). A small number of patients preferred not to use the patient diary that was designed to help them set goals and monitor their recovery. As reported by other researchers (White, Howie-Esquivel & Caldwell, 2010; Hodge, 2013), the majority of patients in this study found the diary helped them monitor their lifestyle behaviours and daily activities. A small number found using a diary was not for them.

Recently, the importance of optimising the health literacy of patients recovering from MI has come to light in Australia (Beauchamp et al., 2017). Qualitative data from patients and mentors suggests the AHGP, consisting of mentor support and audiovisual media, helped patients' understanding of CHD including what they should do about

their health condition; indicating it improved their health literacy. The ACSQH defines health literacy as "the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action" (ACSQH, 2014a, p.2). Low health literacy has been found to be common among patients (Fraser et al., 2013; van Schaik et al., 2017). Although low health literacy has been implicated with poorer patient outcomes (McNaughton et al., 2015), improving the health literacy of patients enables them to live with and manage the disease (Bell et al., 2016). Bailey and colleagues (2015) used predictive modelling to investigate the relationship between health literacy and 30 day hospital readmission after MI. They found health literacy to be a significant independent and modifiable predictor of hospital readmission for cardiac patients. From this, before patients can effectively self manage their health condition, they must first undertand CHD so they can make informed choices about their treatment and recovery path (Chen et al., 2014). The data indicated using plain language was important when communicating directly with patients. The resources improved the health literacy of patients by providing visual text that was fun, easy to read and comprehend, and a narrative approach to providing information, vignettes, pictures to summarise important messages and the use of personal stories improved the health literacy of patients in this study. The information was also motivating for patients. Most patients in this study agreed that learning and understanding as much as they could about CHD was important in terms of their recovery and understanding the importance of reducing their risk of further cardiac disease.

In this study, PCC was used to provide direction in patient care because nurse mentors in this study could work individually with patients rather than providing group based care sessions commonly utilised in hospital based CR programs. PCC engages patients through a shared decision making process that enables a stronger patient commitment to recover (Hoglund et al., 2010), promotes self-efficacy and empowers patients to take responsibility for their healthcare (Orrego et al., 2014) in terms of their culture, beliefs and preferences (Cribb & Entwistle, 2011). Despite the acknowledgement that PCC improves the patient care experience (ACSQHC, 2011) some mentors in this study found adopting PCC a significant departure from their normal work duties. This finding was in part to be expected as PCC was used to direct care for patients transitioning from hospital care to home care. There is little evidence

to suggest that PCC has been used previously to direct home based CR. According to research, the main component of PCC is the therapeutic relationship between care giver and patient. However, there remain inherent problems in measuring PCC as an outcome (McCormack & McCance, 2010; Rathert, Vogus & McClelland, 2016). There remains little guidance available in the literature concerning how best to implement PCC in the clinical domain (Groene et al., 2009; Kieft et al., 2014).

PCC has been found to be beneficial in assisting patient recovery following MI (Meterko et al, 2010: Petricek et al., 2015). Although moving away from a nursecentric model of care to one based on principles of PCC was initially difficult for some mentors in this study, Ekman and colleagues (2012) provides valuable insight regarding PCC in the context of cardiac care. They suggest it entails developing meaningful partnership with patients, understanding their perspectives and preferences and sharing in decision making (Ekman et al., 2011). Consistent with previous research that suggests PCC improves the self efficacy of patients with CHD (Ekman et al., 2012; Fors et al., 2016), and helps them adjust to the challenges associated with recovery (Fors et al., 2016), mentors in this study found a patient-centred approach improved patient confidence and ability to make decisions about their health. Adapting the core components of PCC has been found to allow mentors to use the patient narrative to direct care, share in goal setting and decision making and develop a meaningful partnership between patient and mentor (Ekman et al., 2011). This may promote patient engagement, decrease levels of stress and anxiety, and improves patient QOL of patients (Sol et al., 2011; Fors et al., 2016). Consistent with other research findings reporting patient experiences of PCC (Keating et al., 2002), mentors in this study believed gaining a patient's trust was integral in terms of developing a meaningful therapeutic relationship with patients.

The AHGP used mentors to deliver the operational aspects of the program, thus mentoring was considered a program resource. Mentors found that the AHGP and its audiovisual resources generally easy to use. A strength of the program lies in recognition that the audiovisual resources were uniform in presentation and engaging, using humour and lay language to convey explicit health messages. The program used operational guides and checklists to provide mentors with a structured approach to CR. Although the program was individualised to meet each patients needs, a structured

approach ensured that all patients received comparable advice concerning their treatment and transition to self care. These findings compare favourably with other research highlighting the use of a structured approach to identify what patients understand to be the cause of their illness to plan individualised care and maximise patient outcomes (Lewin et al., 1992; Lau-Walker, 2006; Ades, 2007; Meterko et al., 2010). Thus, because the AHGP is essentially easy to use, the program demonstrates potential for further development.

There were some barriers to AHGP implementation as identified by the mentors such as time restraints and lack of organisational commitment to implementing PCC. Consistent with this finding, other studies have shown that inappropriate staff skill mix in the clinical area and funding structures that aim to increase patient throughput significantly impact on nurses' abilities to adopt PCC (Groene et al., 2009; Rattray & McKenna, 2012; Hesselink et al., 2013). Thus, it appears that organisational barriers play a significant role in terms of mentors being able to model their delivery of CR care based on PCC principles.

Patients offered very few other suggestions to improve the AHGP when they were interviewed and were generally satisfied with the program. Some patients expressed hope that the program would be available in the future to assist other patients recovering from MI. This finding compares favourably with other research using home based CR (Jones, Greenfield & Jolly, 2009, Clark et al., 2010) and specifically, programs using the Heart Manual (Clark, Kelly & Deighan, 2011). Patients were especially mindful that usually, apart from normal discharge planning, once leaving hospital, support was often not available to patients in rural or isolated areas, a finding consistent with other research (Chew et al., 2013). Findings from the data suggest the AHGP's adaptablility to the Australian setting compares favourably with similar home based CR projects undertaken in New Zealand and in the UK (Henwood & Barnes, 2008; Clark, Kelly & Deighan, 2011).

#### **Nurses as mentors**

This study provides a detailed description of the role of nurse mentors in the AHGP including both the training they require and received and their role including the knowledge and skills they required. Previous research has not investigated the role of

nurse mentors facilitating home based CR programs in any depth, however there has been some research on nurses as mentors in other areas such as nurse training and academia. This study supports the findings of prior studies that suggest nurse mentoring patients improves job satisfaction and the transitional care experience of patients (Henwood & Barnes, 2008). One study reported nurses mentoring patients with chronic obstructive pulmonary disease in their community setting found their work satisfying when patients improved their QOL (Wood-Baker et al., 2012). While there is no universal definition of mentoring, there is evidence to suggest that clinicians who can adapt to this role can improve the patient experience (Henwood & Barnes, 2008) in terms of satisfaction of health care received (Wood-Baker et al., 2012).

This study identified that nurse mentors were valued sources of knowledge, guidance and support to patients. Patients believed that the mentoring component of the AHGP was important in their recovery in terms of preparing them for hospital discharge and supporting them in their first days of being home. The importance of supporting patients transitioning from acute care to home is well reported (Prvu Bettger et al., 2012; Cowie et al, 2014) with patients who do not receive follow-up care and support more likely to suffer adverse health outcomes (Naylor & Keating, 2008). Previous research has identified that the first few days to weeks after hospital discharge represents a critical point in terms of patient healthcare experience. Experiencing problems, feeling isolated and unable to cope with the consequence of MI can lead to adaptation issues and poor health outcomes for patients (Yilmaz & Emiroglu, 2005). Patients in this study stated that they were satisfied with the psychosocial support they received from their mentors. Thus, using nurses to mentor patients in home based CR programs, while relatively new and novel, appears to be well received by patients recovering from MI.

Feedback from mentors suggested that their training was integral in the successful delivery of the program. The need to provide a detailed training program to upskill nurses to become mentors has been reported previously with over 2,000 health care workers have been trained to provide a home based CR program in the UK (Lewin et al., 2002). Advanced training aims to upskill generalist nurses so that they can confidently take up the role of CR facilitator, mentor or case manager to assist patients undertaking home based CR (Lewin et al., 1992). Feedback from mentors in this study

suggest training was essential to help them prepare for changes distinct from their normal nursing roles. Mentors believed appropriate training must be provided by suitably qualified health professionals to adequately prepare mentors for their role, provide CR program audit and future credentialing if the AHGP is to be widely implemented in the future.

To be effective and skilful patient mentors, nurses modelled patient information and advice based on cardio-rehabilitative care principles and guidelines and by understanding all operational aspects of the AHGP. Skills relating to PCC appeared to develop with their mentoring experience. Research suggests PCC skills develop over time as nurses become more culturally aware as they experience patient encounters (Campinha-Bacote, 2011). Mentors believed their knowledge and skills concerning CR helped patients to meet their health needs through appropriate health goal setting, regular contact to review progress and positive reinforcement of patient efforts to change unhealthy lifestyle behaviours. Thus, it appears mentor knowledge, skills and experience are necessary to develop safe and sustainable transition pathways for patients.

Mentors in this study placed high value on their skills as CR clinicians in terms of providing after hospital care and support to patients. Thus, it appears mentor proficiency and keeping up to date in terms of knowledge and clinical skills are necessary to ensure standards of home based CR care and patient expectations are met. As identified by other research, mentor friendliness, knowledge and proficiency in the delivery of information relative to their individual needs was deemed important by patients in this study because it assisted patient learning, decision making and active participation in their recovery (Asadi-Lari, Packham & Gray, 2003; Jones, Greenfield & Jolly, 2009; Polikandrioti & Ntokou, 2011). Thus, patients placed considerable importance on both having a good relationship with their mentors and receiving information from them.

