# Care-seeking behaviours for worsening symptoms in heart failure

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# Certificate of original authorship

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This research is supported by an Australian Government Research Training Program Scholarship.

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# Abstract

**Purpose:** Symptoms of breathlessness, fatigue, and peripheral oedema are a part of daily life for patients with heart failure (HF). These symptoms are the number one cause of HF-related hospitalisation, yet over 50% of patients with HF delay seeking professional care for worsening symptoms. Delayed care-seeking increases the risk of emergency hospitalisation, can lead to frequent re-admissions, longer lengths of stay, and death. Little is known about what lies behind patients' decisions to seek or avoid professional care. The literature shows that misconceptions and lack of understanding of HF is common amongst patients with HF. The literature also tells us that patients with HF are likely to be cognitively impaired, have inadequate health literacy, and get most of their HF information from their providers. Whilst knowledge and understanding is assumed to be a major contributor to delayed care-seeking, educational interventions to reduce pre-hospital delay have, to-date, been unsuccessful. This thesis aimed to measure what is known to impact health related decisions, ascertain patients' educational needs and perspectives of patient/provider communication, and explore their perspectives of factors that influence care-seeking behaviour, to inform a novel approach to promote timely care-seeking in HF.

**Methods:** This mixed-methods study, guided by the self-regulation model of illness behaviour, involved 72 symptomatic patients with HF recruited from a larger longitudinal study at a tertiary hospital in Sydney, Australia. Quantitative data measuring illness perceptions, health literacy, HF knowledge, and self-efficacy were collected via validated questionnaires, and analysed using descriptive statistics in SPSS. Qualitative data eliciting patients' experiences of and attitudes and beliefs about seeking professional care, educational needs, and perceptions of patient-provider communication were obtained through in-depth semi-structured interviews with 15 participants. Interviews were conducted face-to-face in hospital or over the phone, audio-recorded, transcribed verbatim, and were analysed using interpretative phenomenological analysis (IPA).

**Results:** Interview findings revealed avoidance of care-seeking despite quantitative data reflecting high levels of self-efficacy, HF knowledge (12.3±1.9 out of 15), and above-average health literacy levels (75% adequate - 15% higher than average in HF). Participants described delayed care-seeking due to values and beliefs associated with healthcare use, and desire to avoid hospitalisation. The experience of being hospitalised represented a loss of freedom and control and served as a reminder of being ill. Perception of illness as a threat to identity led to rejection of treatment, whilst fear of being a burden to others also led to avoidance behaviours. Uncertainty about the cause and likely trajectory of symptoms often led to a 'wait and see' response, as symptoms were not perceived as serious. Professional care was often viewed as a last resort, when all alternative coping strategies were exhausted, and participants could no longer cope with the physical and emotional impact of symptoms. Patient-provider interpersonal relationships and preferences for continuity also impacted care-seeking. Participants relied heavily on providers for HF information and support, expressed numerous unmet educational needs, and had mixed feelings about quality of communication, which influenced subsequent care-seeking.

**Conclusion:** Findings suggest that whilst patients may possess skills and HF knowledge, previous healthcare experience affects subsequent action. Improving patient-provider communication is key, not only to keep patients informed, but also to build supportive, trusting relationships to encourage timely care-seeking.

## List of outputs associated with thesis

**Ivynian S.E.**, DiGiacomo M., Newton P.J. Care seeking decisions for worsening symptoms in Heart Failure: A qualitative meta-synthesis. *Heart Failure Reviews*. 2015; 20(6):655-671.

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**Ivynian S.E.**, DiGiacomo M., Jha S., Crossley C., Newton P.J. Care seeking decisions for worsening symptoms in Heart Failure: A qualitative meta-synthesis. Poster presentation - Cardiac Society of Australia and New Zealand Scientific meeting: Melbourne, Australia. 13-16 August 2015

**Ivynian S.E.**, Hwang C., McDonagh J., DiGiacomo M., Inglis S.C., Newton P.J. Poster presentation - Impact of multiple symptoms on quality of life and event-free survival in Chronic Heart Failure. Poster presentation - European Society of Cardiology Scientific Sessions: London, England. 29 August – 2nd September 2015

# List of abbreviations

**ABS** Australian Bureau of Statistics

**BIPQ** Brief illness perception questionnaire

**COPD** Chronic Obstructive Pulmonary Disease

**CSANZ** Cardiac Society of Australia and New Zealand

**DASS** Depression Anxiety Stress Scale

**DHFKS** Dutch Heart Failure Knowledge Scale

**ECG** Electrocardiograph

**ESAS** Edmonton Symptom Assessment Scale

**GP** General Practitioner

**HF** Heart Failure

**HFPEF** Heart Failure with Preserved Ejection Fraction

**HFREF** Heart Failure with Reduced Ejection Fraction

**IPA** Interpretative Phenomenological Analysis

**IRSAD** Index of Relative Socio-economic Advantage and Disadvantage

**KCCQ** Kansas City Cardiomyopathy Questionnaire

**LACE** Living and in the community with symptoms burden with heart failure **S-**

**MI** Myocardial Infarction

**MMPR** Mixed Methods Phenomenological Research

**NYHA** New York Heart Association

**PHQ** Patient Health Questionnaire

**SEIFA** Socio-Economic Indexes for Areas

**SPSS** Statistical Package for the Social Sciences

**SRM** Self-Regulation Model

**S-TOFHLA** Short Test Of Functional Health Literacy for Adults

# Glossary of terms

**Appraisal delay:** the time in which a person first notices a symptom is out of the ordinary, to which a conclusion is made that the physical sensation is a sign of illness.

**Care-seeking:** the behaviour by which a person seeks professional guidance, advice and/or care from a paid healthcare provider.

**Delay:** total time from when a person first notices a symptom, to when they enter treatment.

**Illness delay:** the time from which a person has concluded that a symptom indicates illness, to when a decision has been made to seek professional care.

**Illness representation:** or illness perception, indicates how an illness is perceived or made sense of. This includes beliefs about its identity, cause, consequences, timeline and curability/controllability.

**Multidisciplinary heart failure (HF) management program:** Multidisciplinary care programs are recommended by HF guidelines globally for all people who have been hospitalised with HF, and are symptomatic. Their aim is to provide biomedical care, self-care education and support, psychosocial care, and palliative care for patients with HF post-discharge. These programs are delivered by a multidisciplinary care team, ideally involving pre-discharge and home review by a specialist HF nurse, pharmacist, and allied health personnel with education regarding prognosis, compliance, exercise and rehabilitation, lifestyle modification, vaccinations and self-monitoring.

**Self-care:** Self-care in HF involves a range of behaviours carried out by patients to actively manage their condition. Effective self-care is paramount in the sustained management of chronic conditions such as HF. Self-care involves self-care maintenance and self-care management behaviours.

**Self-care maintenance:** Self-care maintenance refers to behaviours performed to maintain physiological stability (e.g. treatment adherence and lifestyle choices)

**Self-care management:** Self-care management involves actions taken in response to changes in symptoms when they occur. Care-seeking for worsening symptoms in HF falls into this category. Self-care management often involves complex decision-making processes that are sometimes difficult for patients to grasp.

**Self-efficacy:** Self-efficacy refers to self-care confidence, and can be defined as the perceived confidence to actively manage the chronic condition and to persist despite obstacles.

**Self-regulation:** The process by which a person copes with illness by trying to restore a sense of normalcy. Self-regulation processes occur in a constant feedback loop, where coping efforts are constantly appraised and results of this appraisal inform subsequent coping decisions.

**Symptom appraisal:** determining meaning behind symptoms and making judgements about its identity, cause, consequences, timeline and curability/controllability.

**Symptom perception:** recognising somatic sensations of symptoms i.e. perceiving their presence.

**Utilisation delay:** the time from when a decision to seek professional care has been made, to when the patient actively seeks care.

# Chapter 1
# Introduction

## 1.1 Introduction

Delayed care-seeking for heart failure (HF) symptoms remains a pertinent issue in HF self-management, as over 50% of patients with HF (hereafter, patients) delay seeking care until symptoms require emergency hospitalisation. Many HF hospitalisations are considered preventable with proper self-care. Improving self-care behaviours is, therefore, paramount to reduce the burden of HF on patients, their families, and the health system. The HF self-care literature largely focuses on medication adherence, yet, little is known about what factors contribute to delayed care-seeking and what prompts a timely response to worsening HF symptoms.

This chapter provides an overview of the epidemiology of HF in Australia, the cost associated with HF management, and the potential to reduce avoidable HF admissions through exploration of self-management behaviours. This chapter introduces care-seeking behaviour as an undervalued aspect of HF self-care, and discusses factors known to be associated with patients' capacity to self-manage. This chapter also discusses the significance of the study, presents the research aims, and outlines the structure of this thesis.

## 1.2 Defining concepts: care-seeking and delay

Within this thesis, 'care-seeking' is defined as making contact with a healthcare provider in response to worsening symptoms.(1) Calling friends or family for help or advice does not qualify as care-seeking in this definition, as the focus of this thesis is on formal care-seeking behaviour which involves making contact with a paid health provider for professional advice or care.

Furthermore, making decisions to seek care for worsening symptoms does not involve one decision only, such as to seek or avoid professional care. Safer and colleagues suggest that the time from when a person first notices symptoms to when they enter treatment actually involves three semi-independent decisions, collectively contributing to total delay time.(1) The first decision involves an individual asking themselves ‘am I ill?’ wherein the person links or does not link symptoms with illness.(1) The second decision involves an individual asking themselves ‘do I need professional care?’ wherein the person decides if symptoms are severe enough to warrant professional care.(1) The third question asks, ‘is that care worth the costs?’ and reflects the stage where the person negotiates the benefits versus the disadvantages of seeking professional treatment and makes a decision about whether to enter treatment.(1) Delay can occur at any of these three stages, and different types of factors are thought to influence delay time in each stage.(1) The concept of delay is further elucidated in Chapter 2. Within this thesis, all three stages of delay involved in care-seeking decisions in HF are explored.

## 1.3 Background

### 1.3.1 Heart failure in Australia

Heart failure is a highly burdensome chronic condition associated with multiple restrictive symptoms. The national guidelines for the prevention, detection and management of chronic heart failure in Australia defines HF as:

> *“a complex clinical syndrome with typical symptoms (e.g. dyspnoea, fatigue) that can occur at rest or on effort, and is characterised by objective evidence of an underlying structural abnormality or cardiac dysfunction that impairs the ability of the ventricle to fill with or eject blood (particularly during physical activity). A diagnosis of CHF may be further strengthened by improvement in symptoms in response to treatment”.(2)*

Heart failure is a progressive syndrome that causes the cardiovascular system to weaken over time and is often viewed as the end stage of multiple cardiac conditions. Coronary heart disease, previous myocardial infarction, and long-term hypertension are the largest contributors to the development of HF. Preceding factors that precipitate these events, including poor diet, smoking, lack of physical activity, and high cholesterol can contribute to risk of HF. As a result, comorbidities such as diabetes and excess weight (particularly abdominal obesity), are also commonly associated with HF. Multiple cardiac and non-cardiac comorbidities are a common occurrence in HF,(3) with patient rarely suffering from HF alone.

Heart failure impacts the lives of 1.5-2% of Australians, and is most commonly prevalent in the elderly, affecting 6.3% of men and women aged 60-85 years (95%CI, 5.0-7.7).(4) These figures are more than likely to increase in the years to come due to: Australia's ageing population (13.5% over the age of 65 years);(5) improved survival from myocardial infarctions;(6) increasing prevalence of diabetes;(7) and increasing rates of overweight and obesity (3 in 5 adults and 1 in 4 children were overweight or obese in 2007-2008).(8)

As an antecedent of HF, cardiovascular disease remains the leading cause of death worldwide, with HF being one of the major contributors to mortality and morbidity rates.(9) A nationwide Scottish study revealed that with the exception of lung cancer, HF prognosis was worse than all common types of cancer in men and women respectively, even on an age adjusted basis.(10) Similarly, in a US study, over half of patients died within five years of HF diagnosis, confirming poorer outcomes than most cancer related survivals.(11) The Australian Institute of Health and Welfare (AIHW) has shown that those over 85 years experience a six-fold increase in HF mortality compared to those in the 75-85 year age group.(8) The AIHW has also provided evidence of significantly higher mortality rates in Aboriginal and Torres Strait Islander populations (3.8 and 2.2 times greater in males and females respectively compared to other Australians).(8) However, over the last two decades there has been a sustained decrease in 30-day and one year mortality rates in Australia, which can be attributed to the development of more effective pharmacological therapy.(12) Improved mortality, however, indicates that patients are living longer with symptomatic HF.