Although mentors were generally satisfied with the training they received to implement the AHGP, they believed they needed more intensive training to improve their competency in the areas of CBT and motivational interviewing; two techniques found to support lifestyle improvements (Mittag et al, 2006; Hanssen et al., 2007; Nekouei, Yousefy & Manshaee, 2012; Heron et al., 2016). Mentors also recognised

they lacked formal training in conducting follow-up phone meetings to assist and support patients after hospital discharge. Others have reported difficulties associated with conducting clinics or counsel by telephone (Holmstrom & Hogland, 2006). Specific training in conducting phone meetings using motivational interviewing techniques may have been of value in helping mentors to cope with some of the challenges in assisting patients by distance. Given some mentor activities are beyond the skill set of most nurses, it is evident that both training and ongoing support is required to help develop mentor skills. Thus, it is apparent that mentor training is important, and nurses need to be upskilled appropriately prior to implementing home based CR programs.

Although mentors found their new role as mentor positive, there were some limitations expressed about the increased responsibility associated with delivering the home based CR program. As identified by others, nurses can become disenchanted with patients who fail to show any willingness to change unhelpful lifestyle behaviours (Jallinoja et al., 2007). Some mentors felt personally responsible for a patient's inability to make significant improvements in their recovery and this may have led to dissatisfaction in terms of their skill set and or training. Similar experiences have been identified by other researchers whereby nurses felt they did not possess the counselling skill set needed to assist poorly motivated patients (Jansink et al., 2010). Another study reported that home visits by nurses prompted effective communication by helping nurses understand the patient's life context and priorities (Henwood & Barnes, 2008). From the findings, it is evident that mentors also need support from their colleagues and clinical networks to assist patients unable to change unhealthy lifestyles during their recovery.

# Organisational infrastructure and support for the AHGP

This study highlighted several issues relating to organisational infrastructure and support for the AHGP. Mentors believed that patient access to the AHGP may have been impacted by organisational support, system factors that may have influenced access to care and multidisciplinary involvement in the program. Similar factors have been found to influence health care efficacy by others (Williams, Byles & Inder, 2010; Mosadeghrad, 2014). Although all hospitals agreed to implement the AHGP, mentors concluded that the AHGP was generally not well supported at an organisational level.

Collaboration between mentors and other health care professionals, including other nurses, was lacking at times with mentors disappointed that cardiology medical staff often did not actively encourage patients to join the AHGP. In particular, some cardiologists appeared disinterested in the program or in the benefits of referring patients to CR. Physician endorsement of CR (De Vos et al., 2013; Ghisi et al., 2013) has been found to be a primary indicator of patient referral and participation in CR programs (Beckstead et al., 2014; Dunn et al., 2016). From this, it is apparent that physicians could do more to convince patients of the benefits associated with CR and potentially improve patient outcomes by encouraging them to access CR and adhere to prescribed treatments.

Mentors believed time constraints impacted on patient recruitment and access to the AHGP. The mentoring role associated with the AHGP did appear to increase the work load of CR nurses and mentors had to sometimes contact patients out of normal work hours and this may have impacted on their recruitment and ongoing mentorship practices. Increased workloads created obvious difficulties in mentoring more than one or two patients at a time. In other countries, personnel are renumerated for time allocated to visiting patients in their homes or for telephone based patient reviews (Lewin, et al, 1992) but this was not the case for the AHGP. Thus, findings from this study indicate authentic organisational support and stakeholder engagement must be considered a priority in terms of promoting and establishing a new and successful CR program.

In summary, several important structural components were identified from the findings of this study. Offering the AHGP to rural patients improved the uptake and completion of CR and mentors identified the importance of specific mentor training to provide them with the skills to become proficient mentors. This included the need for ongoing mentor support and training to implement a PCC approach to CR. Knowledge and skill, a positive work culture, staff workload and hospital environment were all important factors contributing to the structure of the AHGP. Generally, nurse mentors were well received by patients, who found them very informative and supportive. The nurse mentors thought they provided a good service to patients during their recovery. While their training somewhat prepared them for their new role, the PCC approach and CBT were new to them, they wanted more training to improve their practice. Finally,

because the mentorship role was not renumerated, this may have affected recruitment of patients and the mentoring process.

# **AHGP Processes**

Donabedian (1988) believed that in terms of SPO, "process" refers specifically to what is done in terms of treatment and the provision of care including factors such as the delivery of services, the therapeutic relationship, communication and shared decision making. The following discussion details what was learned from the study in terms of the various process variables relating to the delivery of care to patients by mentors in this study. The findings are discussed in relation to three general areas of the delivery of care; mentors providing individualised support, mentors providing information and education during patient recovery, and mentors helping patients to reduce their lifestyle risk behaviours.

## Providing individualised support during patient recovery

In this study, mentors met the patients in hospital and telephoned patients weekly after discharge from hospital for six weeks to provide follow-up support and guidance. Although most patients who completed the AHGP valued the advice and information, reassurance and support they received from their mentors, this study found there was a lot of variation in terms of how patients coped with their diagnosis and the range of emotions experienced during their recovery and rehabilitation. This variation has been noted by others reporting on patient reaction to CHD diagnosis (Hevery, McGee & Morgan, 2007; Petricek et al., 2015). Research has demonstrated the importance of patients being able to cope following MI (Son, Thomas & Friedmann, 2012; Kroemeke, 2016) to maximise their functional health outcomes and QOL (Fredriksson-Larsson, Alsen & Brink, 2013; Bhattacharyya, Stevenson & Walters, 2016). Patients cope better in their recovery from MI if they have well developed support networks in place (Wieslander et al., 2013) and understand what has happened to them (Madsen & Birkelund, 2016). For patients without these networks, mentoring appears to help patients at least in the short term and especially soon after hospitalisation (Junehag, Asplund & Svedlund, 2014).

Nearly all patients who completed the AHGP valued the reassurance and support they received from their mentors despite how they individually approached their rehabilitation. Patients mostly believed their mentors helped them regain their independence and ability to cope with their illness. These findings compare favourably with previous studies that have identified the importance of patients having their emotional needs met as they recover from MI (Jackson, Gregory & McKinstry, 2009; Salminen-Tuomaala et al., 2012). Other researchers have found patients equate recovery from MI with their progress toward life reorientation (Fredriksson-Larsson, Alsen & Brink, 2013) or return to a state of perceived normalcy or previous level of health (Henwood & Barnes, 2008, Simony et al., 2015). In this study, patients who confidently predicted a successful recovery needed less support from mentors compared with others who were unsure.

Studies investigating the social support of patients post MI have found those with low levels of support have a poor prognosis and higher rates of readmission and reinfarction (Barth et al, 2010; Bucholz et al, 2011; Bucholz et al., 2014). Patients in this study reported it was important for their mentors to support their family members. This view is consistent with other research suggesting the key role partners and family play in helping patients maintain their cardiac health (Gallagher, Luttik & Jaarsma, 2011; Wieslander et al., 2013; Compare et al., 2013). However, in this study, some mentors commented on a perceived lack of interest by some spouses in reading the AHGP information workbook specifically designed for them. This infers the importance of gaining the cooperation of spouses to promote better understanding of the expectations surrounding the process of CR and the importance of lifestyle modification.

Additionally, perhaps future research relating to the development of support programs for CR patients should include family involvement to explore what spouses and families need.

According to patient interview data, mentors helped patients to manage their negative emotions. Mentors found some patients required a lot of ongoing emotional support during the program. Others have reported similar findings, suggesting patients require social and psychological support in hospital and as they transition from hospital to home (Junehag, Asplund & Svedlund, 2014; Albert et al., 2015). Mentors believed emotions such as low confidence, poor motivation, ambivalence, anger or frustration impacted on the revovery of some patients and their ability to improve their lifestyle. Previous researchers report patients may experience anger, hostility, disgust, fear,

anxiety, depressive mood, agoraphobia, denial and frustration linked to change in physical functioning (Mierzyńska et al, 2010). Patient findings in this study concerning negative emotions draw comparison with other CR research (Ziebland et al., 2014; Iles-Smith et al., 2017) suggesting patients commonly exhibit fear, anxiety, depression, lack of confidence and self-blame after MI. Performing this type of emotional screening would have been difficult to complete if the AHGP had been conducted entirely by telephone. Thus, it appears that the mentor-patient interview in hospital was necessary to esure a baseline understanding data and relevant issues acted on. This further supports the need to ensure cardiac patients are screened appropriately for anxiety and depression prior to leaving hospital.

According to mentors in this study, patients with low confidence or lacking belief in their ability to make a full recovery sometimes reduced their chance of meeting their desired goals. Thus, implementing strategies to improve patient confidence remained a priority for mentors during the program. This resonates with other research outcomes suggesting that improvements in patient self care efficiacy leads to improvements in confidence and the ability to maintain lifestyle change (Sol et al., 2011; Ludman et al., 2013). Given that negative emotions have the capacity to impact on the recovery of patients after MI, it appears mentors must continually provide support to improve patient confidence and foster their ability to enact changes that lead to health impovement.

In conjunction with mentors identifying the importance of their face to face interview with patients while in hospital, mentors recognised the significance of assessing each patients level of confidence in terms of their ability to recover and cope with the chronicity of their illness. As recommended by concensus statements advocating the importance of screening patients quickly to identify and treat psychosocial and emotional sequelae impacting on patient recovery from MI (Whalley et al., 2011; Glozier et al., 2013) mentors also conducted risk assessments during their interviews with patients.

Auditing patient efforts to improve their lifestyle behaviours represented a large proportion of mentor work following their discharge from hospital. Monitoring patient progress in their rehabilitation via audit, action planning and feedback improved patient motivation, adherence to medical therapy and assisted patients to achieve their recovery

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and lifestyle behaviour change goals. Research has shown audit and feedback is effective in changing behaviour (Gardner et al., 2010; Flottorp et al, 2010; Le Corvoisier et al, 2013).