### 1.3.2 Symptom burden and hospitalisation

Characteristic signs and symptoms of HF include breathlessness (dyspnoea), peripheral oedema, and fatigue. These symptoms are often a part of daily life for those suffering with HF, impacting physical function and making it difficult to carry out even the simplest of tasks. The corresponding loss of freedom and independence associated with restrictive symptoms also impacts on patients' general wellbeing. Consequences of HF symptoms, therefore, stretch beyond the physical, with studies illustrating their devastating effect on psychological and social wellbeing and quality of life.(13, 14)

Another important consequence of HF symptoms is hospitalisation. Symptom exacerbation is the most common cause of HF-related hospitalisation, contributing to the largest proportion of healthcare expenditure associated with HF management. In the UK and Switzerland, hospitalisations account for approximately two thirds of total healthcare spending on HF.(15) Similarly, data from a contemporary Australian clinical trial showed that approximately 85% of costs related to the management of HF were attributed to hospitalisations.(16) Despite promising trends in incidence and reduced mortality, an overall increase in hospitalisations has been observed (those over 65 years experienced a 40.5% increase from 1990-2005).(12) With symptoms being the main cause of HF hospitalisation and more people living with HF, these figures are not surprising. Studies have also shown that almost 50% of patients with HF are re-hospitalised at least once within 6 months.(17) Heart failure management, therefore, carries a heavy economic burden and also affects patient quality of life due to frequency of readmissions.(18)

As described, worsening symptoms, such as breathlessness and oedema, are the most common reason people living with HF present to emergency departments and are the main reason for seeking care.(19-22) Despite this, more than 50% of people with HF delay seeking care until their symptoms become so severe that they require emergency hospitalisation.(21) Delayed care-seeking is linked with an increased risk of hospitalisation and re-admission.(23, 24) Furthermore, severe symptoms on admission require more complex treatment and are associated with longer lengths of stay and higher risk of mortality.(25-27) It has been suggested that many of these hospitalisations can be avoided with effective self-care.(28-36) Part of HF self-care involves recognising signs and symptoms of exacerbation early, and making prompt decisions to seek care when necessary. As noted, HF hospitalisations are frequent and account for the majority of the cost associated with HF management. Furthermore, cardiovascular disease leads at $7.9 billion (11%) of Australia's total spending on health goods and services, and hospitals alone account for the largest proportion (39.8%) of recurrent health spending.(8) Promoting timely care-seeking behaviour in HF is an opportunity to reduce avoidable re-admissions, both to the benefit of patient outcomes, and cost to the healthcare system.

### 1.3.3 Care-seeking as an underrepresented aspect of heart failure self-care

Effective self-care is paramount in the sustained management of chronic conditions such as HF. Self-care in HF involves a range of behaviours carried out by patients, often with the help of family members or caregivers, to actively manage their condition.(37) Heart failure self-care includes both self-care maintenance and self-care management activities. Self-care maintenance refers to behaviours performed to maintain physiological stability (e.g. treatment adherence and lifestyle choices).(37, 38) Self-care management involves actions taken in response to changes in symptoms when they occur (e.g. taking an extra diuretic when needed and seeking care when necessary).(37, 38) Care-seeking behaviour falls under the umbrella of self-care management in HF self-care. Self-care management, or self-management, involves complex decision-making processes that are often difficult for patients to grasp. Despite HF disease management programs involving self-care education, engaging patients in self-care remains a challenge in HF. As noted, self-care failures are said to be responsible for the majority of avoidable HF admissions. Failure to seek treatment for worsening symptoms in a timely manner is an important aspect of ineffective self-care that leads to worse outcomes for people with HF. Delayed care-seeking is specifically an example of a self-care management failure. Whilst self-care maintenance practices, such as adherence to medications, have been well-established in the HF literature, less is known about more complex self-management practices including why patients seek or avoid professional care, and the underlying decision-making processes involved.

### 1.3.4 Barriers to heart failure self-care

Understanding the factors associated with poor self-care in general provides insight into what may influence care-seeking decisions in HF. A number of self-care theories in HF have identified key barriers to self-care management.(37, 39, 40) As care-seeking is situated within the self-management aspect of HF self-care, several of these factors are also likely to impact care-seeking decisions in HF and are described below.

#### *Lack of disease-specific knowledge*

Knowledge of the general concepts of HF, pharmacological and non-pharmacological therapy, as well as knowledge around symptom recognition, appraisal and how to appropriately respond in the case of worsening symptoms is a necessity for effective self-management. Patients must primarily have knowledge of these topics in order to follow with the appropriate action. Whilst these vital topics of education are promoted by HF guidelines worldwide, it is recognised that knowledge alone is not sufficient to change behaviour.(41)

#### *Health literacy*

Moser's model of HF self-care(37) and the Middle Range Theory of Self-Care of Chronic Illness(39) feature health literacy as a key factor influencing decision-making in HF self-care. Health literacy impacts a person's ability to understand and act on health information, and has been recently identified as an area of concern in HF, as almost 40% of people with HF have low levels of health literacy.(42) Low health literacy is associated with poorer health outcomes and use of healthcare services (greater use of emergency care and hospitalisation, lower probability of the use of preventative services).(43) A recent study has also confirmed health literacy as an independent predictor of self-care behaviour in HF.(44) Health literacy is therefore a key outcome in health education, not just in HF, but across all populations.

The World Health Organization (WHO) defines health literacy as follows:

> *"Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health"*(45)
>
> *"Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment"*(45)

This definition reflects the three different types of health literacy, together epitomising its general concept: basic/functional literacy; communicative/interactive literacy; and critical literacy. Each of these concepts are differentiated based on what each type of literacy allows you to do.(46) Basic/functional literacy refers to reading and writing skills that allow effective functioning in daily life.(45) Communicative/interactive literacy requires more advanced cognitive and literacy skills that enable interpretation of different forms of communication, which can be used to participate in everyday activities. In combination with social skills, communicative/interactive literacy enables people to apply new information to changing circumstances.(45) Critical health literacy requires even more advanced cognitive skills which, together with social skills, can be used to critically analyse information, similar to communicative/interactive literacy, but also to use this information to exert greater control over life events and situations.(45) Moving between these levels of literacy is, therefore, inherently dependent on cognitive skills,(45) which is also problematic in HF. Prevalence of cognitive impairment in HF varies from 25%(47) to 80%(48) depending on how cognition is assessed.(39) Memory, attention, and problem solving are affected in this population and have been shown to have direct negative consequences on the capacity to engage in self-management.(49, 50)

There is hope for improving health literacy in patients with HF, as health literacy is also dependent on exposure to different information/health messages and the way these are delivered.(45) Adequate access to, and quality of, health communications are vital in improving health literacy in HF. Improving health literacy enables a greater level of autonomy and empowerment.(45) Delivering health messages in such a way that facilitates health literacy draws attention to patient-provider communications as key opportunities to educate and empower patients to engage in self-management. A focus not only on *what* information is delivered, but *how* information is delivered is invaluable in the effort to promote health literacy in this population.

### *Self-efficacy*

Self-efficacy, or self-care confidence, can be defined as the perceived confidence to actively manage the chronic condition and to persist despite obstacles.(51) Self-care confidence has been shown to be an important factor influencing HF self-care, even more so than cognition in one study.(52) In a recent systematic review, perceived self-efficacy was also linked with better self-care.(53)

Additionally, the construct that is health literacy posits that exposure to health information/messages is impacted by a person's response to this communication, which is mediated by personal and social skills, and self-efficacy in relation to defined issues.(45) In other words, patients with HF with lower self-efficacy may be less inclined to access information about their condition and are likely to respond differently to health communications pertaining to their condition compared to those with higher self-efficacy. This may explain the outcomes associated with self-efficacy in HF self-care and likely plays an important role in health-related decisions including care-seeking.

### *Affective symptoms*

Depressive and anxious symptoms are common in HF. (54) It has been well documented that depression and anxiety can interfere with one's capacity to self-manage,(55) with particular inferences for adherence to treatment regimes,(56) and implications for psychosocial adaptation and coping.(57-59) A recent systematic review in HF revealed that in addition to cognitive impairment, anxiety and depression can decrease patients' ability and interest in performing self-care.(53)

### *Illness perceptions and self-regulation*

Whilst these factors are known to impact self-care behaviours in HF, the purpose of this thesis is to explore a specific act of self-management in HF – care-seeking. Making decisions to seek or avoid professional care are likely to be affected by the above-mentioned factors; however, the principles of self-regulation more specifically describe processes that may be involved in this self-care management practice. The self-regulation model of illness behaviour, or SRM, proposes that how a person will respond or cope with a health 'threat' is dependent on symptom perception, cognitive representations of the health threat (i.e. what the health threat means to the person, and their emotional response to it). Heart failure symptoms are a highly personal and individualised experience, and thus, the way patients decide to act upon their exacerbation is dependent on how they conceive their health situation. Beliefs associated with HF have already been shown to impact compliance in HF,(60) but their impact on care-seeking behaviour has yet to be explored. The SRM provides a framework for exploring patients' perspectives and representations of their illness and symptoms to better understand how they problem solve to cope with worsening symptoms, whether it be to seek immediate care, or delay. The SRM and its potential use in HF is described in further detail in Chapter 2.

## 1.4 Significance of the study

It has been proposed that early recognition and a timely response to worsening HF symptoms may reduce HF-related hospitalisations by up to 50%, (61, 62) yet research is scarcely focused on this component of self-care management. Other aspects of HF self-care, such as adherence to medications, are well-established in the literature. Yet, little is known about the decision-making processes involved in care-seeking in HF. Whilst other disease populations are generally encouraged to self-manage and avoid utilising professional health services, prompt care-seeking is urged in people with HF. Characteristic HF symptoms are vague and often difficult to appraise.

Fatigue, peripheral oedema and breathlessness can easily be overlooked and interpreted as non-illness related bodily sensations, or linked with other comorbid conditions that share a similar symptomology. People with HF often do not recognise and act on symptoms in a timely manner, leading to acute HF symptom exacerbation that cannot be effectively managed at home. The negative outcomes associated with seeking care only when symptoms are severe and unbearable (high readmission rates, long lengths of stay, poorer quality of life) makes timely care-seeking a priority in this population.

The SRM provides a framework where the core tenet is to understand how personal representations of illness and symptoms drive decision-making. With the shift away from the traditional medical model and rise of person-centred care where providers work together with patients to develop appropriate solutions, understanding patient perspectives/representations is key in the provision of best-practice care. The SRM has been used extensively to understand and address factors contributing to pre-hospital delay for symptoms of acute myocardial infarction (AMI) and stroke.(63-70) This study is the first to use the principles of self-regulation to illuminate how personal representations of symptoms and illness can impact care-seeking in a HF population.

Whilst the HF self-care literature has provided invaluable insight into factors contributing to self-care in general, little is known about how more complex cognitive and personal factors influence response to worsening symptoms and lead to delayed care-seeking. The underlying processes of care-seeking decisions in HF remain unclear. A combination of what is already known and the exploration of what is not well understood through theory-driven mixed methods research can offer advanced insight into treatment-seeking decisions in HF. Furthermore, a focus on health communication in this population is vital given the issues around health literacy and the importance of providing *usable* information to empower patients to become more engaged in self-management.(71) Insight into patient preferences and perceptions of health communications can provide HF-specific targets for intervention. Identifying and exploring factors that influence timely care-seeking in HF may facilitate opportunities to develop targeted interventions to reduce patient delay and improve outcomes including, hospitalisation, mortality and quality of life whilst reducing the high cost associated with HF management. For these reasons, this thesis adopted an exploratory sequential mixed methods approach, with a qualitative emphasis, to provide the best chance of capturing the complexities of care-seeking, and answering the research questions detailed below.

## 1.5 Research aim

The purpose of this thesis is to explore care-seeking behaviours in patients with heart failure to provide a better understanding of patient decision-making by:

### 1.5.1 Objectives

1. Identifying a comprehensive range of factors that influence how patients with HF respond to worsening symptoms; and
2. Exploring ways in which these factors influence care-seeking decisions through the integration of qualitative and quantitative findings.

### 1.5.2 Research questions

1. What are the factors that influence care-seeking in HF?
2. How do Australian patients with HF perceive and understand their health condition and symptoms?
3. In what way do patient-, provider-, and systems-level factors influence care-seeking decisions in an Australian HF population?
4. What are Australian patients' perceptions of and preferences for HF information delivery and patient-provider communication?
5. How do Australian patients with HF make decisions to seek or avoid professional care in the context of illness perceptions, self-efficacy, affective symptoms and health literacy?

6. What are Australian patients' perceptions and preferences of HF information delivery and patient-provider communication in the context of health literacy and HF knowledge?

## 1.6 Structure of the thesis

**Chapter One** describes the prevalence of HF in Australia and outcomes associated with the chronic condition, both in terms of those affected and costs associated with HF management. The problem of delayed care-seeking is introduced and posited as a way of reducing avoidable HF admissions and the deleterious outcomes associated with delay. Key factors known to impact self-care management are defined and the importance of understanding patient representations to understand care-seeking behaviour is highlighted. The significance and aims of the study are described in this first chapter.

**Chapter Two** describes the concept of delay and elucidates the processes of self-regulation according to the self-regulation model (SRM) of illness behaviour. This chapter provides an in-depth explanation of how the concepts of self-regulation can be used to better understand decisions to seek professional care in HF.

**Chapter Three** presents a qualitative meta-synthesis identifying factors influencing care-seeking decisions in HF, addressing the first research question of this thesis. Findings show that whilst many factors that influence patients' decisions to seek or avoid care are accounted for in the SRM, provider and system-related factors that are vital in care-seeking decisions are not well-represented or unaccounted for in the model. This suggests the need for further consideration of the impact of previous healthcare experiences in subsequent care-seeking behaviour.

**Chapter Four** describes the quantitative and qualitative methods used to fulfill the aims of this mixed methods thesis, and provides justification for the methodology adopted. Ethical considerations are also discussed in this chapter.

**Chapter Five** details the quantitative findings of this study, providing clinical and demographic information about the study cohort and presenting results from the self-report questionnaires measuring factors known to impact health-related decisions including health literacy, HF knowledge, illness perceptions, affective symptoms, and self-efficacy.

**Chapter Six** reports findings from in-depth semi-structured interviews detailing patient, provider- and systems-related factors contributing to care-seeking decisions for worsening HF symptoms.

**Chapter Seven** reports findings from in-depth semi-structured interviews pertaining to preferences for information delivery and perceptions of patient-provider communication in HF.

**Chapter Eight** integrates quantitative and qualitative findings and discusses results within the context of the SRM and the wider literature. Implications for policy, practice and research are also discussed and the strengths and limitations of the study are described.

## 1.7 References

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# Chapter 2
# Conceptual framework

## 2.1 Introduction

Over 38 million people worldwide have chronic heart failure (HF) (1) and live with limiting symptoms such as breathlessness, fatigue, and oedema on a daily basis. As described in the previous chapter, rapid worsening of HF symptoms, otherwise known as acute symptom exacerbations or acute decompensation, is the number one cause of HF-related hospitalisation (2). Reducing readmissions to hospital remains a key objective in the management of HF, as HF hospitalisations are often frequent (3-5) and associated with long lengths of stay (6) and mortality (7, 8). Whilst some HF hospitalisations are unavoidable, it has been proposed that 50% are due to poor self-care, and thus, can be prevented (9-11).

Self-care maintenance behaviours, such as adherence to medications and strategies including adherence to fluid restrictions, have been widely studied in the HF literature. However, little is known about the processes underlying decisions to seek professional care for worsening HF symptoms – a self-care management behaviour. More than half of people with HF delay seeking professional care (12), which signals the urgency of this area of research to promote timely care-seeking in HF. Acting on HF symptoms before they reach the stage of acute decompensation may reduce preventable HF hospitalisation, length of stay, health care expenditure, and death.

Avoiding hospitalisation is an important outcome that signifies decreased cost and burden to the patient and health care system. Yet, it is vital that patients do seek professional care upon symptom exacerbation in HF, regardless of an emphasis on avoiding healthcare utilisation. Patients may perceive mixed messages – on the one hand, we want to do everything possible to keep them out of hospital; on the other hand, we want them to seek out professional help (i.e. call an ambulance or healthcare professional and attend hospital) when their symptoms are getting worse. Given the nature of HF symptoms and the widespread 'wait and see' attitude adopted by most patients with HF, which often leads to worse outcomes, patients with HF are urged to call for help as soon as they notice worsening symptoms.

Whilst factors influencing pre-hospital delay in patients with acute myocardial infarction (AMI) have been extensively studied, there is little research offering a framework specific for patients responding to HF symptoms. A timely response is paramount for both AMI and patients with HF, as presenting to hospital or calling for help early when symptoms are less severe makes treatment less complicated and more effective and ultimately requires less time in hospital. Heart failure symptoms, however, have the added complexity of being unpredictable and inconspicuous in nature. Heart failure symptoms are not always easily identifiable as they are often masked by other comorbid conditions with corresponding symptoms. Furthermore, HF symptoms that are indistinct by nature, such as fatigue and breathlessness, are often misattributed to benign causes, such as ageing. Living with HF symptoms can feel like a rollercoaster ride (13), as fluctuations in presence and severity abound. Heart failure patients, therefore, require an expert level of self-care management skills to distinguish HF symptoms from other 'normal' bodily sensations. They must be able to interpret subtle cues that are indicative of a forthcoming symptom episode in order to act appropriately in a timely manner.

To explore this decision-making process involving if/how HF symptoms are recognised, appraised, and acted upon, this chapter discusses how Leventhal's Self-Regulation Model (SRM) of illness behaviour can be applied to patients with HF. Understanding the factors involved in decisions to act or not act upon symptoms can shed light onto ways to address delayed care-seeking behaviour and promote a timely response to worsening symptoms. The stages of delay in HF are described in this chapter before a discussion of how the SRM can be used to understand care-seeking behaviours in HF.

## 2.2 Stages of delay in heart failure

It has been suggested that delay should be conceptualised as a separable measure involving 3 semi-independent stages; appraisal delay, illness delay, and utilisation delay, as defined below:(14)

***Appraisal delay****:* the time in which a person first notices a symptom is out of the ordinary, to which a conclusion is made that the physical sensation is a sign of illness. This is the stage where individuals ask themselves 'am I ill?' (e.g. a person with HF experiencing increasing levels of breathlessness concludes that the sensation is in fact due to HF, rather than lack of fitness).

***Illness delay:*** The time from which a person has concluded that the symptom indicates illness, to when, a decision is made to seek professional care. This is the stage where individuals ask themselves 'do I need professional care?' (e.g. the person with HF decides that self-care is no longer sufficient in relieving his/her breathlessness and professional care is required)

***Utilisation delay:*** the time from when a decision to seek professional care has been made to when the patient actively seeks care. In this stage, patients overcome perceived barriers to the utilisation of services. This is the stage where individuals ask themselves 'is that care worth the costs?' (e.g. the person with HF decides that the benefit of seeking professional care outweighs the financial and psychological cost, overcomes these barriers, and seeks professional care)

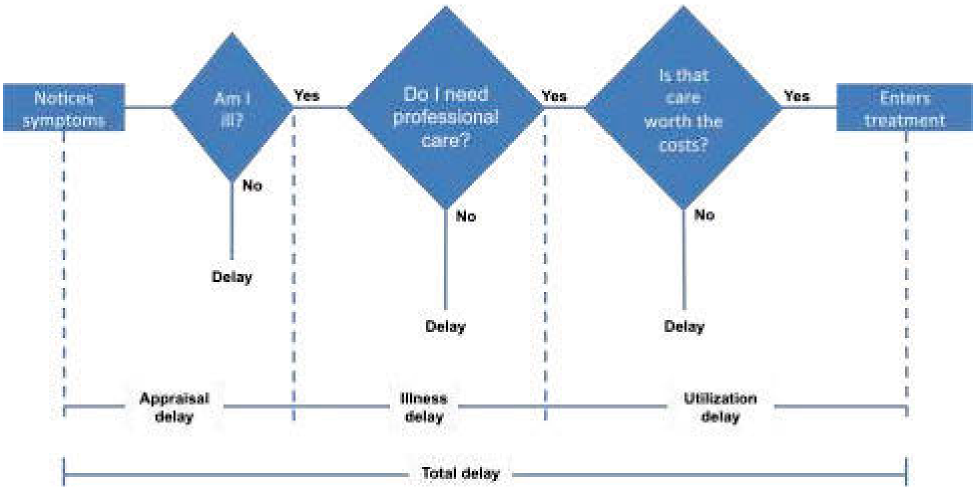

Figure 2.1 Decisions to seek or delay care in three stages of an illness episode
Safer et al, 1979(14)

The sum of these 3 stages (Figure 2.1) represents total delay time until a person actively seeks professional care after recognising a symptom. The processes involved within each of these stages may differ greatly from one another. Thus, the rationale for conceptualising delay as a separable measure is that a homogenous measure would confound the impact of multiple factors that influence delay. Although conceptually independent, each stage may vary in length and therefore the length of delay in one stage may impact the length of delay in another (14). Various factors that impact each stage of delay, using examples in HF, are discussed below.

### 2.2.1 Factors influencing appraisal delay

Safer and colleagues suggest that predictors of appraisal delay include perceptual and sensory factors that impact awareness of symptoms, such as noticing physical sensations and its attributes. How these physical sensations are made sense of or appraised, whether it is through active monitoring, passive monitoring, or information seeking, also impacts this stage of delay(14).

Examples of sensory and perceptual factors that impact appraisal delay in HF involve issues in relation to poor HF symptom specificity in combination with reduced patient sensitivity to HF symptoms. HF symptoms are inherently non-specific and can be misattributed to a range of causes. Well-defined and severe symptoms are likely to lead to a rapid appraisal that there is a specific issue (14). However, patients with HF often suffer multiple comorbid conditions with overlapping symptoms, making it difficult to attribute symptoms to HF, specifically (15). Another example of poor specificity is that patients with HF often describe vague non-descript feelings of being ‘unwell’ rather than concrete identifiable symptoms (15). To further compound confusion, patients often develop reduced sensitivity to symptoms over time. For example, patients may grow accustomed to persistent symptoms, such as peripheral oedema, and fail to notice their presence over time or take steps to minimise impact (16). These perceptual and sensory factors lengthen appraisal delay in HF, extending the time from which a patient first notices a symptom, to when it is linked with HF.

Noticing the physical sensation of a symptom alone, however, is unlikely to prompt care-seeking behaviour. An appraisal process is also involved before making the decision to seek professional care. Different types of appraisal include active monitoring, passive monitoring, and information seeking (14). The chosen process of appraisal impacts the length of appraisal delay.

Active monitoring involves monitoring symptoms for changes, new symptoms, or disappearance, and subsequently testing out strategies to alleviate them before seeking care. Passive monitoring involves thinking about the symptom and what it means, or trying to ignore symptoms and carry on with daily life as usual, a common response in HF (16, 17). As there is no criteria for action in passive monitoring, this type of appraisal process is linked with increased delay, as opposed to active monitoring (14). It is unclear how information-seeking impacts appraisal delay. On one hand, seeking information through reading could lead to further information searching rather than decision-making (14). On the other hand, seeking information from others may propel appraisal, as people are more likely to perceive symptoms as serious and requiring medical attention when they are present in other people rather than when they experience symptoms themselves (18). The HF literature demonstrates that those who employ passive monitoring strategies do experience longer appraisal delay (15, 16), however the impact of information-seeking on appraisal delay is an area not yet explored in the context of HF.

### 2.2.2 Factors influencing illness delay

Predictors of illness delay include factors that impact the perceived severity of symptoms and cause patients to believe they can or cannot treat symptoms adequately themselves. Emotions and attitudes towards receiving professional treatment are also predicted to influence illness delay.

Illness delay is another problem area in HF as patients often downplay the severity of symptoms, perceive them as minor, or believe that they are able to cope with them effectively at home. As a result, patients are often reluctant to call for help (19). Secondly, when an individual accepts that they are ill in the appraisal stage, negative emotions may result and carry on into the illness stage. These negative emotions may either motivate health behaviour, or lead to maladaptive coping. The latter response has been exemplified in patients with HF (20), where in some cases, patients have turned to self-harm, alcohol or cigarettes to cope with the incapacitating physical and psychological burden of living with chronic illness.

Attitudes towards receiving professional care also have a strong impact on patients' decisions to seek care for worsening symptoms. Safer and colleagues state that when beliefs about the curability or controllability of the health threat are stronger than the beliefs about the discomfort caused by treatment, illness delay will be reduced (14). In HF, previous negative experiences in hospital caused greater discomfort than the experience of severe symptoms for some, motivating avoidance behaviour relating to interaction with the health care system (19, 21).

### 2.2.3 Factors influencing utilisation delay

The cost and inconvenience of care-seeking, competing personal problems, perceived barriers between patient and physician, and difficulty navigating health services are proposed predictors of utilisation delay (14).

In HF, this stage is generally very short as patients typically make the decision to seek professional care at the point where immediate care is absolutely necessary. The two preceding stages of delay are comparatively much longer in HF, however, utilisation delay is still described in this population. The cost of care-seeking has been described as a reason why patients did not seek care earlier (16), and the literature also reveals that managing HF symptoms is not always the priority for those who have competing caregiver responsibilities.

## 2.3 Using Leventhal's Self-Regulation Model of illness behaviour in heart failure

The first half of this chapter explained the concept of delay, the importance of regarding it as a separable measure, and various factors that may influence each stage in HF. The following sections detail how the self-regulation model of illness behaviour can be applied to HF to further enhance our understanding of the complex processes involved in making decisions to seek professional care for worsening symptoms in HF.

Seeking professional care can be conceptualised as a coping process that people with HF choose to act upon if they perceive it is the most appropriate way to adapt to threatening symptoms. Leventhal's Self-Regulation Model (SRM) of illness behaviour (22-25) has been widely used to understand how people adapt to health threats. The basic principles of self-regulation have been used to explore a variety of health behaviours in illnesses such as hypertension (25), osteoarthritis (26), end stage kidney disease (27), and cancer (28). In its early years of development, the SRM was used to explore determinants of delayed care-seeking in patients seeking medical treatment in a clinic for a symptom for the first time (14). More recently, a self-regulatory approach has been used to study delayed care-seeking for symptoms of acute myocardial infarction (AMI) (29-31). Despite its ability to unravel the processes underlying care-seeking decisions, the SRM has not yet been applied to understand care-seeking for HF symptoms. The use of the SRM in HF facilitates the in-depth study of care-seeking behaviours, revealing problem areas that can become targets for intervention to reduce delay and its associated negative outcomes.