The findings of this study are consistent with previous research evidence suggesting motivation plays a vital role in patient recovery (King et al., 2001; Fleury & Sedikides, 2007; Shahsavari, Shahriari & Alimohammadi, 2012). Mentors found motivated patients, who believed they could recover and make positive changes to their lifestyle, ultimately were more likely to adhere to prescribed therapies and achieve positive health outcomes. Conversely, a small number of patients who were poorly motivated or ambivalent regarding their ability to recover or could not envisiage the need to make changes in their lives struggled to meet their health goals. Similar findings were reported by Jolly and collegues (2007) where they found compared with hospital based CR, patients enrolled in a home based CR program often lacked the motivation to exercise. Other studies have found patients with CHD often experience ambivalence in the form of conflicting feelings about the need for lifestyle change (Kehler et al., 2008) independent of what format of CR is available to them (Everett et al., 2009). According to Herber and colleagues (2017) patients who choose not to undertake CR often think they are unsuitable for CR or have poor knowledge concerning the benefits of completing CR.

Patients who lack motivation following MI may have difficulty in adhering to medical therapy after MI (Bauer, Caro & Beach, 2012). Mentors in this study believed low patient motivation impacted negatively on some patients in terms of them achieving their desired health goals meeting their health goals. Although research has identified the benefits of motivational techniques to improve adherence to treatment and motivation in general (Thompson et al., 2011; Soliman & Selim, 2013; Castenuovo et al, 2014), a home based CR program used in New Zealand, found face to face visitation by their facilitators improved motivation by promoting effective communication. This helped nurses to understand their patient's life context and priorities in their recovery care and patient adherence to treatment (Henwood & Barnes, 2008). As face to face meetings were not possible once patients returned to their homes in this study, there appears a need for mentors to receive training in communicating with patients by telephone and techniques

such as motivational interviewing included in all models of CR (Soliman & Selim, 2013) to help encourage and motivate during their recovery.

# Mentors providing information and education during patient recovery

Providing patients with information and education is an essential component of CR (Anderson et al., 2017) and this was an important component of the AHGP. It has been found that some patients do not retain knowledge gained during in-hospital education (Martin et al., 2005) and can experience an information gap soon after discharge (Hanssen et al., 2007). Having the AHGP resources at home and mentors available via telephone to revisit information and answer questions was appreciated by patients soon after they returned home. This helped prevent misinformation and reinforced key messages. Patients require knowledge if they are to be empowered to make positive lifestyle change to lessen their cardiac risk (Redfern et al., 2007). Other researchers have found that patients who understand their risk factors are more likely to adhere to lifestyle changes in the long term (Alm-Roijer et al., 2004; Redfern et al., 2007; Polikandrotiu & Babatsikou, 2013). Therefore, educating patients about reducing their lifestyle risk and providing them with strategies and encouragement remain integrally important in any CR program or setting.

## Mentors helping patients to reduce their lifestyle risk

Lifestyle modification has been shown to reduce the risk of cardiovascular events and subsequent readmission to hospital following MI (Fernandez et al., 2009; Chow et al., 2010; Cole et al., 2011; Gulliksson et al., 2011; Hardcastle et al., 2013). However, research suggests that many patients find changing and managing lifestyle behaviours confronting and difficult to achieve (Astin, Horrocks & Closs, 2014; Nunes, Rego & Nunes, 2016). Some have reported that patients lose hope after MI (Eriksson et al, 2013) and need to go through a process of reorientation to progress toward recovery (Hildingh, Fridlund & Lidell, 2006). Helping patients restore lost hope improves a patients' QOL and their outlook towards making positive changes to their lifestyle to enhance their future. From the findings, mentors in this study helped many patients change lifestyle behaviours implicated in risk factors associated with CHD. They used positive encouragement and reinforcement when checking patient progress during their

recovery. As identified by other research (Hardcastle et al., 2013), this led to patients understanding the benefits of lifestyle behaviout change and then set realistic goals with the aim of ultimately improving their HRQOL and reducing their potential risk of further coronary events. Mentors used several strategies to assist patients with their lifestyle goals. This result reflects the growing evidence suggesting the merits of including CBT and motivational interviewing in the delivery of CR. These effective strategies have been found to improve patient self care abilities and their engagement in terms of adopting healthier lifestyle behaviours (Young, 2014; Pietrabissa et al., 2015; Heron et al., 2016).

Patients in this study valued mentor efforts to motivate them to change lifestyle behaviours that may have impacted on their health. The emotional support given by mentors to patients in the first weeks of their recovery appeared to positively influence a patients' motivation to get well. Supporting and motivating patients to achieve lifestyle based health goals is consistent with CR guidelines (Balady et al., 2011; NICE, 2014; Woodruffe et al., 2015) advocating the importance of assisting patients to recover, restore and maintain their optimal physiological, psychological, social and vocational status after MI.

Researchers have reported that many patients with CHD are unaware of the risk factors associated with lifestyle and the development of CHD (WHO, 2007; Banks et al., 2016). Furthermore, only approximately 50 % of patients adhere to prescribed recommendations based on CR guidelines (WHO, 2013). Telephone based CR programs that use health workers to coach patients and correct maladaptive lifestyle health choices have been found to be successful (Jelinek et al, 2014). Although some degree of coaching was undertaken by mentors in this study, the AHGP set out to deliver a CR program modelled on PCC and which provides patients with comprehensive and holistic support ion all aspects of their care.

In this study, there was variation in the extent to which patients changed their lifestlyes. Despite the positive outcomes attributed to advancing patient knowledge and understanding in terms of cardiac risk, patients were sometimes not able to achieve their lifestyle behaviour change goals. Mentors reported frustration when patients were unable to make healthy choices. These findings are consistent with other research where patients, despite reporting substantial progress in terms of engaging in lifestyle

change, do not practice behaviours change in a way that results in a reduction of their cardiac risk (Elis et al., 2008). Although some researchers suggest lifestyle behaviour change is often difficult for patients to achieve and sustain (Stewart et al, 2013), there was evidence in this study to suggest that many patients were able to make significant changes. These included reducing or quit smoking, improvements in level of exercise and dietary choices, reducing their weight, improving their coping in terms reducing their anxiety or stress through relaxation techniques and adhere to medication regimen. However, lifestyle improvements for patients in this study were variable because some, but not all, patients were able to meet their health goals. Additionally, a small number of patients found it too difficult to maintain some of the changes they had made. Although lifestyle behaviour change may be considered difficult to sustain, mentors tried to motivate patients to cease lifestyle behaviours known to increase cardiac risk.

Previous researchers have discovered patients may become resistant when given traditional or directive advice concerning lifestyle change (Rollnick et al., 2010). In keeping with other health care settings where motivational interviewing enhances behaviour change (Rubak et al., 2005), mentors in this study used motivational interviewing, empathy and a reflective listening to help patients explore their short and longer term goals related to reducing their lifestyle risk. Findings from the mentor clinical notes reflected that some patients lost interest in achieving their goals, particularly if they lacked spousal support, believed that they had recovered sufficiently from MI or felt that existing comorbid health issues made undertaking lifestyle change goals too challenging. Previous research findings suggest patient barriers to compliance include boredom, lack of motivation (Sage, 2013) and time (De Vos et al, 2012), too fatigued by renumerated work, exercise or other activities, low perception of the negative consequences or perception that they can solve their own problems related to their illness (De Vos, 2012). Other patient barriers to compliance include, pre-existing comorbidities (Brown et al, 2009), lack of spousal support, work and family obligations (Marzolini et al, 2008) and dietary issues concerning the taste, cost and availability of a healthy diet (Yohannes et al., 2007; De Angelis, Bunker & Shoo, 2008; Marzolini et al., 2010; De Vos, et al., 2013).

In summary, the processes of the AHGP provide insight in terms of the delivery of care by mentors and the therapeutic relationship between mentor and patient. The processes also included the mentor and patient's evaluation of them and included aspects of care such as shared decision making, communication, ability of mentors to be supportive in their role and unexpected outcomes such as coping with negative emotions.

#### **AHGP Outcomes**

The Donabedian SPO model suggest outcomes refer to the effects of health care and services on the health status of patients (Donabedian, 1988) which may include improvements in patient knowledge, symptom control and self-care abilities (Doran, 2011), and changes in behaviour and patient satisfaction (Donabedian, 1988). The following discussion details what was learned from the study in terms of patient, and mentor outcomes. In this section, the quantitative findings from this small before and after study and the qualitative findings from patient interviews, mentor surveys and mentor field notes are discussed. As the quantitative sample size was small, caution is required when interpreting the findings in this part of the discussion.

## Patient outcomes relating to anxiety and depression

Patient anxiety but not depression scores decreased after the completion of the AHGP as measured using the HADS (Snaith, 2003). Anxiety and depression have previously been linked to poor CR outcomes (Turner et al., 2010; Clozier et al., 2013; Hare et al., 2013; Watkins et al., 2013) with depression doubling the risk of adverse events following MI (Van Melle et al., 2004). A recent meta-analysis, found depression to be independently associated with a 22% increase in all-cause-mortality and a 13% increase risk of cardiac related events (Meijer, et al., 2013). In this study, patient anxiety and depression was measured while patients were in hospital and then again at program completion 6-8 weeks later. Anxiety levels decreased by approximately 25% and depression levels by approximately 30% although depression scores were not statistically significant. This improvement compares favourably with previous studies investigating home based CR program delivery that used the HADS instrument to measure anxiety and depression as clinical outcomes (Lacey et al., 2004; Dalal et al., 2007; Jolly et al., 2009). This small study suggested the AHGP could provide positive measurable outcomes relating to reducing anxiety and depression in affected patients recovering from MI.

## Patient outcomes relating to exercise and physical activity

Results showed a moderate increase in patient exercise in this study. Sedentary lifestyle represents a major modifiable risk factor in patients with coronary heart disease. Research has demonstrated that exercise-based CR compared to no exercise can reduce cardiovascular mortality [27 trials; risk ratio (RR) 0.74, 95% CI 0.64 to 0.86] (Anderson et al., 2016), reduce levels of anxiety and depression and improve general health (Milani & Lavie, 2007; Sattelmair et al, 2011; Sharif et al, 2012). However, one issue with analysing data from home based exercise programs is that health workers cannot reliably predict whether exercise regimens and advice will be followed (Jolly et al, 2009). In this study, patients improved their tolerance for moderate levels of exercise during the AHGP. No other exercise data such as rating the intensity of undertaken exercise reached statistical significance. However, as suggested by others, even a small increase in the amount of exercise undertaken by patients may have been of some benefit (Sattelmair et al., 2011).

Analysis of mentor surveys and clinical notes revealed that patients were routinely questioned regarding their exercise and activity output. Patients were encouraged to enter their daily exercise program (amount of time and intensity) in their patient diary (program resource). Recent studies have used technology to inspire patients to exercise in their own homes (Buys et al, 2016). Cardiac telemonitoring (Kraal et al., 2013) or telerehabilitation (Thorup et al., 2016; Brouwers et al., 2017), smartphone-based (Walters et al., 2010; Varnfield et al., 2014) and computer-based technologies (Reid et al., 2012) have been used to monitor patient exercise output and appear to be feasible in that they are safe, cost effective and help motivate patients to exercise. Thus, as new health technologies emerge, they may play an important role in future home based CR and healthy lifestyle orientated programs delivered by distance. In this study, a more appropriate or user friendly instrument may have yielded improved results. Alternatively, pedometers may have been a reasonably inexpensive way of encouraging patients to record their exercise output.

# Patients' perceptions of illness

There was no difference in patient's perception of illness before and after the AHGP's implementation as measured using IPQ-R (Moss-Morris et al., 2002).

However, the instrument did not demonstrate reliability in the study sample. Mentors suggested it was important to seek responses from their patients about their perceptions relating to their cardiac illness and provided some insights in to patient understanding relating to illness and potential for recovery. Research about patient beliefs about illness, commonly referred to as illness perceptions stem from the self-regulatory model of illness (Levanthal, Meyer & Nerenz, 1980). A previous study focusing on the relationship between MI patient perceptions and their CR attendance showed patients who see their illness as controllable, feel they understand their condition and are aware of the severe consequences of cardiac disease are likely to attend CR (French, Cooper & Weinman, 2006).

Positive changes in illness perceptions were noted in patients following CR in earlier studies (Slack et al, 2006). Although patients showed good knowledge on their risk factors to their MI, there were no differences in patient illness perceptions pre and post the AHGP. The small sample size of this study may have lacked the power to detect effects. Alternatively, the relatively short length of time between the two questionnaire surveys (six weeks) may have been too short to detect changes in effect. Patients may have not had sufficient time to alter their beliefs in terms of their ability to recover from MI. Having patients complete the IPQ-R at 6 and 12 months post program completion may have yielded different results in terms of their ability to control their illness early in to their recovery and beyond. Patients can have a severe psychological reaction to a potentially life threatening condition such as MI (Mierzyńska et al., 2010) and other researhers have likened this reaction to a form of post traumatic stress disorder that may manifest as anxiety and depression (Meister et al., 2013). Conceivably, this could potentially impact on the way patients in this study may have viewed their illness. According to previous research, if patients have a strong belief they can be cured and the illness will be of relatively short duration, minor consequences might be expected (Moss-Morris et al., 2002). Given the IPQ-R performed poorly in terms of reliability, no conclusions can be drawn from the data.

# Patients' quality of life

There was a significant improvement in the mean scores of the MacNew HRQOL (Oldridge et al., 1991) across the emotional, physical, social and global domains after the AHGP. MI has been found to detrimentally impact on patient QOL (Rancic et al.,

2011). However, a positive relationship has shown to exist between cardiac rehabilitation program attendance, improving hospital after care and improvements to HRQOL (Shepherd & While, 2011; Khalife-Zadeh, Dorri, & Shafiee; 2015; Soo Hoo, Gallagher & Elliot, 2016). To date, there have been several studies undertaken to investigate the effectiveness of home based CR programs that have used HRQOL as a outcome measure. Unfortunately, many of these studies used different instruments to measure HRQOL outcomes, making it difficult to compare results across studies (Lacey et al., 2004; Hofer et al., 2004; Dalal et al., 2007; Karim & Gormley, 2007; Jolly et al., 2009; Nakajima et al., 2009; Dalal et al., 2010; Oerkild et al., 2012; Moholdt et al., 2012; Dal Boni et al., 2013; Salavati et al., 2016; Buckingham et al., 2016). However, irrespective of the type of instrument used, researchers have consistently found evidence to demonstrate that home based CR improves patient QOL.

Significant improvements occurred in the mean MacNew HRQOL scores across the emotional, physical, social and global domains after completion of the AHGP. A prior study used the MacNew HRQOL instrument to compare HRQOL outcomes between home based and hospital based CR found that there were no differences in HRQOL between groups, however, both groups showed significant improvements in HRQOL over time (Dalal et al., 2007). Another study by Yohannes and colleagues (2010) reported similar outcomes for 105 patients receiving CR. Patients were surveyed over four independent time points (at baseline, six weeks, six and 12 months) using the MacNew HRQOL instrument and showed significant positive values at all time points suggesting the positive effect of CR on QOL. In comparison with other research using the MacNew HRQOL instrument to measure the QOL of patients following MI, it appears from this study results, the AHGP is promising in terms of assisting patients to improve their HRQOL following MI.

## Patients regaining and maintaining their health

An essential component in each patient's recovery from MI is to find ways to cope with the consequences of MI, regaining and managing their health. According to research, fear of dying, helplessness and perceived severity of MI are common forms of distress among cardiac patients which can adversely affect recovery (Whitehead et al., 2005; Wiedemar et al., 2008; Von Kanel., 2011). Some patients in this study struggled to regain a sense of normality after experiencing a MI. Petricek and colleagues (2015)

found in their qualitative study, many patients had their life perspectives severely altered after receiving a diagnosis of MI and therefore, needed safe ongoing support and care following discharge from hospital. This study found patients valued the support provided by their nurse mentors after discharge. Having a mentor available to provide individualised post hospital care and support assisted patients to gain normalcy during the period discharge period. As reported in other research, this appeared to occur inconjunction with a renewed sense of control once they understood what had happened to them, the treatments involved and reassurance concerning their future (Salminen-Tuomaala et al., 2012).

#### Patient and mentor satisfaction

Patients in this study were satisfied with the information, guidance and support they received from their mentors during the AHGP. Patient satisfaction with healthcare received has become an important outcome indicator for determining health care quality (Browne et al., 2010; Bjertnaes, Ingeborg & Hilde, 2011; Al-Abri & Al-Balushi, 2014). Although there have been reports of patients not being satisfied with the level of support available to them or have unmet health needs following discharge from hospital (Asadi-Lari et al., 2003; Junehag, Asplund & Svedlund, 2014), patients in this study were satisfied with their progression from hospital to home where they continued to value the support of their mentors during the remainder of the AHGP and subsequent CR.

Likewise, mentors were generally satisfied with the program in terms of its ease of use and the information, advice and education contained in the audiovisual resources. Satisfaction gained by helping patients enrol and complete the program, successfully meet their CR goals by improving their self care abilities and undergo lifestyle change modification to decrease their cardiac risk were important outcomes for mentors.

In summary, outcomes of the AHGP were derived from both quantitative and qualitative data. In keeping with previous research efforts relating to the effects of home based CR on patient outcomes, this study found similarities with other research. Findings from this study reported patient levels of anxiety decreased after completion of the AHGP. Similarly, patient HRQOL improved across physical, emotional and social domains and there were encouraging signs that patients were enaging more directly in exercise after discharge from hospital. Although there is little published research to

compare findings, the AHGP appears to show potential in terms of developing in to a quality home based CR program. Outcomes from this study suggested patients improved their health by completing the AHGP. Specifically, when compared to the small number of home based CR programs published, patients were satisfied with the audiovisual resources and the support given by mentors. Other studies have found patients require ongoing information, lifestyle guidance and psychosocial support following hospital discharge. Outcomes from this study appear to be comparable to many of the psychological outcomes reported via CR programs in other countries. That is, patients needfollow-up support soon after discharge from hospital.

# **Update on the AHGP**

To date, due to the governance issues previously described, the program has not been further developed or used in Tasmania. However, findings from this case study may inform and assist others planning similar programs or a large effectiveness trial. Despite the AHGP not being currently available in Tasmania, it's antecedent, the Heart Manual has continued to evolve. According to the Heart Manual website (theheartmanual.com), the Heart Manual is cited in at least 390 peer reviewed articles, and has become an evidence based benchmark for home based CR and in the UK, the program meets the needs of 14,000 individuals and their families every year. The program is used by numerous health boards throughout the UK and as far afield as Canada and Singapore. Further development has seen the MI version become available digitally (Deighan et al., 2017). A Revascularisation (Post Percutaneous Intervention) digital edition has also been developed along with foundation work on a Stroke Manual and and the Heart Manual department recently collaborated with the Rehabilitation Enablement in Chronic Heart Failure (REACH-HF) project (Greaves et al., 2016).

The Heart Manual program continues to be available in available in England, Wales, Ireland and Scotland and negotiations are underway to have Scotland's join the national audit for cardiac rehabilitation in 2018. In summary, although the Heart Manual programme is currently available and is being developed further, it has not continued to impact greatly on the utilisation of centre based programs which currently attract about 50% of eligible patients.

# Limitations of the study

There were several limitations relating to qualitative and quantitative aspects of this research study and include issues relating to data collection, patient recruitment, mentorship, program delivery, stakeholder engagement and patient referral. These issues are reported as follows.

First, there are several limitations in this study which relate to the AHGP delivery (including the use of mentors), the recruitment of the sample and methods and tools used for data collection. Some of these limitations have affected both the qualitative and quantitative components of this research and others are unique to one phase only. The first limitation relates to the AHGP and its delivery as a new home based CR program. According to the Medical Research Council of the UK, the AHGP is a complex intervention (Craig et al., 2013). Complex interventions have several interacting components and because of this, there is no way to determine the extent to which each component is effective. In the case of the AHGP, the components include the program resources such as the patient and partners and family workbook, pocket diary, audiovisual media as well as the mentors who delivered the program and provided additional resources as needed. There is no way to identify the extent to which any one of these components contributed to the qualitative or quantitative findings.