The main feature of the SRM is that it focuses on patient models to explain behaviour. Patient models reflect the world according to the patient. This includes how they conceive their condition, and how they best see fit to manage it. Understanding patient models is crucial in order to promote behaviour change. This is particularly vital for practitioners who can, through communication during clinical encounters, potentially identify misconceptions in patient models, explain their detrimental effect, and help reshape and replace these misconceptions in order to redirect patients towards appropriate health behaviours (32, 33). This approach has proven successful in improving medication adherence in those with hypertension (34). Results from this study showed that when physicians were trained to address patient models, which included the meaning of symptoms, their perceived timeline, and consequences, patients were able to maintain blood pressure control significantly better than those who received standard care (34). Understanding patient reality, the realm in which health decisions are made, is, therefore, key to providing tailored information to help reconstruct representations that inform health behaviours. Practitioners are thus confronted with the dual task of treating patients bio-medically, but also for behavioural management (35). For patients suffering chronic illnesses in particular, attention to behaviour is crucial to ensure effective long-term management and improved outcomes (35).

To illuminate these valuable patient models, this chapter discusses the application of the SRM in HF, with a specific focus on how patients' perceptions of reality impact care-seeking behaviour.

### 2.3.1 Development of the model

The SRM (alternatively known as the common sense model of self-regulation, the illness perceptions model, the illness representations model, the parallel response model, dual process model, or Leventhal's model) describes how representations of reality inform coping decisions and direct coping processes in a continuous feedback loop. The cognitive revolution of the 1950's and 1960's saw the dominant behaviourist approach to psychology shift to cognitive psychology. This shift is exemplified in the SRM, which represents patients as active problem solvers who regulate their own health practices, rather than passive respondents to health information upon whom we could impose health actions (36).

The SRM integrates two theoretical approaches to explain the motivation of health behaviours; the health belief model (37), which represents the directive (choice) aspect of motivation, and the fear drive model (38), which represents the intensive (drive) aspect of motivation (39).

#### *The Health Belief Model*

According to this directive approach, when faced with a health threat such as HF, people will decide how to respond based on four variables that collectively form a cognitive representation of their illness. These variables include: perceived vulnerability to the threat, perceived severity of the threat, perceived benefits versus cost of taking recommended action, and finally, cues prompting action, such as symptoms (37). The latter is an important variable, turning favourable attitudes towards taking the recommended action, into taking the action itself. For example, a patient must perceive that they are at risk of HF, believe its consequences are of great severity, and must believe the benefits of treatment outweigh the potential cost (monetary cost and personal cost), in order to be motivated to seek professional care. According to the Health Belief Model, these motivations are translated into action only in the presence of appropriate cues, which in this case, are worsening HF symptoms, such as breathlessness. These health beliefs are multiplicative, with any increase in each of these variables leading to an increased likelihood of adopting the health behaviour (40).

This model, however, does not account for the influence of emotions and makes the assumption that the changes in health beliefs or attitudes, combined with cues to action, will lead to changes in health decisions and behaviour (36). As shown by Leventhal's early work, threatening health communications led to adoption of favourable health attitudes, but did little to influence behaviour (41, 42). Only when fear-arousing messages were combined with specific instructions explaining how to operationalise behaviours, did participants engage in the recommended health behaviour. This evidence suggests that information highlighting the frightening consequences of delay such as emergency hospitalisation, frequent, long, and complicated admissions, and even death, may lead to favourable attitudes towards seeking timely care, but unless patients with HF are given specific instruction about exactly when and how to get help, the fear-arousing information is unlikely to cause behaviour change.

### *The Fear Drive Model*

The fear drive model postulates that a health threat triggering fear will cause a response involving thoughts and actions to reduce the fear. According to this approach, fear induced by the health threat will cause emotional discomfort or tension, stimulating action, in which there is a linear relationship between level of discomfort and motivation to act. For example, unbearable HF symptoms affecting a patient's sleep, daily life, and ability to carry on with regular activities are likely to motivate action to a greater degree than more tolerable subdued symptoms that do not interfere with daily life to the same extent. In response to the threat of fear-inducing HF symptoms, patients will generate a list of potential strategies to eliminate the fear. Strategies may include professional care-seeking, ‘wait and see’, adapting medication dosages, or adapting daily routine to alleviate symptoms. Patients will then choose the most effective method of reducing fear by figuratively or literally ‘trying out’ each of these responses. The most effective fear-reducing strategy is then decided and acted upon (36).

The part of the health threat that evokes fear is important to note, as this may explain failure to manage health threats that arouse a high level of fear. Fear messages may be induced by the illness, its symptoms, its long-term consequences, or by procedures involved in treatment and hospitalisation. Health behaviours may deviate from the recommended health-promoting practice if the fear is attached to the action itself rather than the health threat. In HF, fear attachment is somewhat problematic. A recent review has revealed that patients are often motivated to act, not because of fear of HF and its associated symptoms, but driven by fear of hospitals, fear of being a burden, fear of losing independence and control, and even fear of heart transplant (43). Therefore, patients acting on these bases delay care-seeking, as the threat to their independence is greater than the threat of HF, or that their fear of hospitals and seeking care motivates avoidance behaviour. For example, patients who were afraid of being confined in a hospital delayed care-seeking, as receiving treatment in hospital was viewed as a threat to their independence (21). Fear was attached to the notion of treatment, which drove coping processes in an unexpected direction (delay).

Another important consideration is that fear may be debilitating and result in loss of hope. People may feel unable to take the necessary actions to manage the threat, and lack the confidence to generate and execute coping processes. Rosen and colleagues found that when those with low self-esteem were exposed to a health message that evoked high levels of fear, they were less likely to take recommended actions. Recommended actions were adopted, however, when their self-esteem was boosted before exposure to a threat (44). This is an important point to note, as many people with HF struggle with low self-concept (20, 45-47), and depression (prevalence of up to 40% in those with severe symptoms) (48), which is an independent predictor of re-hospitalisation and death (49), and influences care-seeking decisions (50). A study by Dickson and colleagues revealed that patients with HF reporting depressive symptoms were more likely to cope with worsening symptoms by *'taking to bed'* and *'waiting it (symptoms) out*'. Self-care in general was often neglected during depressive episodes, and patients had no motivation to act on symptoms or take medications, becoming hopeless and adopting the belief that therapy was not effective (50). This highlights the potential benefit of patient empowerment to help these patients feel able to protect themselves from the threat of HF. This should involve providing encouragement and a specific action plan to effectively manage HF symptoms, as these patients are unable to generate their own.

As demonstrated, emotional responses can strongly motivate coping processes, but the direction of the chosen process is reflective of the cognitive representation of the health threat and interpretation of fear. The SRM integrates both the cognitive response and the emotional response, generating a more comprehensive model to help understand how people adapt to health threats, which is appropriate in HF.

### 2.3.2 Key features of the Self-Regulation Model

#### *Prototypes*

Patients must first perceive a state of illness, or detect a deviation from the 'norm', in order to stimulate self-regulatory processes. This is the first step in the care-seeking process (35). Recognising deviations from a normal state is dependent on how an individual defines their 'illness' or 'wellness' prototype. Underlying prototypes of the physical and functioning self can change over time with age, in circumstances of accident, disease, and even based on observations of others. What is perceived as 'normal' in HF often includes persistent breathlessness, social isolation, and fatigue shadowing daily activities. Patients often grow accustomed to HF symptoms, and for this reason, view them as not out of the ordinary and thus, do not perceive any reason to alleviate symptoms through self-regulatory processes. In the study of delayed care-seeking by Safer and colleagues, ongoing symptoms were the best predictor of total delay, which presumably became part of these patients' 'normal' prototypes.

### *Stages of the Self-Regulation Model*

The SRM can be divided into three stages (**Error! Reference source not found.**). The first stage involves constructing a representation of the health threat. Representations give meaning to health threats and provide definitions. Generating representations requires interpretation of both abstract and concrete information. In the second stage, action planning or coping processes are then developed, selected, and performed, based on representations constructed in the first stage. In the third stage, coping processes are evaluated based on set criteria to appraise the effectiveness of regulating the health threat. This final stage is called the appraisal or monitoring stage which feeds back to any of the previous stages (i.e. appraisal of chosen coping procedure can reshape illness representations) (23).

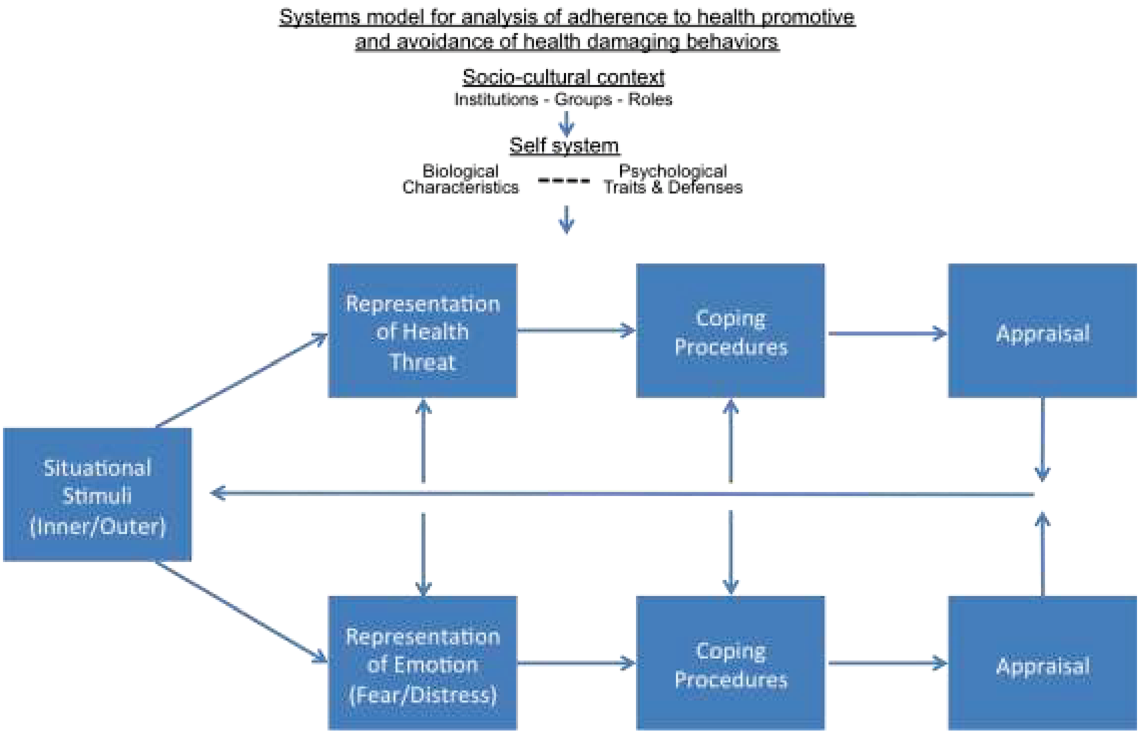

Figure 2.2 Self-regulation model (51)

*Stage 1 – Representation of health threat and emotion*

The cognitive representation (objective representation) of the health threat includes five attributes that help define the illness for the individual. Four of these five attributes overlap with the health belief model and form the basis on which coping processes are generated. These attributes are:

1) *Identity:* labels for the symptoms and illness
2) *Cause:* perceived contributing factors
3) *Consequences:* physical, social, and economic consequences
4) *Duration/timeline*: whether the threat is acute, cyclical, or chronic in nature
5) *Cure/control*: potential for curing or controlling the health threat

This cognitive representation is formed from both current and previous experience and abstract and concrete information. Current experience includes concrete sensory perceptions of changes in symptoms and mood, as well as abstract information from external sources such as providers, family, friends, and media. Input from previous experience includes concrete memories of symptoms that were associated with an illness episode, as well as abstract memories of health information about friends and family. Both sources of input are integrated across the illness trajectory to form an up-to-date cognitive representation of the health threat. Cognitive representations are therefore not static, and are constantly being updated.

A fundamental issue in HF, is that many patients have unclear cognitive representations of their condition. Few patients are able to assign appropriate labels to both their condition and their symptoms (43), and many attribute HF symptoms, such as breathlessness and fatigue, to factors such as old age or comorbid conditions (17, 52). Whilst many are aware of the restrictive consequences on daily life, few recognise the severity of their condition (16). A common misconception is the acute nature of their condition. Despite HF diagnosis, patients do not often recognise that symptoms are indicative of an underlying chronic condition, instead adopting an acute model perspective of illness (16). Finally, whilst some believe it is a personal responsibility to manage symptoms and seek professional care when necessary, others resign this responsibility to others (e.g. healthcare providers or family members), perceiving that they have little control over the situation (17).

The emotional representation (subjective representation) of the health threat includes feelings such as fear, distress or anxiety, which the individual also generates coping processes to regulate. Emotional arousal is highly receptive to concrete information. Sights, sounds, and other sensory perceptions are more likely to evoke an emotional response, rather than abstract verbal health communications highlighting the threat of the illness. For example, episodes of acute breathlessness, or memories of the acute episode where patients recall desperately gasping for air, would evoke fear to a greater degree than verbal or written information about the threat of symptoms.

### *Stage 2 – Coping processes*

Coping processes can be defined as cognitive and behavioural actions that are taken, or not taken, to restore a sense of normalcy in response to a health threat (53). The chosen coping process is based on cognitive representations formed in the first stage. For example, mild breathlessness that is perceived to be due to being unfit might prompt decisions to engage in greater physical activity, whereas severe breathlessness that is attributed to HF is more likely to lead to a decision to seek professional care. Coping procedures are embedded in 'IF-THEN' rules, where the 'IF' signifies aspects of a patients' cognitive representation (perceived identity, cause, timeline, curability and consequences), and the 'THEN' represents the action (coping process) that needs to be taken according to the representation (54). For example, IF it is fitness related, THEN take up more exercise.

### *Stage 3- Appraisal*

Representations are constantly updated. If the generation and performance of coping procedures is formed by the representation of the health threat, then the performance and appraisal of coping procedures in turn shapes the representation of the health threat. In the appraisal of coping procedures, the ‘IF-THEN’ rules operate in reverse, where the ‘IF’ involves evaluation of the coping process, and the ‘THEN’ is the newly formed representation of the health threat. Using the same example as above, if a patient with HF experiences breathlessness walking to his mailbox and attributes the physical sensation to his perceived reduced fitness level, he may decide to engage in a greater level of physical activity. As a consequence, he may experience even more breathlessness and will be forced to reconsider and reshape the notion that his breathlessness is due to poor fitness.

### *Parallel processing*

The SRM also postulates that self-regulation involves two types of feedback loops; one for the regulation of subjective emotion (emotion control), and one for the regulation of the objective health threat (danger control). These two processes are partially independent of one another (hence the name dual-process model, or parallel-process model) and thus, individuals will develop two separate coping processes to regulate the objective health threat, and regulate subjective emotion, such as fear and distress, respectively. Generating separate plans to regulate each feedback loop means that coping processes can either be congruent with one another (mutually facilitating) or mutually interfering (36). For example, coping process developed according to fear representations, may conflict with the coping process generated by the objective health threat. Heart failure patients who experienced previous negative hospital admissions involving painful procedures and providers they perceived to be disrespectful and incompetent led to the development of fear of receiving treatment in hospital (19-21). Therefore, despite suffering severe symptoms requiring medical care, patients did everything in their power to regulate the threat of hospitalisation by engaging in harmful avoidance behaviours. Fear was attached to the notion of treatment, which drove coping processes in an unexpected direction (delay).

### *Hierarchical processing*

Another important feature of the SRM is that the underlying processing system functions at a concrete and an abstract level in a hierarchical fashion (Figure 2.3). In other words, the health threat is interpreted via concrete sensory perceptions of symptoms, as well as abstract conceptual beliefs about symptoms, representing different levels of abstraction (14). As shown in Figure 2.3, hierarchical processing involves the integration of information from current and previous experience.

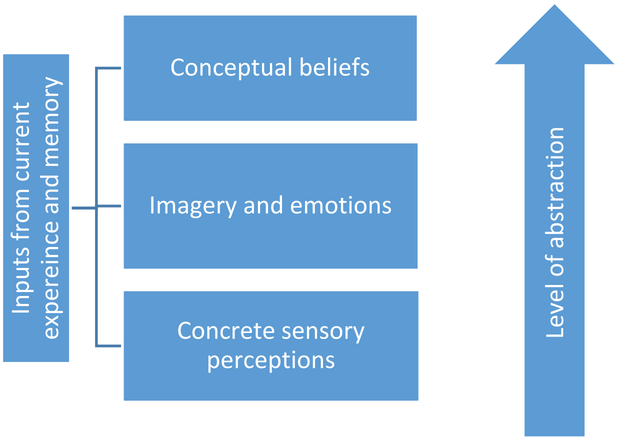

Figure 2.3 Hierarchical processing

For example, feeling physically out of breath represents breathlessness at its most concrete and least abstract level. Imagery associated with feeling breathless and emotional responses are conditioned reactions to the concrete experience of feeling breathless, and therefore represent an intermediate level of abstraction. Conceptual beliefs about breathlessness are the highest level of abstraction, as they are generated by the physical feeling of breathlessness, emotional responses to it, and imagery associated with the symptom (14). It has been suggested that the concrete physical experience of symptoms and how people cope in response are more strongly predictive of delay than abstract conceptual beliefs. For example, when sensory factors are strong, they are likely to override barriers to utilising care and health beliefs (i.e. strong symptoms such as severe pain are likely to hasten care-seeking behaviour).

Nevertheless, in the absence of strong sensory perceptions, conceptual beliefs still play a major role in directing coping behaviour. Abstract conceptual information is a result of cultural information (53), and for patients with HF, conceptual beliefs about HF are largely shaped by their providers (19, 20). Effective patient-provider communication is therefore vital to help patients construct accurate cognitive representations of HF and its symptoms. When patients can properly define their condition, they will be better equipped to generate suitable coping processes. The literature reveals that there are many communication issues that may impede patients' ability to adequately define the identity, cause, consequences, timeline and controllability/curability of HF. These issues include the use of inconsistent and complex medical language, which often leaves patients confused and can lead to gaps in knowledge and misconceptions about HF (29). Other issues involve perceived lack of trust, which affects the interpersonal relationship between patient and provider and thus, impedes communication (55).

Not only can inputs to the system be concrete or abstract, but they also integrate current and previous experience on both levels, to form a self-regulation system. For example, representations are generated from concrete symptoms happening at the time, and memories of concrete symptoms (schematic memory). Similarly, they can be shaped by abstract information provided by healthcare professionals during consultation about the cause of HF, and memories about previous health messages about HF from the media, previous consultations, or friends and family (conceptual memory). The generation of representations and coping processes therefore utilises previous and current experience (56) where schematic memory processing is linked to emotional reactions and somatic memories (memories of symptoms), and conceptual memory is linked to labelling, reasoning, and evaluating the meaning of illness states (51).

The ability to process these different types of information at different levels is dependent on a patient's executive function or capacity to detect and select cues that prompt action, problem-solve, plan, and evaluate action. Executive function is, therefore, embedded in all stages of the

SRM and can facilitate or thwart desired health behaviours. Executive function can be limited by level of knowledge and working memory (35). In HF, cognitive impairment affects memory and detection and interpretation of somatic sensations, which impedes the ability of patients to process perceptual and conceptual information from previous and current experience (57). Furthermore, approximately 39% of patients with HF have low health literacy, which affects the ability to process and act on health information (58).

### 2.3.3 Generating a coherent model

There is no single component of the SRM that is fundamental to evoke behaviour change. The key, rather, is the formation of a stable self-regulatory system, which is dependent on the integration and coherence of all components. Coherence of a system depends on how well each component of the SRM fits with the others, fits with the patient's cultural context and health providers, and fits with the patient's personality.

#### *Coherence within self-regulatory processes*

Coherence within the self-regulatory processes denotes consistency between each of the stages. For example, attributes of the cognitive representation must be consistent with coping processes generated by these attributes, and appraisals of coping processes must be consistent with the outcomes set by the attributes of the cognitive representation. All parts must fit together to generate a coherent system. In a coherent system, behaviours can be carried out with a level of autonomy and can be maintained long-term, which is crucial for patients suffering with chronic illness. A single inconsistency is, however, unlikely to cause a rupture in the system, unless the anomaly forms part of an alternative coherent system for self-regulation. For example, a patient with HF may believe his or her breathlessness is due to lack of exercise, but begins to notice feeling breathless at rest. The validity of his or her system may be questioned, however this single inconsistency is unlikely to displace the entire system unless it is interpreted as part of an alternative coherent system that the patient is equally able to believe and adopt.

### Coherence with cultural context and providers

It is important to note that self-regulation occurs in context. Patients' representations and coping processes are often shared with friends, family, and practitioners, and can therefore help shape or reinforce self-regulatory processes (51). Due to this notion, Leventhal and colleagues suggest that social modeling/social communication should not be conceptualised as an additional set of factors (36). Coherence with cultural context and providers refers to the degree of agreement between the views of the patient and that of their family, friends, and practitioners. Inconsistencies impede the ability to generate a coherent system, which may negatively impact adherence to the recommended health behaviour. For example, patients with HF often told that they look well, when in fact, they feel terrible. Many patients with HF describe it as an invisible illness that people can't see, particularly the symptom of fatigue (59). The inconsistency between concrete perceptions of feeling unwell, and being told by others they look well can cause a strong emotional response such as doubt, bewilderment, and fear (60), which can impact coping behaviours. Similarly, there is often a mismatch between what patients believe about their condition and what healthcare professionals tell them. Consistency of representations between patient and practitioners is commonly lacking in HF, which can lead to rejection of the recommend action. For example, a healthcare professional may recommend daily weight monitoring to a patient in order to prevent exacerbation, however, this does not match the existing representation of HF being an acute condition. The patient is therefore not likely to adopt the recommended actions prescribed by the doctor because the recommendation of daily weight monitoring does not make sense in the context of how the patient perceives their condition (ie. acute).

### *Coherence with personality*

Self-regulation systems are unlikely to remain coherent long-term if they do not correspond with a patient's personality (51). An individual will develop cognitive representations and coping processes that are consistent with their personality biases (51).

It has been proposed that personality factors impact self-regulation by 1) influencing attention to somatic states (i.e. symptom recognition and vigilance); 2) determining interpretation of somatic states (i.e. symptom appraisal); and 3) affecting the choice of coping processes for managing health threats and the appraisal of outcomes (i.e. generation and evaluation of coping processes). For example, patients with HF with a type D personality, characterised by high social inhibition and negative affectivity, were more likely to notice symptoms, appraise them at worrisome, and yet, were less likely to cope with symptoms by seeking-care (61). Furthermore, when personality and the self-regulatory system are coherent, they can be supported by social context. For example, a patient's carer may encourage them to believe that the only way to gain control over HF is to have a heart transplant, which may provide support for an existing belief about HF.

## 2.4 Conclusion

The SRM provides a well-rounded model for explaining the processes involved in coping with health threats. It takes into consideration patient perceptions of reality whilst recognising the impact of environmental, or external, stimuli. Whilst it does not specifically describe how self-regulatory systems operate in context, it alludes to notion that the system does not exist in a vacuum. The SRM considers both the patient's view of themselves, as well as their view of their environment,(53) and is the conceptual model used in this thesis to understand care-seeking behaviour in HF.

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# Chapter 3
# Literature review

## 3.1 Preface

This chapter presents a qualitative meta-synthesis of the HF literature that identifies factors influencing care-seeking in HF. Findings are discussed in relation to the principles of self-regulation and provide scope for the research focus: delayed care-seeking in HF. This meta-synthesis has been published in Heart Failure Reviews(1) and is presented as published.

## 3.2 Introduction

Heart failure (HF) remains the leading cause of hospitalisation in older people worldwide. Symptom exacerbation is the most common cause of HF-related hospitalisation. Characteristic signs and symptoms such as breathlessness, fatigue and oedema are a daily struggle for people living with HF, and represent the most common reasons for presenting to emergency departments (ED)(2-4). Worsening symptoms are frequently noted as the main reasons for seeking professional care (2-5), however, over 50% of patients delay seeking help when these signs and symptoms manifest, to the point of requiring emergency medical attention.(4)

Delay is associated with increased risk of hospitalisation and readmission (6, 7), as failure to seek care in a timely manner increases the risk of acute symptom exacerbation. Severe symptoms on admission to hospital are associated with longer length of stay (LOS) and increased mortality rates (8-10). With up to 50% of patients re-hospitalised at least once within six months (11), HF management carries a heavy economic burden, whilst dually affecting patient quality of life due to frequency of re-admissions (12).

It has been proposed that these admissions are largely preventable, as the majority of HF re-hospitalisations can be attributed to ineffective self-care (13-21). Part of HF self-care includes recognising worsening HF symptoms early and appropriately interpreting their meaning in order to prompt care-seeking behaviour. Patients may delay seeking care if they do not notice worsening symptoms or do not perceive them as being important. Lack of knowledge around symptoms are assumed to be the reason for poor symptom management, therefore, educational interventions are chiefly employed to promote symptom recognition (22). Evidence suggests that patients remain unsure about what is causing their symptoms and confused about their implications. Moser's model of HF self-care posits health literacy, which has recently been highlighted as important in HF (23), to be a factor influencing decision-making, affecting patients' ability to understand and act on health information (24).

Symptoms are complex, multi-dimensional, and much more than a response to physical stimuli. Patients' emotional and cognitive representations of illness, including beliefs about the identity, cause, consequences, timeline and curability/controllability of HF can shape how symptoms are perceived(25, 26). Leventhal's Self-Regulation Model (SRM) of illness behaviour (Figure 3.1) highlights the impact of personal attitudes and perception of condition and symptoms on processing physical stimuli (25, 26). This emotional frame of reference influences the way symptoms are recognised and appraised, as well as having influence over how patients cope with their condition (25, 26).