Second, limitations regarding the nurse mentor component of the AHGP were also evident. Thirteeen mentors were originally trained to deliver the AHGP but only seven mentors consistently mentored patients. Some mentors became unavailable due to retirement or transferred to other clinical areas of nursing. Others did not want to mentor patients outside their normal working hours or did not recruit patients due to their workload. Similar experiences were reported in two comparable home based CR studies where nurses voluntarily facilitated programs with out financial reward (Henwood & Barnes, 2008; McIvor, 2014). In comparison with the UK where program facilitators are renumerated via the NHS, it could be that mentoring cardiac patients to warrants monetary reward for this service.

Additionally, while all nurse mentors were experienced CR nurses or cardiology nurses and received the same mentor training, it is not known whether the program was

delivered consistently to all study participants. As there was no script for mentors to follow, mentor approach may have been quite varied and may have impacted on results. However, this may reflect what might occur if the AHGP was to be adopted more widely. Recently, researchers are adopting a pragmatic, real world approach (Patsopoulos, 2011; Sacket, 2013a, 2013b) to their research to understand which cardiac interventions improve current clinical practice (Stewart et al., 2016; Salisbury et al., 2016., Creber et al., 2016). Using a pragmatic approach to understand the effects of patient centred home based interventions may prove beneficial in developing future telehealth based interventions for patients unable to attend centre based CR.

Another limitation relates to the recruitment of the sample with two issues, stakeholder engagement and patient referral contributing to this limitation. Although all relevant health agencies were approached to gain ethical clearance to conduct the study, and key stakeholders were informed of the study, it became clear that not all relevant stakeholders in each hospital knew of the AHGP. In retrospect, ensuring all relevant stakeholders understood the aims and benefits of the AHGP may have improved both organisational and individual support for the study. Also, greater awareness of the organisational issues confronting the implementation of a research project in the hospital environment may have translated to a wider acceptance of the AHGP, improved recruitment and ultimately improved CR access for patients unlikely to attend hospital based CR. Although details of the patients recruited were available, the numbers of patients approached and declined and the reasons for declining to participate were not recorded. Other research has shown up to 85% of patients do not participate in CR (Neubeck et al., 2011). In addition, recruitment was slow, which resulted in the study being extended over two years. It is possible that over this period, patient treatments and care may have altered along with mentor skills and motivation, which may have impacted on the findings.

In terms of recruitment and the quantitative phases of the study, the sample size was much smaller than anticipated, which may have affected the power of the study to detect significant changes. However, there were significant improvements in depression, anxiety, HRQOL and one aspect of physical activity. While statistics rule out chance for these improvements, it is always possible that other confounding factors or some bias such as selection bias may account for these improvements.

The next limitation relates to the data collection process and instruments used with different issues for the qualitative and quantitative phases of the research. In terms of the qualitative phases, patients were interviewed by telephone. It is possible that face to face interviews, either individually or in groups, may have resulted in more in depth or additional insights, however the distance that would be required to travel made this option not viable. While the length of these interviews varied from 10 to 30 minutes, it is possible that sending patients the interview guide prior to the interview may have resulted in additional information. In addition, open ended emailed mentor surveys, where they typed their responses, was used on mentor request. Like the patient interviews, had face to face interviews been used, it is possible additional information may have emerged, but the decision was made to honour mentors' preferences.

Additionally, mentors did provide in-depth rich descriptions of their experiences, which facilitated understanding of their perspectives. Finally, data was collected from mentors at the end of their experience as "mentors". Perhaps other insights may have emerged had data been collected during the study.

In relation to the collection of quantitative data, another limitation related to the complexity and time constraints associated with using some of the study instruments. This may have led to participant fatigue, a phenomenon linking poor data quality with fatigue (Rathod & LaBruna, 2005). Participant fatigue, particularly for patients recovering from MI, may have impacted on the numbers of patients wishing to participate in the study or may have contributed to the failure of some patients to complete their program evaluation. Notably, some patients judged the IPQ-R instrument as being too complex for them to complete. Retrospectively, for the purposes of this study, a brief version of the IPQ, consisting of a nine item scale (Broadbent et al, 2006) could have been used. Unfortunately, in this study, the IPQ-R did not show evidence of being a reliable instrument, therefore, any meaning ascribed to the IPQ-R results is questionable. Additionally, a small number of patients indicated that the MacNew HRQOL instrument, while specifically designed for cardiac patients recovering from MI, was too taxing to complete due to its length. Another HRQOL instrument such as the SF-12 (Short-Form 12-Item Health Survey, Ware, Kosinski & Keller, 1996) may have been better received by patients due to it's ease of use.

Patient outcomes were only measured over a relatively short period of time. The measurement of patient outcomes at six weeks post intervention may have been too short in duration to affect lifestyle behaviour change. Research has shown that when an intervention is stopped the effect of that intervention becomes diminished over time (Oerkild et al., 2012). As a result, some researchers have discovered that patients who are able to change lifestyle behaviours in the short term may find it difficult to maintain this progress over a longer period of time. It is possible that had the study had a longerfollow-up, the benefits identified in the short term may not have lasted.

According to Clark and colleagues (2005), it can take up to two years to confirm the mortality benefits associated with study end points and secondary prevention programs. In terms of this study, a 12 month patient follow-up reporting outcomes may have added strength to the value of the AHGP as a quality intervention.

The last limitation of the research relates to the generalisability of the qualitative findings and quantitative results. The qualitative findings from this study may not be generalisable because each participant's individual experiences and descriptions relate to the personal meanings attached to them within the context they occurred. However, qualitative research does not aim for generalisability; instead, it aims to advance conceptual understanding. This study does provide conceptual insight into a new home based, mentor supported CR program and the findings may be applicable to other similar programs. Because of its small sample, the findings from the quantitative phase of the study cannot be generalised, however, the findings do suggest the AHGP may have beneficial effects, and thus a large, adequately powered study appears warranted.

Despite the limitations previously highlighted, this study does present clinicians with some insight in to what aspects of post hospital care patients recovering from cardiac related illness find meaningful. Further, the findings of this study appear to suggest that CR trained mentors may provide a viable possibility for people living in geographically remote locations to get support and have their CR needs met.

Although the results of this study lack generalisability, this case study provides valuable insight concerning the new role of nurse mentor and the applicability of the AHGP in terms of meeting the CR expectations of patients recovering from MI and their perceptions of the mentoring component of the program. By evaluating the SPO of the AHGP, the strengths and weaknesses of the program were highlighted indicating

the program demonstates promise in terms of developing the AHGP as a standalone home based CR program.

# Implications and recommendations

There exists a global mandate for all persons suffering the effects of MI to have access to CR, but evidence clearly states that this service is grossly underutilised in many countries (Kotseva et al., 2012), despite research efforts to clarify why there is suboptimal program uptake (Karmali et al., 2014). Home based CR programs have been proposed as an alternate method of CR delivery, aiming to attract patients who would normally not attend a hospital based CR program. In the context of this study, patients living in rural areas of Tasmania, who did not have access to traditional CR, were encouraged to participate in a newly developed home based CR program supported by nurse mentors. Implications of the sudy findings and associated recommendations for patients, mentors, nursing education and practice, health care organisations and future research are detailed next.

## Implications and recommendations for patients

The study demonstrated that patients who could not attend a traditional CR program were able to gain benefit from the AHGP. For patients, access to the AHGP enhanced the realisation that they can take an active role in their care and importantly, improve their health even though they have a chronic medical condition. Positive findings from the study indicated that patients were satisfied the AHGP (which included the educational resources and the mentoring component), met their expectations in terms of a CR program. The AHGP has shown potential as a new model of home based CR for patients and thus as a result of this study, the recommendation to further develop the AHGP including the structures such as mentor training and organisation support is made. Finally, developing and evaluating strategies to incorporate families into this or similar home based CR programme may help to improve its uptake and completion in the future.

# Implications and recommendations for mentors

The study provided new and valuable insights relevant to the role of nurse mentor. Using nurses to provide mentorship to patients recovering from MI after hospital has up

to now been surprisingly lacking in the research literature. Quantitative research has in the past compared hospital and home based CR outcomes with little acknowledgement concerning the actual role of nurse mentor. Thus, their contribution in terms of assisting patient recovery and their efforts to modify patient lifestyle risk after MI has not been forthcoming. This study further builds on a study in New Zealand (Henwood & Barnes, 2008) where nurse facilitators provided home based CR to patients. It also provides additional insight to another unpublished pilot study using nurse mentors to deliver a home based CR program in New South Wales (McIvor, 2014). Findings from this study suggested mentor work consisted of working collaboratively with patients to meet their health goals and modify unhelpful lifestyle behaviours by correcting misconceptions and misinformation about CHD. However, mentors required training on how to adopt a PCC approach to their practice, and they became more patient centred as they gained more experience. Thus, future mentor training programs should include an explicit focus on what PCC is and how it can be enacted. Developing and testing various mentor training interventions in the future may result in mentors who are able to use various techniques to better influence and support patient efforts to undergo lifestyle behaviour change. The sustainability of both mentor based CR programs and their long term impact on patient behaviours and subsequent health outcomes could be further explored in the future.

Data from this study revealed several mentor perceptions relating to the effectiveness of the training they undertook. With similar home based CR programs in other countries offering training over 2-3 days withfollow-up refresher sessions (Henwood & Barnes, 2008), this may have contributed to some mentors perceiving a lack of preparation in terms of their skills. To adequately prepare future mentors, more practical training is recommended, especially in CBT strategies and motivational interviewing. This would enable mentors to readily assist patients struggling with ambivalence or motivational issues in terms of their ability to undertake lifestyle behaviour change.

Mentors in this study were professionally rewarded when patients recovered and achieved their health expectations. This suggests that it was important for nurse mentors to follow the patient care experience (underpinned by PCC) from hospital to home and provide information, guidance and support as needed. In general, the

findings from this study suggest it would be appropriate for nurses to use mentoring as a basis for providing seamless cardiac care to patients recovering from MI in the Australian setting.

Although most mentors were satisfied with their work as mentors, some found implementing a new model of care difficult. Mentors found PCC to be time consuming and found the role transformation from "nurse expert" to "nurse mentor" was initially conflicting for a small number of mentors. This implies that one cannot assume all nurses will be able to adapt to the new role and that more support, education and mentor role model practice is warranted. Mentors that are stressed are unlikely to be motivated to take on more mentoring roles which could impact negatively on the CR recruitment of patients unable to travel to hospital based CR services. Although mentors did appear to adapt to PCC with experience, the time needed to develop and maintain a therapeutic relationship with patients based on PCC, continued to impact on busy work schedules. Therefore, it is recommended that nurses receive more intensive training on techniques such as CBT and patient centred approaches to care prior to becoming patient mentors. In addition, more education is needed to explain the concept of PCC in the clinical setting to enable clinical managers to understand the benefits associated with the concept and provide appropriate clinical support and time to mentors. Although PCC may appear time consuming in practice, developing the self care abilities of patients may improve their HRQOL and reduce health care costs.

# Implications and recommendations for policy and health care organisations

Health care organisations can benefit from ensuring all patients have access to CR after MI. Policy stakeholders and health care organisations should appreciate that patients who understand CHD and their role in actively managing their recovery are less likely to be readmitted to hospital. The AHGP has demonstrated its applicability as a model of CR because patients not only agreed to use it; all patients who accessed the program completed it. Furthermore, although findings are not readily generaliseable, the AHGP appeared to improve patient health outcomes. In view of Australia's ageing population and the chronicity of CHD, preventing hospital readmission may lessen the burden of burgeoning hospital costs.

The AHGP has shown potential in terms of assisting patients to take a more active role in their care and health care agencies should support the ongoing development of home based CR programs in the future. Thus, because of the positive findings from this study it is recommended that the AHGP be extended beyond the six week time frame to enable patients who are unable to meet their lifestyle goals during the program support over a longer period of time. Although this study demonstrated the AHGP could satisfy the health needs of its participants, the implications of a much larger roll out in Australia concern major issues of monetary funding, future specialist mentor training and credentialing.

Other issues such as the future development and production of AHGP resources, endorsement of the program by physicians to improve the uptake of the program, improved communication between all other health stakeholders and the distribution and overall governance of the AHGP as an entity also need to be remedied. Support in Australia may be difficult to realise without government funding as the Australian Cardiovascular Health and Rehabilitation Association, though potentially willing to further develop and administer the AHGP, do not have the monetary funds to implement such a program on a national scale. The study findings firmly recommend that governance issues concerning the need to establish a health provider be finalised prior to any further larger scale research relating to the AHGP being conducted.

Associated with determining the cost of implementing thie AHGP more widely, a larger effectiveness study may help determine if widespread use of the program should be advocated.

A further implication arising from this study concerns the future development of collaboration between hospital based cardiology services and primary care givers in the community. This study reported examples of mentor frustration, where a lack of continuity existed in terms of communication between hospital based services and primary health care. In view of some patients needing a much longer time frame to work through their health issues than a six week home based program, long term monitoring by the patient's primary health care provider might still render lifestyle change to be achievable. The study recommends this situation must be improved by ensuing all health providers involved in the patient's care are fully cognisant of the aims and structure of the AHGP including the role and function of nurse mentors delivering

the program. This would involve doctors, nurses and other allied health professionals in hospital and extend to health providers in the community including the patient's primary care physician. Other countries have experienced shortcomings in terms of providing a seamless transition from discharge to home. The need to provide follow-up primary care after hospitalisation is well recognised (Dalal, Wingham &Taylor, 2015). In a recent study in New Zealand involving home based CR programs (Henwood & Barnes, 2008), the CR program was coordinated from within the community setting rather than from withinthe hospital. This experience evidently was an effective long term strategy to foster improved relationships between hospitals and primary care givers.

## Implications and recommendations for future research

The findings from this research confirm that in terms of CR service delivery, the AHGP appears promising, and thus a larger study needs should be undertaken in the Australian setting. This would help determine if the AHGP could feasibly be rolled out in other states of Australia. In the future, researchers should consider following patients for a minimum of 12 months post program completion to determine whether patients are able to maintain lifestyle change in the long term. Further, CR stakeholders are also acknowledging a range of CR programs should be made available to encourage choice between the various forms (such as hospital, telephone and computer based programs) and improve CR uptake, attendance and program completion (Davies et al., 2010). The findings from this study support this view, therefore it may be both complimentary and feasible to administer and operate different CR models from centralised services.

Although the aim of this study was not to observe the dynamics of spousal or family support of the patient undertaking the AHGP, further research in this area may contribute to new nursing knowledge and further help identify unknown factors that may contribute to understanding why patients may or may not be able to make lifestyle improvements despite having participated in a home based CR program. While the mentor clinical notes revealed examples of mentors engaging with spouses and other family members, mentors thought in the future, mentor training should include information relating more specifically to the needs of spouses and family as the self-perceived needs of recovering cardiac patients may be quite different from needs expressed by spouses. Other research has identified the benefits of positive family

support in assisting patient recovery and family adjustment after MI (Dunbar et al., 2008; Henwood & Barnes, 2008). Future AHGP and mentor planning input should focus more attention on spousal and family issues relevant to the patient's recovery and maintenance of long term lifestyle change. Additionally, family data needs to be collected and analysed in future studies to better understand the role family members play in home based CR and in importantly, what support structures may help them cope with the chronicity of CHD.

## **Conclusions**

The AHGP has the potential to be a quality home based CR program in terms of its structures, processes and outcomes (SPO). Both patients and mentors perceived the AHGP to be successful. As mentorship represents the cornerstone of the AHGP, the study also aimed to provide an understanding of the SPO specific to nurses mentoring patients in their homes and the extent to which mentoring assists patients to improve their health outcomes. Due to the paucity of information currently available relating to nurses mentoring patients specifically in their homes, insights derived from this study provide the nursing profession with much needed information relating to this new role.

Structures important to the success of the AHGP included the timely recruitment of patients, the development of the program's resources, the specific training required to operationalise the six week program, and the specific skills, knowledge and commitment of nurses to improve their patient's care experience by implementing specific cognitive-behavioural strategies. Processes included the development of a therapeutic relationship and rapport between mentors and patients, the suitability of the program within the Australian cultural setting, promoting positive lifestyle behaviours and implementing a patient-centred approach to CR care. Outcomes indicated the AHGP assisted patients in their recovery from MI. The program also reduced levels of anxiety and improved their HRQOL. Patients were satisfied with the program's audiovisual resources and valued the support, guidance and care provided by mentors during their transition from hospital Many patients were able to change unhelpful lifestyle related behaviours. Outcomes for mentors indicated that although there were rewards and barriers associated with being a patient mentor, the AHGP was easy to use and the majority of them were satisfied with their new role.

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Additionally, in the past, the role of mentor in the context of home based CR, did not appear to have been well explored. The role of nurse mentor in the setting of home based CR was closely examined in this study and significantly contributes to new nursing knowledge. Importantly, a new and unique therapeutic relationship was found to exist between patients and nurse mentors. Mentors found the mentoring experience professionally rewarding and satisfying because the service was underpinned by the model of PCC which encourages patients to participate in the decision making about their health and wellbeing. The patient data in this study supported the use of mentorship, suggesting it was an integral component of the program in terms of providingfollow-up support after hospital discharge and assisting patients in their efforts to undergo lifestyle behaviour change.

A major strength of the AHGP is that it promotes patient centredness and typically, patients are encouraged with nurse mentor assistance, to actively engage in decision making about their own health. Furthermore, the AHGP resources have been found to be easily understood by patients and importantly, the mentor-patient relationship appears, according to study findings, to remain the essential ingredient in terms of supporting their recovery from MI and assisting patients to adopt positive health behaviours. The quantitative and qualitative results of this study confirm that the AHGP can lessen the burden of heart-related disease and potentially change health care delivery and CR policy in Australia. Ultimately, the AHGP has the potential to become a viable CR program in Australia if issues relating to future specialist mentor training, various governance issues and future resource supply and development can be overcome. For people with CHD living in rural areas, the delivery of home based CR programs cannot happen soon enough.

# **Appendices**

# **Appendix 1: Information summary sheet for participants**

## **Information Summary Sheet for Research Participants**

### The Evaluation of the Aussie Heart Guide Program

The implementation and evaluation of a home based [mentor supported] cardiac rehabilitation program for cardiac patients in regional Tasmania.

February 08, 2010 (Form version\_3)

Researcher:

#### **Terry Frohmader RN**

PhD Candidate, Griffith University Clinical Staff Nurse Coronary/Intensive Care Unit Launceston General Hospital Tasmania, 7250

#### **INTRODUCTION**

You are invited to participate in a research study to be conducted in regional Tasmanian Hospitals. For you to decide if you want to be part of this research study, you must know enough about its risks and benefits to make an informed decision. Please take as much time as you need to think about or discuss taking part in this study with family or friends before making your decision.

This form contains information about "informed consent." It explains

- The purpose or aim of this research study.
- What will happen during the study and what you will need to do.

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- The risks of you having problems because of your participation in this study.
- The benefits of being in this research study
- The answers to any questions you may have.

This form may contain words that you may not understand. Please ask the coronary care nurse caring for you or your cardiac rehabilitation nurse to explain any words or information you do not clearly understand. You will also be able to ask any questions you have about the study.

If your questions have been answered to your satisfaction and you decide to take part, you will be asked to sign a consent form. Results of the study can be made available to you if you wish to be informed.