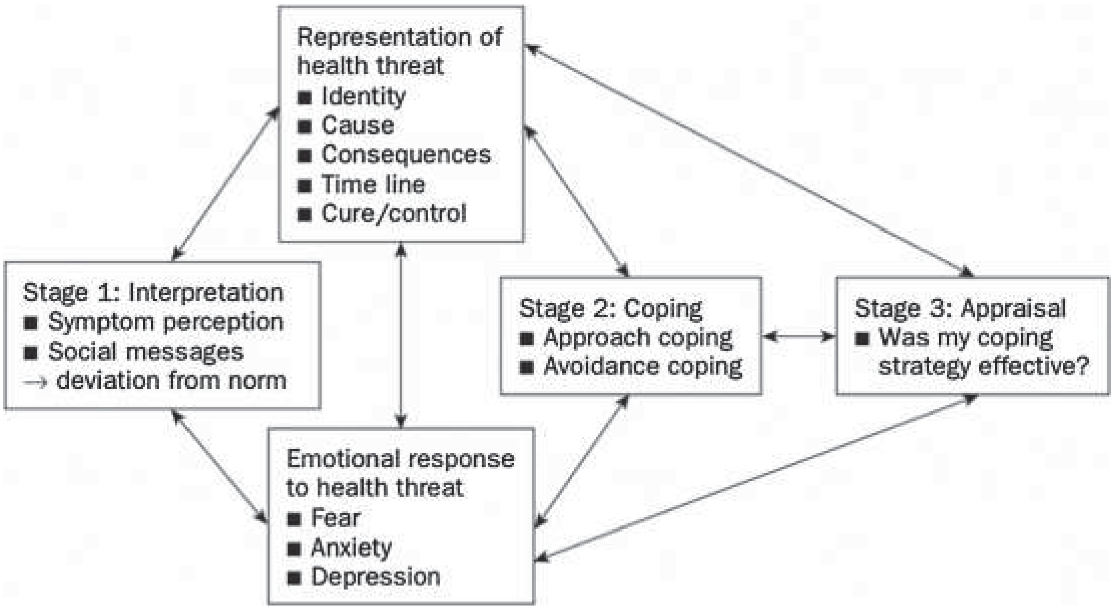

Figure 3.1: Leventhal's SRM

According to the SRM, patients will respond to a perceived illness 'threat' by engaging in coping behaviours to regain a sense of normalcy (Figure 3.1). In Leventhal's model, the perceived ‘threat’ of HF is influenced by these aforementioned factors, and informs patient coping strategy, which includes professional care seeking behaviour. These factors collectively form a personal representation of symptoms that is unique for each patient and has the ability to drive decision-making, thus affecting the decision to seek professional care before symptoms become acute. The SRM has been used extensively in acute coronary syndrome (ACS)/acute myocardial infarction (AMI) patients to understand and address factors associated with pre-hospital delay (27-36). Leventhal’s SRM can therefore also be used to offer insight into treatment seeking decisions in HF.

Little is known about how these more complex cognitive and personal factors influence response to worsening HF symptoms. It has been proposed that early recognition and a timely response to worsening HF symptoms may reduce HF-related hospitalisations by up to 50% (37, 38), yet research has scarcely focused on this component of self-care. Research into adherence to medications is well established, yet, understanding how patients with HF perceive their condition and symptoms, and how that affects their care seeking behaviours remains unclear.

Identifying and exploring factors that influence timely care-seeking may facilitate opportunities to develop targeted interventions to reduce patient delay and improve outcomes including, hospitalisation, mortality and quality of life whilst reducing the high cost associated with HF management.

The synthesis of qualitative data, framed from the perspective of the affected person, provides useful insight into the highly personal symptom experience by illuminating the voice of the patient. Quantitative data alone would be less able to capture the complexities of symptom burden and thought processes involved in responding to worsening symptoms. Previously published reviews offer a more general account of self-care in HF or the experience of living with HF (39-44), rather than care seeking decisions specifically, or do not go beyond summarizing what is already reported in the literature (45). This metasynthesis goes beyond aggregating findings and offers a new understanding of professional care-seeking decisions in HF.

## 3.3 Aims

This review aims to synthesise qualitative literature reporting patients' experiences of symptoms associated with HF. This qualitative meta-synthesis was conducted to:

1) identify factors influencing response to symptoms, and
2) explore ways in which these factors impact decisions to seek professional care.

## 3.4 Methods

A qualitative meta-synthesis was undertaken, using the SRM, to extend our understanding of what is already known about HF patients' responses to worsening symptoms and provide a more comprehensive account of patients' decision-making.

### 3.4.1 Search Strategy

Electronic database searching was conducted from April to July 2014 using MEDLINE, CINAHL and Embase. Relevant studies concerning symptoms in a HF population were identified using search terms and related Medical Subject Headings (MeSH) involving *heart failure, symptoms,* and *qualitative research.* Search strategies were adapted, as appropriate, for each database (see Appendix 1).

One author screened the resulting abstracts (S.E.I.) and discarded studies that did not meet the inclusion criteria. Studies that met the inclusion criteria underwent further investigation through full-text review.

### 3.4.2 Inclusion and exclusion criteria

Studies were included if they were 1) written in the English language; 2) peer-reviewed journal articles; and 3) reported perspectives of patients with HF derived from qualitative data collection and analysis. Studies not limited to a HF patient population were included if they reported HF patient population findings separately from other conditions/viewpoints. Included studies described factors related to symptom recognition and/or care seeking behaviours. Mixed methods studies wherein qualitative data was unable to be differentiated from quantitative results were excluded.

### 3.4.3 Quality appraisal

Quality appraisals were undertaken on each article to assess how data collection and reporting may influence how findings were presented, rather than being used as a basis for exclusion, for which there is little evidence (46). With no single widely accepted appraisal tool suited to compare all forms of qualitative research (47), questions developed by Kitto and colleagues (48) were used to appraise the studies, irrespective of methods used. Each article was assessed based on clarity of research questions and aims, justification of approach, transparency of data collection techniques and analysis, representativeness of the sample, interpretation of data, reflexivity and evaluative rigour, and transferability of findings.

### 3.4.4 Data synthesis

Studies were analysed using the approach of Thomas and Harden (46). Thematic synthesis occurred in three-stages. The first step involved data extraction, wherein data describing the perspectives of HF patients, and qualitative findings of mixed methods studies, were extracted. All text under results and discussion sections of each study were included for synthesis, except in mixed methods studies where discussion of qualitative and quantitative findings were already integrated. Line-by-line coding of extracted data followed, in which one or more descriptive codes were attached to each sentence. In the second stage, descriptive codes were then organised into descriptive categories, and in the third stage, these were further condensed into analytical themes. At all three stages, results were discussed and compared with an independent researcher (M.D.), by mapping out emerging concepts, in order to check for consistency of interpretation. In addition, the SRM was used to organise emerging concepts from the literature into a pre-existing framework, to further enhance understanding of factors involved in patients' responses to worsening HF symptoms.

## 3.5 Results

### 3.5.1 Selected studies

Following retrieval of 582 unique articles, forty articles were included in the synthesis (Figure 3.2).

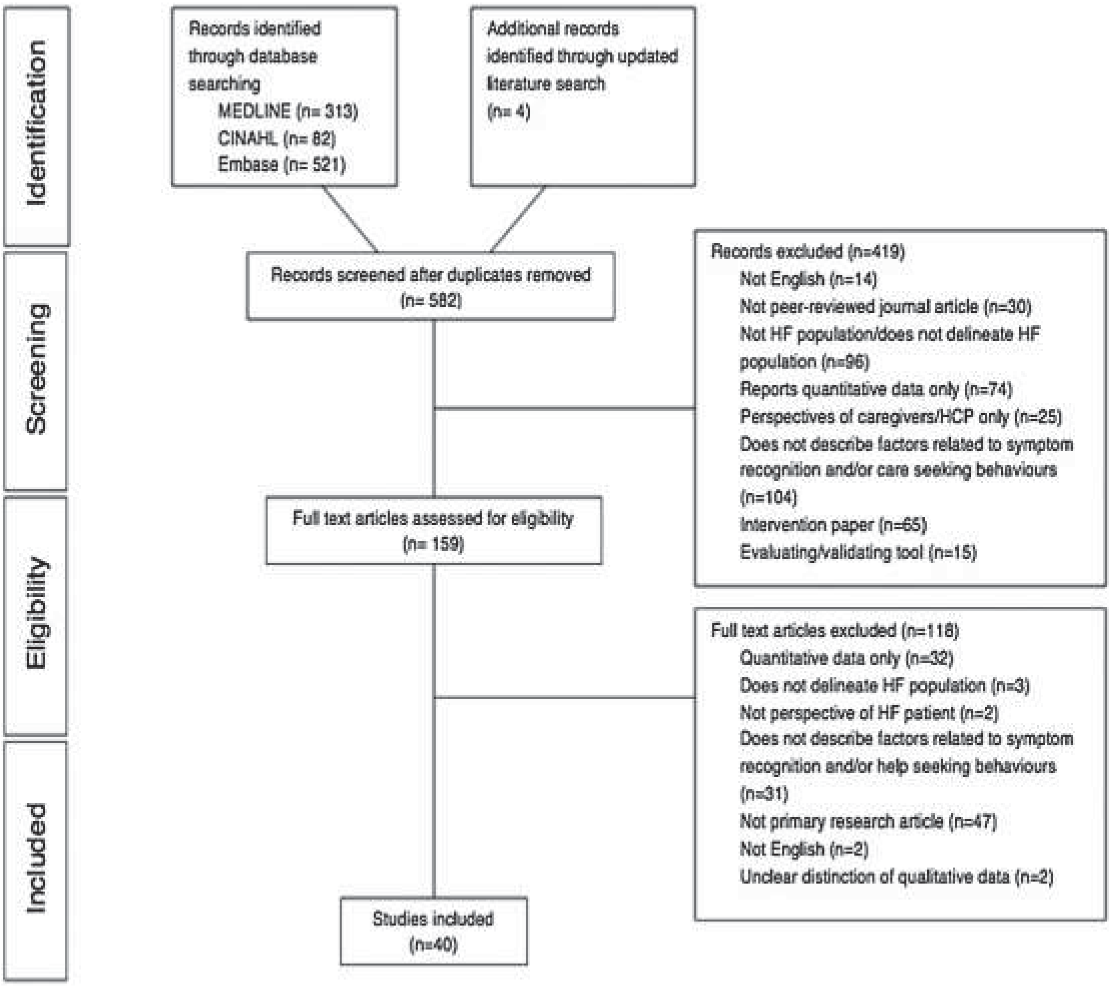

Figure 3.2 PRISMA flow diagram

Based on the demographic information available, studies involved a total of 1110 respondents with HF (596 male, 404 female, 110 unidentified), aged 18-98 years, from an outpatient/community setting (n=24), inpatient setting (n=5) or both (n=9). Two studies were conducted with residents in aged care facilities (49) or long-term care (50). The majority of studies were conducted in the United States (US) (n=17) and United Kingdom (UK) (n=11), with fewer studies conducted in Sweden (n=5), Canada (n=3), Australia (n=2), Thailand (n=1) and Ireland (n=1). Three studies involved a high proportion of participants at or below poverty level (51-53).

Two articles explored self-care in an ethnic minority population (54, 55) and one in a rural community (56). The majority of studies explored the experience of living with HF and its symptoms (n=14), or self-care generally (n=13), rather than a specific focus on professional care-seeking behaviour. Six studies explored symptom recognition and decisions to seek care, and five studies focused on HF knowledge, representations and communication. Two studies explored the characteristics and experiences of patients admitted for HF (2, 57). The predominant methods of data collection were semi-structured or unstructured interviews (n=33), followed by open-ended survey questions (n=5). One study conducted focus groups (58), and another conducted both focus groups and interviews (59). (Table 3.1)

Table 3.1 Characteristics of included studies

| Study ID | Setting | Participants | Qualitative methods | Topic |
|---|---|---|---|---|
| **Martensson, 1998** | Outpatient setting in Sweden | 12 individuals with HF, NYHA II-IV, 65-83 years, 0% male | Semi-structured interviews analysed through a phenomenographic approach | How women with heart failure conceive their life situation |
| **Rogers, 2000** | Inpatient/ outpatient setting in UK | 27 individuals with HF, NYHA II-IV, 38-94 years, 74% male, and experienced at least one HF admission within the last 20 months | Unstructured interviews analysed through a constant comparative approach | Knowledge and communication difficulties for people with CHF |
| **Parshall, 2001** | Acute hospital setting in US | 57 individuals being treated in ED for HF, triage classification emergent (54%) or urgent (46%), 34-94 years, 5% male | Retrospective open ended questions analysed through content analysis | Influence of dyspnea duration, distress and intensity on decisions of patients to come to an ED |
| **Riegel, 2002** | Community setting in US | 26 individuals with HF, NYHA class II-IV, 56-91 years, 65% male, had at least one HF related hospitalisation, income below poverty 46%, income at poverty 28% | Semi-structured interviews analysed through content analysis | Barriers and facilitators to self-care |
| **Rogers, 2002** | Inpatient/outpatient setting in UK | 27 individuals with HF, NYHA II-IV, 38-94 years, 74% male, and experienced at least one HF admission within the last 20 months | Unstructured interviews analysed through a constant comparative approach | Understanding of HF symptoms and drug therapy |
| **Welsh, 2002** | Community/inpatient acute hospital setting in US | 57 individuals with who had been/were being treating in the ED for HF, 34-94 years, 46% male | Open ended questions analysed through content analysis | Characteristics of patients in the ED |
| **Zambroski, 2003** | Inpatient/outpatient /community setting in US | Nine individuals with HF, 50-81 years, 56% male | Semi-structured interviews analysed through a constant comparative method | Describe problems, challenges and processes of living with heart failure |

| | | | | |
|---|---|---|---|---|
| **Bosworth, 2004** | Outpatient setting in US | 15 individuals with HF who visited a VAMC at least once in 1999, NYHA I-IV, 47-82 years, 100% male | Semi-structured (stratified by NYHA class) analysed through a constant comparative method | Components of quality of life |
| **Boyd, 2004** | Community setting in UK | 20 individuals with advanced HF, their informal carer, general practitioner, and other key professionals. Individuals with HF were NYHA class IV, 57-92 years and 55% male | Semi-structured longitudinal interviews analysed through narrative analysis | Views on health and social care in the last year of life |
| **Horowtiz, 2004** | Community/outpatient setting in US | 19 individuals with HF, NYHA class II-IV, 52-89 years, 53% male | Semi-structured interviews analysed through constant comparative method | Patient factors that may serve as barriers to effective self-management in response to fluctuating heart failure symptoms |
| **Aldred, 2005** | Community setting in UK | 10 individuals with HF and their informal carers (partner). Individuals with HF were NYHA II-IV, 60-77 years, 70% male | In-depth interviews analysed through thematic analysis | Impact of heart failure on the lives of older patients and their informal carers |
| **Edmonds, 2005** | Community/outpatient setting in UK | 27 individuals with HF with at least one HF hospitalisation in the last 20 months, NYHA II-IV, 38-94 years, 74% male | Semi-structured interviews analysed through constant comparative analysis | Patient descriptions of breathlessness in heart failure |
| **Barnes, 2006** | Community setting in UK | 542 individuals with HF and primary care professionals. Unclear how many were interviewed. Individuals were NYHA II-IV, >60years, 54% male | Interviews and focus groups. Methods of analysis not reported | Symptoms in heart failure |
| **Barnes, 2006** | Community setting in UK | 44 Individuals with HF and primary care professionals. Individuals were NYHA III-IV, >60 years, 52% male | Semi-structured interviews (patients) and focus groups (health professionals) analysed through thematic analysis | Attitudes of older people and primary care professionals toward communication of diagnosis, prognosis and symptoms |

| | | | | |
|---|---|---|---|---|
| **Gary, 2006** | Outpatient setting in US | 32 individuals with HF, NYHA II-III, >50 years, 0% male, income below poverty 59%, income at poverty 22% | Semi-structured interviews analysed through content analysis | Self care practices in women with heart failure |
| **Schnell, 2006** | Outpatients setting in Canada | 11 individuals with HF, 43-79 years, NYHA II-III, 64% male | Semi-structures interviews analysed through content analysis | Influences that enhance or impede self-care and behavioural response of influences |
| **Brannstrom, 2007** | Community setting receiving PAHC in Sweden | One patients with severe HF and his spouse, NYHA IV, 70 years, male | In-depth longitudinal interviews analysed through phenomenological-hermeneutic analysis | Narratives of a man with severe CHF and his wife over a 4.5 year period |
| **Cortis, 2007** | Outpatient setting (HFSP: Heart failure support program) in UK | 10 individuals with HF, NYHA II-IV, 80-90 years | Semi-structured interviews analysed through constant comparative analysis | Experiences of older adults living with CHF |
| **Patel, 2007** | Inpatient setting in Sweden | 88 individuals with HF identified from the ED or within 72 hours after hospital admission, NYHA II-IV, 46-95 years, 61% male | Semi-structured interviews analysed through content analysis | Reasons for seeking acute care |
| **Dickson, 2008** | Outpatient setting in US | 41 individuals with HF, NYHA II-III, 18-65 years | Semi-structured interviews analysed through thematic content analysis | Effect of attitudes, self- efficacy and cognition on self-care in non-elders |
| **Dickson, 2008** | Outpatient setting in US | 41 individuals with HF, 48.8% employed, NYHA II-III, 25-65 years, 63% male | In-depth interviews analysed through content analysis | Effect of cognition, physical functioning, attitudes and self-efficacy on self-care in the context of employment |
| **Hedemalm, 2008** | Acute inpatient setting in Sweden | 42 individuals with HF identified from the ED or within 72 hours after admission, 21 immigrants and 21 natives, 57% male | Semi-structured interviews analysed using content analysis | Explore symptom recognition and health care seeking patterns among immigrants and native Swedes |

| | | | | |
|---|---|---|---|---|
| **Macabasco-O'Connell, 2008** | Inpatient/outpatient setting in US | 65 individuals with HF, 27-90 years, 45% male, annual income ≤ $10 000 56%, 57% ≤ high school education | Open-ended questions analysed through content analysis | Explore challenges and barriers in HF self-care in indigent patients |
| **Rodriguez, 2008** | Outpatient setting in US | 25 individuals with HF who visited VA outpatient care, 53-87 years, NYHA I-IV, 96% male | Semi-structured interviews analysed using constant comparative method | Patients' knowledge and experience with HF |
| **Thornhill, 2008** | Inpatient/outpatient setting in UK | 25 individuals with HF, 84% male | In-depth semi-structured interviews analysed through interpretive phenomenological analysis | Experiences of living with congestive HF |
| **Clark, 2009** | Rural community setting in Canada | 42 individuals with HF and 30 nominated carers. Individuals with HF were NYHA II-III, 64% male | Semi-structured interviews analysed through thematic analysis | Explore the individual and contextual factors reported to influence willingness and capacity to undertake HF self-care effectively |
| **Jurgens, 2009** | Acute/inpatient setting in US | 77 individuals with HF who were living independently and in the community, > 65 years, 52% male | Open-ended questions analysed through iterative and emergent theme development | Describe contextual factors related to symptom recognition and response |
| **Rerkluenrit, 2009** | Inpatient/outpatient setting in Thailand | 35 individuals with HF | In-depth interview analysed through constant comparative analysis | Self-care management |
| **Ryan, 2009** | Outpatient setting in Ireland | 9 individuals with advanced HF, NYHA III-IV, 54-82 years, 67%male | In-depth interview analysed through phenomenological analysis | Experience of living with advanced HF |
| **Riegel, 2010** | Outpatient setting in Australia | 29 individuals with HF, NYHA II-III, 35-94 years, 72% male | Semi-structured interviews analysed through iterative and emergent theme development | Symptom recognition: influence of age on ability to detect and interpret symptoms |

| | | | | |
|---|---|---|---|---|
| **Riegel, 2010** | Outpatient setting in Australia | 27 individuals with HF, NYHA II-III, 35-94 years, 70% male | Semi-structured interview analysed through content analysis | Gender specific barriers to self-care |
| **Andersson, 2012** | Community/outpatient setting in Sweden | 11 individuals with HF, 60-90 years, 45% male | Semi-structured interview analysed through content analysis | Experience of living with heart failure |
| **Jones, 2012** | Outpatient setting in US | 26 individuals with HF, NYHA II-IV, 51-71 years, 69% male | Semi-structured interviews analysed through thematic analysis | Experience of fatigue |
| **Close, 2013** | Residential aged care homes in UK | 17 individuals with HF living in residential aged care, 8 care facility staff, 3 HF nurses and 5 GPs. No demographic data available | In-depth interviews analysed through thematic analysis | Experiences and expectations in interpreting suspected symptoms of HF and deciding whether and how to intervene |
| **Dickson, 2013** | Outpatient/inpatient setting in US | 30 black individuals with HF, NYHA II-III, 26-98 years, 60% male | Semi-structured interviews analysed through thematic analysis | Sociocultural influences on HF self-care |
| **Dickson, 2013** | Outpatient/inpatient setting in US | 30 black individuals with HF, NYHA II-III, 26-98 years, 60% male | Semi-structured interviews analysed through thematic analysis | Influence of depressive symptoms on self-care |
| **Kaasalainen, 2013** | Long term care setting in Canada | 7 residents with HF and 7 family members, mean ±SD age, 84.6±5.7. No other demographic data available | Semi-structured interviews analysed through thematic content analysis | Experience of heart failure patients living in long term care |
| **Retrum, 2013** | Inpatient setting in US | 28 individuals with HF who had been readmitted to hospital within 180 days for any reason, 29-88 years, 64% male | Semi-structured interviews analysed through iterative and emergent theme development | Patient perspectives concerning heart failure admissions |

| | | | | |
|---|---|---|---|---|
| **MacInnes, 2014** | Community/outpatient setting in UK | 12 individuals with HF, mean ±SD age, 70.1±12.8; 58% male | Semi-structured interviews analysed through thematic analysis | Illness representations and treatment beliefs in heart failure |
| **Skaperdas, 2014** | Outpatient setting in US | 39 individuals with HF receiving care at a VAMC (veterans affairs medical centre), 53-89 years, 95% male | Semi-structured interviews analysed using thematic analysis | How patients with CHF engage with health services and perform self-care |

### 3.5.2 Quality of included studies

Aims and research questions were consistently reported clearly in all 40 studies. However, authors did not always justify why their chosen methodological approach was used to fulfill the aims of their research. Most studies reported techniques of data collection and analysis with transparency, and explained the transferability of their findings to policy and practice. Sampling techniques were also consistently described. Results were discussed with links to new or existing theory variably, and did not always include and discuss negative cases. Very few studies included a reflexive account. Only five studies described the effect of the researcher's views and methods on the data and seven studies evaluated the potential effects of the participant/researcher relationship (48).

## 3.6 Meta-synthesis of qualitative data

Much of the literature fit within the SRM, however this model did not account for all factors reported in the literature that influenced patients' care-seeking behaviours for worsening symptoms. Findings that aligned with the model involved patients' cognitive representations of HF and emotional responses to living with HF, which collectively influenced how symptoms were perceived and coping strategies chosen in response to worsening symptoms. Seeking professional care for worsening HF symptoms was not always the obvious choice, as the perceived identity, cause, consequences, timeline, and curability/controllability of HF were not clearly understood for the majority of HF patients. Factors not represented in the SRM included the role of external appraisals, previous care-seeking experiences, and financial, system and provider-related barriers that influenced patients' decisions to seek professional care.

### 3.6.1 Identity

#### *Labels*

Patients had great difficulty assigning appropriate labels to their condition and symptoms, and did not often identify with a diagnosis of "heart failure" or the medical terms for labeling symptoms such as "breathlessness" or "fatigue". Patients were more likely to use informal language to describe their condition, such as *"problems with the heart", "weak heart", "bad* *heart", "heart trouble",* or *"only pumping 20%"*, and very few actually labeled their condition as *"heart failure"* (50, 60-63). Labeling symptoms was also problematic for patients, who frequently used vivid and emotive language to describe their symptom experience, rather than medical terms. Breathlessness and oedema were commonly described using terms relating to wind and water eg *"huffing and puffing", "short winded, "blowing", "gasping", "where you feel like you are drowning",* too much *"fluids"* or *"liquids"* (62, 64). Fatigue was commonly described as energy being *"sapped", "being tired", "body tired", "physically tired"*, and also using descriptors relating to not having *"full energy"* or *"low energy levels"* (65). Patients seldom used technical terms such as breathlessness, dyspnea and fatigue to describe their symptoms.

### *Patient-provider communication*

The literature revealed that patients relied heavily on verbal communication with health care providers (HCPs) as a primary source of information about their condition (52, 64, 66). Ineffective patient/provider communication, therefore, led to gaps in patient knowledge, which made it challenging for patients to assign appropriate labels to their condition and symptoms and identify with HF diagnosis. For example, medical language used by HCPs held little meaning to patients and caused confusion and loss of interest.

> *"]f they talk in layman's language ... ordinary language, I can understand it. When they get to the fancy words, that loses me completely ... It sounds very nice, but it don't mean a damn thing does it, not to me, so, er, I don't like 'em to talk to me like that because it's beyond me"* (59)

Quality of patient/provider communication and the resulting confusion was further compounded by patients' own cognitive deficits (memory loss, poor concentration) (59) and inconsistent language used by HCPs (53, 67). This resulted in patients piecing together seemingly disjointed information to develop their own label/definition of HF.

> *"It was 'left ventricular systolic dysfunction' then I got a letter saying 'dilated cardiomyopathy, ischaemic heart disease' so I'm a bit confused"* (67)
>
> *"Every time I talk to somebody I feel like I get a different answer"* (53)

*Preconceptions*

Pre-conceived ideas about HF symptoms also made it difficult for patients to label their condition as HF. Patients expected to feel chest pain for problems relating to the heart, so experiences with breathlessness and fatigue did not 'appear' to correspond with HF. This made it difficult for patients to link these symptoms to HF, and identify with the diagnosis (60).

> *''When you hear about having heart problems, …you're supposed to feel maybe a pain in your left arm, maybe a pain in your chest, or pressure"* (60)

Furthermore, when sensations did not fit with preconceived ideas about what heart-related symptoms should feel like, patients did not feel there was a valid reason to call for help (60).