#### **AIM OF THE STUDY**

The broad aim of this project is to determine if the Aussie Heart Guide, a home based, mentor supported cardiac rehabilitation program can satisfy the needs of patients who have recently suffered a heart attack and who are unable to access a hospital based cardiac rehabilitation program. Under normal circumstances, all patients admitted to hospital with heart related health problems are invited to take part in a hospital based cardiac rehabilitation outpatient program (usually lasting about 6 weeks in duration). Some people are unable to access these programs for a variety of reasons such as travel distance to rehabilitation services, cost of travel or family commitments.

There is little doubt that many people experiencing heart related health problems become very anxious regarding the prospect of returning home to their community after hospitalisation. Therefore, to support you make this adjustment, a home based cardiac rehabilitation program has been designed to support your recovery. Broadly speaking, the aim of the program is to provide you and your family with information and support so you can better understand what has happened to you and what you may be able to do to prevent further heart problems occurring in the future.

The Aussie Heart Guide Program has been modified from a very successful home based cardiac rehabilitation program used to help over 10,000 people per year recover from heart attack in the United Kingdom. The project hopes to find out whether the Aussie

Heart Guide program meets your expectations by assisting you to achieve your health goals and return to good health.

Your feedback will be invaluable in terms of helping the authors to improve the program and to advise other health care agencies of its value as a model of care and its potential availability Australia wide.

#### WHAT EXACTLY IS THE AUSSIE HEART GUIDE PROGRAM?

The Aussie Heart Guide is a program that has been designed to help you live well with coronary artery disease (or heart problems). It should be used in addition to, and not instead of, your recommended medical treatments. The program has several audiovisual resources. They consist of paper based reading material (The Aussie Heart Guide Part 1 and Part 2, the Aussie Heart Guide for Partners & Families and the Aussie Heart Guide Personal Diary) and a Relaxation Audio CD and a Multimedia Health Education CD ROM. However, the most important feature of the program is the fact that the program is delivered by specially trained cardiac rehabilitation mentors who volunteer their time, experience and expertise on a one to one basis over a period of at least six weeks post discharge from hospital.

#### **PROCEDURE**

If you wish to take part in the study, a mentor will be assigned to you to help you prepare for leaving hospital and returning home. Their aim will be to reduce your fear or anxiety and to recommend a suitable rehabilitation plan to meet your individual needs. In most cases, the mentor will spend about an hour with you (and if possible your partner) prior to your discharge from hospital. After you return home they will contact you by telephone at mutually agreed times (week 1-6) to discuss your progress and provide assistance as required. To carefully evaluate whether the program is effective in assisting your recovery after discharge, your mentor or the study investigator will ask you to complete several self report questionnaires. If you have any difficulties understanding the questionnaires, your mentor will assist you.

#### WHY HAVE YOU BEEN SELECTED?

\_You are free to join this study if you are over 18 years of age and have been diagnosed and treated for a heart attack. You are being asked to agree to take part in this research study because the investigator believes that all persons living in rural Tasmanian

communities, with coronary artery disease should have equal access to cardiac rehabilitation, so they can achieve their health goals with the assistance and support of a trained mentor and the Aussie Heart Guide.

#### **IS THERE ANY HAZARD?**

There are no hazards associated with the Aussie Heart Guide Program. The program provides advice and information that stems from medical research which has demonstrated that cardiac rehabilitation and improvements in lifestyle behaviours reduces the risk of future cardiac problems and promotes the return to a full and normal life.

#### **ROUTINE CARE**

You will receive advice and information about returning home after discharge from hospital whether you choose to take part in the study or not.

### **IS THERE ANY BENEFIT?**

Research has demonstrated the positive benefits of cardiac rehabilitation over many years. Several research studies conducted in the United Kingdom have demonstrated that the home based method of cardiac rehabilitation delivery reduces anxiety and depression, reduces re-admissions to hospital and reduces the number of visits to the GP in the first year after a heart attack. In one study investigating the level of satisfaction of a home based, mentored cardiac rehabilitation program, 97% of respondents found the program helpful.

#### FINANCIAL CONSIDERATIONS

Participation in this study will not result in any costs for you. There is no payment available for participating in the study.

#### **CONFIDENTIALITY**

As part of this study, your mentor and the chief investigator will keep a record about you taking part in the study. These study records will include personal information about you, your care and progress in terms of meeting your goals in response to your undertaking of the Aussie Heart Guide program. This also includes other medical information, including medical records, relating to you taking part in the study.

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To evaluate the effectiveness of the Aussie Heart Guide program, the information gathered during the study will be reviewed by the study's investigators. Your identity will be kept confidential and you will not be identified by name or any other identifying details in any reports or articles written by the study's investigators in relation to the study's outcome.

#### **OTHER CONSIDERATIONS**

If you have any questions during the study, please contact Terry Frohmader RN, Coronary Care Unit, Launceston General Hospital (telephone number 63487496).

If you have any questions about your rights as a participant in a research study please contact the Executive Officer of the Human Research Ethics Committee (Tasmania) Network. The Executive Officer can direct participants to the relevant Chair that reviewed the research. [Executive Officer: 03 6226 7479 or email; human,ethics@utas.edu.au.

#### IF YOU CHANGE YOUR MIND

You are free to leave the study at any time without prejudice. Leaving the study will not affect your ongoing medical care in any way.

Before you decide to proceed and sign the consent form please ask any questions about the study or any part of this study that remains unclear to you the study investigators will answer fully any questions you may have before, during or after this study. If you wish to participate in this study you will be given copies of this information sheet and a statement of informed consent to keep for your personal record.

#### **COMPLAINTS MECHANISM** [Griffith University]

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Research Involving Humans*. If you have any concerns or complaints about the ethical conduct of the research project you should contact the Manager, Research Ethics on 3875 5585 or <u>research-ethics@griffith.edu.au</u>.

Griffith University thanks you for your consent and participation in this research.

(Inser	t signature)	

#### A NEW CARDIAC REHABILITATION PROGRAM FOR RURAL PATIENTS

Terry Frohmader RN Researcher (PhD Candidate) Clinical Staff Nurse Coronary Care Unit

Phone Contact: (03)63487111

Principal Research Supervisor Professor Wendy Chaboyer Director, Research Centre for Clinical and Community Practice Innovation Gold Coast campus Griffith University, Qld, 4222 Phone Contact: (07) 5552 8518

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Lecturer, School of Nursing and Midwifery, Centre for Health Practice Innovation Griffith Health Institute,
Griffith University, Australia
Visiting Research Fellow,

Gold Coast Hospital and Health Service

Date: Feb 08, 2008



Department of Health and Human Services



# **Appendix 2: Consent Form**

#### **Consent Form for Aussie Heart Guide Program (Study)**

This Consent Form accompanies

Information Summary Sheet for Research Participants-Aussie Heart Guide Study

Title of Study - The Evaluation of the Aussie Heart Guide Program

The implementation and evaluation of a home based (mentor facilitated) cardiac rehabilitation program for cardiac patients in regional Tasmania, Australia.

- 1. I have read and understood the 'Information Sheet' for this study.
- 2. The nature and possible effects of the study have been explained to me.
- 3. I understand that all research data will be securely stored on the University of Tasmania premises for a period of 10 years. The data will be destroyed at the end of 10 years (or, in the researcher plans to retain the data for longer than this period, specify that the data will be securely stored on the University of Tasmania premises until no longer required, at which time it will be destroyed).
- 4. Any questions that I have asked have been answered to my satisfaction.
- 5. I agree that research data gathered for the study may be published (provided that I cannot be identified as a participant).
- 6. I understand that my identity will be kept confidential and that any information I supply to the researcher(s) will be used only for the purposes of the research.
- 7. I agree to participate in this investigation and understand that I may withdraw at any time without any effect, and if I so wish may request that any personal data gathered be withdrawn from the research.

Name of Participant:	
Signature of Participant:	Date

#### A NEW CARDIAC REHABILITATION PROGRAM FOR RURAL PATIENTS

8. I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

Name of Investigator or Associate		
Signature of Investigator or Associate	Date	



Department of Health and Human Services

# **Appendix 3: Aussie Heart Guide Program's audiovisual resources**



# **Appendix 4: Information protocol for mentors**

#### **Information PROTOCOL for AHGP Mentors**

The following information summarises the main considerations for mentors participating in the Aussie Heart Guide Project

- (1) **Flag suitable study participants** (How you undertake this depends upon your hospital, role, work hours etc. ie You may have cardiology RNs that will flag suitable patients, ward clerk involvement in flagging out of town patients).
- (2) Approach potential study participants if inclusion criteria met.
- (3) Leave study information sheet with potential participants and family to read **or** if practical introduce the study and attend to the information sheet and consent form in one sitting. Please answer all participant questions relative to the study.
- (4) Once consent has been obtained **Conduct interview as per Bob Lewin Workshop** ie introduce aims of the AHGP, role as mentor, conduct interview, establish participant goals and plan SMART outcomes strategy. Arrange next follow up contact and complete baseline questionnaires.

**Participant** completes - HADs, IPQ-R, heiQ, MacNew, Activity Survey **Mentor\_**completes dataset sheet, post GP letter.

- (5) Please email chief investigator as soon as you have completed the dataset with participant's name, spouse, partner or carers name, postal address, age and contact phone number. I will then assign a study number identifier because after analysis, it remains an ethical requirement to de-identify patient details. At study completion all data sheets and other information will have names removed leaving only a study number.
- (6) **Mentor contact** We are aiming to contact participants weekly for a minimum of six weeks, however, this is negotiable and dependent upon their progress and record of goal attainment etc. Please make sure you **document all contacts** on the mentor contact sheet and staple extra sheets as necessary. There is no time limit imposed on discharging participants from your mentorships. Some participants will

have more issues to work through and will require more weeks of mentoring to meet their health needs.

- (7) When you have terminated your mentorship, please remind the study participants that they will soon receive in the mailfollow-up questionnaires (at approximately thetime of program discharge-6 to 8 weeks after hospital discharge) which represent the post AHGP data. This will be followed by a phone interview to gain feedback regarding the program to be organised by research team at a convenient yet to be determined time.
- (8) Please remember to email me when you have discharged participants from the study (at or around 6-8 weeks) so I can perform the post test questionnaire mail out. The mail outs will include self-addressed stamped envelopes and bear no costs to participants (mail out will include MacNew, PIH, IPQ, HADS, Activity, heiQ and participant satisfaction surveys).
- (9) Please photocopy all the relevant study material each time you discharge a study participant and post via the DHHS mail to

### Terry Frohmader RN

The Chief Investigator
The Aussie Heart Guide Study
Department of Intensive/Coronary Care Medicine
Launceston General Hospital

- (10) After receiving the study materials, the data will be entered on to a database for statistical analysis. Please be very careful to keep all your study records together-it remains very important in terms of ethics not to lose data or have persons not involved with the study view confidential information or records.
- (11) Once the study is completed all data files will need to be returned to T. Frohmader at the LGH to be de-identified and placed in long term secured storage (in the Pharmacy Department for 6 years). [NB. By keeping the original documents intact and securely housed in your department (and hospital) if the photocopied data is lost for whatever reason then we have a back up of information].

(12) Please contact me anytime regarding any issue concerning this project.

The study has been approved by the state wide Scientific and Human Research Ethics Committees and as Chief Investigator (Terry Frohmader) I remain responsible for all study operations. At the completion of the study a report will be prepared for ACRA's perusal and results forwarded to participating mentors.

- (13) As mentors, meetings will be organised to discuss the progress of the study and to provide feedback. Please maintain your contact records at a high level including the recording of important issues as they arise so they can be reflected on during the meeting.
- (14) Please record all mentor field notes and issues (in the confidential booklet supplied) that arise during your mentorship that may assist you with your mentor and project evaluation.



Department of Health and Human Services

## **Appendix 5: Patient demographic data set for mentors**

Patient Demographics Data Collection Sheet for AHGP Mentors								
Name:	Study ID:	Date of I Age:	Birth:					
Address:	Postcode:	Religion						
Gender: Male □ Female □	Hospital CCU: Discharge date:	_Date ad	_Date admitted to					
Marital Status: Single □ Married □ Partner □ Divorced □ Widowed □ Unknown □  Name of spouse/carer/significant other; Or lives with Contact details:								
Ethnic origin: Aboriginal: Yes □ No □ Country of Birth: Language spoken at home Occupation: Working? Yes □ No □ Retired □ Self employed □ Pensioner □ disability pen □ Occupation during working life: Name of Family Doctor								
Myocardial Infarction □ Acute Coronary Syndrome □ Bypass Surgery □ PCI □ Cardiac Arrest □ Angina □ Other Surgery □ Heart failure □ Pacemaker □ ICD □ Congenital Heart □ Transplant □ LV Assist Device □ Other								
<b>Date of Initiating Event:</b>	Agreed to HBCR Yes □ No □	Dat HB	e Referred to CR:					
Date Invited to Join HBCR:	Date HBCR Star		e HBCR npleted:					
Reason for not enrolling in AHGP								
<b>Previous Events</b> (any other acute events prior to the current reason for attending)								
Myocardial Infarction□ Acute Coronary Syndrome □ Bypass Surgery □ Angioplasty □ Cardiac Arrest□ Angina□ Other Surgery □ Heart failure□ Pacemaker□ ICD□ Congenital Heart □Transplant□ LV Assist Device□ Other								
Co-morbidity (from case notes or patient completed questionnaires)								
Angina □ Arthritis (osteoarthritis) □ Cancer □ Diabetes □ Rheumatism (rheumatoid arthritis) □ Stroke □ Osteoporosis □ Chronic bronchitis □ Emphysema □ Asthma □ Claudication □ Thyroid Disease □ Chronic Back Probs □ Other								

Administrative and	d Asses	sment de	tails:						
Assessment/Interview Date:					Risk Assessment: Low□ Moderate □ High □				
Identified Risk Factors: Hyperlipidemia □       HT □       Smoker – Current □         Reformed □       Sedentary lifestyle □       Social isolation □       Depression/Stress/Anxiety □         Family History □       Diabetes – Type 1 □       Type 2 □       Overweight □       Obesity □									
<b>Percentage of AHGP completed</b> : 0% □ 1-25% □ 26-50% □ 51-75% □ 76-99% □ 100% □									
Reason for non completion: Achieved aims or goals prior to completion □ Program did not fulfil needs □ Planned/emergency intervention □ Too ill Died □ Returned to work □ Other/Unknown □									
Examinations & Tests (as per protocol in your centre)									
Weight:	kg H	leight:	cn	n <b>B</b> l	MI:	(	Girth:	cm	
Blood Pressure:	/	mm	n Hg	Yes If ye	s, are th	smoked in l No □ ley willing to No □	Unknow	n □ king?	
Cholesterol: Total: HDL: LDL: Triglycerides: mm/l									
<b>Drugs</b> (case record or patient self completion questionnaire)									
Aspirin □ Clopidogrel □ Warfarin □ ACE inhibitor □ Beta Blocker □ Statin □ Other □									
Physical Activity									
Physical Activity Ra	ty Rating 1a. Strenuou			:	1b. Mo	oderate:	1c. Mild:		
2a. Often □ 2b. Sometimes□ 2c. Never/Rarely □		Physical Activity – 30 min duration 5 times a week.  Yes □ No □							
Physical Fitness Score: Very Heavy □ Heavy □ Moderate □ Light □ Very light □									
Daily Activity Score: No difficulty at all ☐ A little bit of difficulty ☐ Some difficulty ☐ Much difficulty ☐ Could not do ☐									
Qualify of Life Scores and various other evaluative questionnaires									
HADS A-Score D-Score			MacNew completed $\square$ IPQ completed $\square$						
heiQ completed □ Satisfaction Survey Completed □									
No of self reported hospitalisations  During AHGP									

# **Appendix 6: Human Research Ehics Committee (Tasmania) Network**

Office of Research Services
University of Tasmania
Private Bag 1
Hobart Tasmania 7001
Telephone + 61 3 6226 7479
Facsimile + 61 3 6226 7148
Email Human,Ethics@utas.edu.au/human\_ethics/

HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK



27 June 2008

Mr Terry Frohmader Department of Intensive/Coronary Care Medicine Launceston General Hospital Charles St LAUNCESTON TAS 7250

Dear Mr Frohmader

**REF NO:** H0009996

TITLE: The Aussie Heart Guide - Validation in Rural Communities of Tasmania

- National Ethics Application Form
- Information Sheet and Consent Form Version 2 dated June 2008
- Patient Questionnaire
- Health Education Impact Questionnaire Version 2.0
- Illness Perception Questionnaire
- Hospital Anxiety and Depression Scale
- International Physical Activity Questionnaire (November 2002)

The Tasmanian Health and Medical Human Research Ethics Committee considered and approved the above documentation at its meeting on 23 June 2008.

All committees operating under the Human Research Ethics Committee (Tasmania) Network are registered and required to comply with the *National Statement on the Ethical Conduct Human Research* (NHMRC 2007).

Therefore, the Chief Investigator's responsibility is to ensure that:

- (1) The individual researcher's protocol complies with the HREC approved protocol.
- (2) Modifications to the protocol do not proceed until **approval** is obtained in writing from the HREC.
- (3) Section 5.5.3 of the National Statement states:

Researchers have a significant responsibility in monitoring approved research as they are in the best position to observe any adverse events or unexpected outcomes. They should report such events or outcomes promptly to the relevant institution/s and ethical review body/ies and take prompt steps to deal with any unexpected risks.



#### A NEW CARDIAC REHABILITATION PROGRAM FOR RURAL PATIENTS

The appropriate forms for reporting such events in relation to clinical and non-clinical trials and innovations can be located at the website below. All adverse events must be reported regardless of whether or not the event, in your opinion, is a direct effect of the therapeutic goods being tested. <a href="http://www.research.utas.edu.au/human\_ethics/medical\_forms.htm">http://www.research.utas.edu.au/human\_ethics/medical\_forms.htm</a>

- (4) All subjects must be provided with the current Patient Information Sheet and Consent Form as approved by the HREC.
- (5) The Committee is notified if any investigators are added to, or cease involvement with, the project.
- (6) This study has approval for 4 years contingent upon annual review. A *Progress Report* is to be provided on the anniversary date of your approval. Your first report is due **23 June 2009**. You will be sent a courtesy reminder closer to this due date.
- (7) A *Final Report* and a copy of the published material, either in full or abstract, must be provided at the end of the project.

Should you have any queries please do not hesitate to contact me on (03) 6226 2763.

Yours sincerely

Katherine Shaw

Health and Medical HREC Ethics Officer

On behalf of the Executive Officer

HREC (Tas) Network



# **Appendix 7: Human Research Ethics Committee of Griffith University**

03/08/3773.

#### GRIFFITH UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE

26-Mar-2010

Dear Mr Frohmader

I write further to the additional information provided in relation to the conditional approval granted to your application for ethical clearance for your project "PRIOR: The Aussie Heart Guide - validation of in rural communities of Tasmania. The implementation and evaluation of a home-based (mentor facilitated) cardiac rehabilitation program for cardiac patients in regional Tasmania, Australia." (GU Ref No: NRS/02/10/HREC).

This is to confirm receipt of the remaining required information, assurances or amendments to this protocol.

Consequently, I reconfirm my earlier advice that you are authorised to immediately commence this research on this basis.

The standard conditions of approval attached to our previous correspondence about this protocol continue to apply.

Regards

Dr Gary Allen Manager, Research Ethics Office for Research Bray Centre, Nathan Campus Griffith University ph: 3735 5585 fax: 3735 7994 email: g.allen@griffith.edu.au

Cc:

At this time all researchers are reminded that the Griffith University Code for the Responsible Conduct of Research provides guidance to researchers in areas such as conflict of interest, authorship, storage of data, & the training of research students.

You can find further information, resources and a link to the University's Code by visiting

http://www62.gu.edu.au/policylibrary.nsf/xupdatemonth/e7852d226231d2b44a25750c00 62f457?opendocument PRIVILEGED, PRIVATE AND CONFIDENTIAL

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