> *"…. I guess it would have been more clear to me if I had chest pain and then I would have said okay, I'll call and say I'm having chest pain but it didn't just seem to me like anything came together where I could call''* (60)

### 3.6.2 Cause

*Aetiology of HF*

Patients expressed great uncertainty in determining the cause of their condition and symptoms. Some patients believed HF was caused by a virus, overwork, or hereditary factors (67). Lifestyle factors, such as smoking, were not generally linked with HF, nor were links made between preceding heart conditions and their current condition (67). Lack of understanding and awareness of diagnosis was, in some cases, compounded by dementia (50). A Swedish study showed that immigrants were more likely to be completely unaware of what was causing their condition as compared to locals (68).

#### *Evaluating symptoms*

Attributing symptoms was problematic as some patients were completely unaware of what was causing their symptoms (52, 59). Some were able to feel or see a difference from normal, but were not able to attribute them to a cause (52, 56, 60, 62). Mechanisms involved with HF (eg fluid retention causing breathlessness) were complex and difficult for patients to understand (59). Inadequate knowledge of HF diagnosis and symptoms meant that patients often looked elsewhere for more comprehensible explanations for their symptoms. A number of patients attributed symptoms to ageing, comorbid conditions, such as atrial fibrillation (AF), stress, medication side effects, cold and flu, environmental causes (hot weather), drinking, or smoking (50, 52, 56, 57, 60, 63, 67-69).

> *"I thought getting winded and tired was part of getting old"* (52)

Patients were inclined to link symptoms with the affected organ. By using 'common sense', patients would often attribute breathlessness to respiratory disorders such as asthma and perceive breathlessness to be a problem of the lungs (60, 67). This misconception made it difficult for patients to link breathlessness with the heart (60). Comorbid conditions with overlapping symptoms further complicated the symptom evaluation process, making it difficult for patients to attribute symptoms to conditions (50, 62, 68).

> *"Well I'm still having the shortness of breath. I don't know whether it's my heart or it is my pulmonary condition"* (62)

### 3.6.3 Consequences

Coping with HF symptoms daily meant that most patients recognised the immediate consequences and limiting effect of symptoms, but often overlooked the long-term consequences of their diagnosis.

#### *Restrictions and limitations*

Breathlessness and fatigue overshadowed many activities including household chores, hobbies, such as gardening and dancing, and disturbed patients' ability to sleep and maintain normal sexual function (52, 61-64, 67-72). Unpredictable symptom onset prohibited patients from taking holidays or participating in spontaneous activity (52, 61). Increased dependence on family and spouses was a consequence of reduced mobility (61, 64-66, 70-73). Patients also described the socially isolating consequences of HF symptoms. Maintaining a social life was a challenge for many, as lack of energy and mobility inhibited patients' ability to see friends and family (52, 62, 65, 67, 71, 73).

> *"..everybody wants to see me and I want to see them, but I get so tired"* (52)

Patients instead described being housebound and isolated as a result of restrictive symptoms (61, 73). The loss of family, gender, and employment roles, were additional consequences of HF described by many (52, 56, 65, 71, 74). Consequences of HF were perceived to affect quality of life, particularly when patients reflected on life pre-HF, as compared to their current health situation(61).

> *"Terrible, really, because we used to enjoy life, didn't we"* (61)

#### *Long-term implications and perceived severity*

Patients often overlooked or were unaware of the long-term consequences of their condition and rarely perceived its seriousness (56, 60).

> *"My heart – it runs fine...There is a little bit of damage to it on the outside, but that is all"* (56)

> *"for some reason I seem to feel that this is lesser of all the heart conditions"* (60)

In some cases, it was not until patients experienced an acute symptom exacerbation that required emergency hospitalisation that the seriousness of their condition was recognised (71).

> *"But it didn't worry me to that extent… but then when it got worse, and then I came into the hospital, for further tests, then I realised it was getting serious"* (71)

### 3.6.4 Timeline

#### *Adopting an acute model of illness*

Patients showed little understanding of the progressive nature of their condition and prognosis. In some cases, they conceptualised HF as an illness that could be overcome (56, 60).

> *"(My heart) doesn't bother me. But a lot people, they didn't get completely over it like I did…it really was tough for a while, but I got over it"* (56)

A focus on symptoms led patients to conceive HF as an acute illness, rather than a chronic condition (60). Rather than viewing exacerbations as an effect of a chronic condition, the following man believed acute attacks indicated HF.

> *"They gave me medicine to keep my heart clean, so it (heart failure) shouldn't happen no more"* (60)

### *Prognosis and uncertainty*

Patients were less inclined to adopt a chronic perception of illness, and as a result, most were uncertain about their prognosis and likely trajectory.

> *"I think it will stay the same or get a bit worse. It won't get any better will it?"* (67)

> *"as far as what the long term prognosis should be, I have no idea…"* (60)

Despite infrequent and disjointed communication with HCPs about prognosis, some patients felt fully aware of their situation and did not expect much time. Even when this was the case, patients expressed little detail of prognoses.

> *"I understand that I am not going to get better"* (61)

Previous experience with chronic illness or ageing helped some patients recognise the progressive nature of HF. One patient drew from previous experience with arthritis to predict the trajectory of his condition in the context of advancing age (67).

> *"Getting old, usually things don't get better. It's like arthritis; it doesn't get better with age does it? If it's the heart that's tired or worn out or failing, it's not going to get better"*(67)

### 3.6.5 Cure/control

Patients who adopted an acute model of illness were more likely to perceive their condition as curable, rather than a chronic issue. Perceived control was low in patients who accepted the limiting effects of symptoms as age related (49, 63, 67), attributed the unpredictable nature of symptoms to fate (56), or believed HF was inevitable due to a genetic predisposition (54). For example, in cases where heart disease was part of cultural identity, patients accepted HF as a condition they must live with, and could do little about (54).

> *"All my people have bad hearts"* (54)

#### *Active versus passive responsibility*

In terms of deciding who was responsible for HF management, some patients chose to take an active role in controlling their HF, whilst others relinquished the responsibility to others, namely physicians (56, 60), family members (60, 64, 69), and/or partners (64). This was not always a conscious choice, as patients who assumed a more passive role, did not always fully understand their potential to self-manage HF (60, 75). Many patients viewed themselves as passive recipients of care, which was an attitude facilitated by a strong sense of confidence in physicians and the medical profession (56, 60). Some patients were completely unaware of their responsibility to take control and call for help when symptoms worsened (75).

> *"If the clinic wants to know how I'm doing and that's part of their job, then they should call me"* (75)

Others believed it was their own responsibility to actively seek help and control their condition. For these patients taking control was empowering and redeemed a sense of confidence and independence. These patients sought active involvement in decision-making (49), and took control even when access to professional care presented itself with barriers (65).

### 3.6.6 Emotional responses to HF

#### *Uncertainty and frustration*

Unclear cognitive representations of HF led to widespread feelings of confusion and uncertainty (60, 63). Feelings of frustration and annoyance were also common, as many patients had great difficulty carrying out banal daily tasks and lost the ability to act on their own volition due to restrictive symptoms (71, 73). This response was perhaps more pronounced in younger patients who had age-related expectations of their physical capabilities and had great difficulty coming to terms with reduced mobility(73).

> *"I'm 54 years old—still young—and when I see 70 yr olds walking the street and passing me by I feel like a right ejit (idiot)—they're flying up the street and I'm crawling up it"* (73)

Absence of communication with HCPs, lack of explanation, and perceived concealment of important information regarding HF diagnosis and prognosis were other major sources of frustration (59, 75), as were perceptions of being unnecessarily coddled by overprotective family, which encumbered patients' independence and freedom (71, 73).

> "*At the start, they explained everything to me. Now, I sometimes find that they just don't explain things"* (75)

> *"She won't LET me—I don't DO anything! She's all 'I'll do this, I'll do that' and I'm all the time sitting and just sitting there eh—I get a bit bored"* (73)

#### *Depression and low/changing self-concept*

Physical limitations often caused patients to feel worthless and not capable of much (70). Inability to spend quality time with family (52, 71), and being forced to give up hobbies that once brought great pleasure and meaning, caused feelings of surrender, sadness, grief and longing (52, 61, 62, 64, 69-71).

Many patients struggled with their self-concept as a consequence of restrictive symptoms that took away their ability to engage in activities that were previously a large part of their identity (64, 69, 75). Role loss in particular, negatively impacted patients' self-identity and self-worth. This included the loss of family roles, gender roles, and employment roles (74). For those whom employment was central to their personal identities, having to relinquish work affected their self-concepts as well as their ability to provide financial support for family. Boredom, distress and sadness ensued as a result, and many felt a loss of purpose with loss of work (71, 74). A sense of unfamiliarity and feeling lost due to the life changes caused by the HF diagnosis were difficult to cope with for some (66, 71).

> *"life has totally changed, and obviously… I don't know quite how I'll build round that"*(71)

### *Being a burden*

Fear of burdening others due to high levels of dependence on family and spouses, and the consequential subversion of gender roles evoked feelings of guilt, particularly in rural populations where traditional masculine tasks were heavily laborious, and patients were conscious of how this would appear to others (56). Patients were increasingly aware of the burden HF may cause their partners as their condition progressed (61).

### *Fear and anxiety*

Expecting death was always frightening (70, 71), and many patients expressed a sense of ubiquitous fear when little was known about how much time was left (73).

> *"Yeah you see—it is it's there all the time–fear- em—'Am I going to die under the next one?' I hope I get over this fear part—that's the worst part"* (73)

Lack of support (70), and inability to predict the onset of acute symptoms was anxiety inducing for many. Patients noted constantly feeling *'on the edge'* and in fear of the next episode (73).

> *"In the interval then I'd be fine but I am all the time worried—worried when this breathing will attack me again"* (73)

For other patients, making decisions about the practicalities of what to do in a crisis caused feelings of anxiety (59).The notion of being required to act and make decisions during a frightening and highly emotional acute symptom episode was worrying. Patients may therefore refrain from making decisions to seek care for the purpose of reducing anxiety. Wanting to avoid the strain of seeking care in these instances was indeed evident (68).

> *"seeking care puts too much strain on me"* (68)

In accordance with the SRM, these emotional responses also influenced the way in which symptoms were perceived and coping decisions, including decisions to seek professional care.

### 3.6.7 Response to worsening symptoms

Cognitive representations of HF and patients' emotional responses to their condition collectively influenced how symptoms were perceived as well as the actions chosen to cope with them. Seeking timely professional care was not often the preferred method of coping.

Patients were far more likely to adopt a *"wait and see"* approach to worsening symptoms, which was described by those who were hopeful symptoms would subside (52, 60, 75).

> *"I know I probably should've called earlier during this last bout, but I kept thinking I would start feeling better, but it just got worse"* (52)

Rural-dwelling HF patients opted to 'wait out' symptoms for days until they became severe, as symptoms were perceived as a part of life that must be accepted, endured and *"worked through"*, not unlike work in a rural setting (56). Patients reporting depressive symptoms were also more likely to respond to symptom exacerbations by *"taking to bed"* and *"waiting it (symptoms) out*" (55). These patients delayed seeking professional care until symptoms led to an emergency situation (55).

Those who expressed a sense of frustration with their health situation reported maladaptive coping strategies rather than care-seeking behaviours in response to worsening symptoms. Some patients turned to alcohol and cigarettes, or even self-harm, for immediate relief when the psychological and physical burden of living with chronic HF became overwhelming (64, 73).

> *"You grab a cigarette and it helps to calm you down"* (64)

Ignoring symptoms and denial were common responses. Signs and symptoms were frequently ignored or not linked with worsening HF, and instead perceived as a less severe, treatable condition (60).

Determination to lead a full and active life despite suffering symptoms drove patients to overexertion and consequent emergency hospitalisation (62, 71).

> *"Once, I said, 'I am going to church if it kills me.' I passed out, and they [had to take] me to the hospital"* (62)

The importance of maintaining role responsibilities took precedence over HF self-care, causing patients to neglect their own condition, ignore symptoms and instead focus efforts towards upholding specific family/employment/traditional roles.

Not dwelling on limitations helped push the burden of symptoms out of mind for some (65). However, whilst important for maintaining emotional wellbeing, this response may be detrimental to self-care.

> *"You know you can't erm, you can't sit there and think, 'I've got a bad heart, I've gotta watch what I'm doing', it's no good is it*?" (71)

Patients may adopt a lax attitude to self-care and symptom monitoring. In being less vigilant, patients may miss important cues indicating worsening symptoms, and in turn, delay seeking professional care.

Others accepted HF to be a part life and were able to reshape expectations and develop a new meaning of 'normal'. Whilst important for psychological wellbeing, accepting this new reality may lead patients to ignore early warning signs or not perceive symptoms as anything out of the ordinary, and thus delay seeking care.

> *"I don't know really; I'm so used to it now"* (72)
>
> *''May be I was kind of tired but it just didn't seem to be anything out of the ordinary''* (60)

Adapting daily routines to accommodate symptoms by limiting/pacing activities in order to conserve energy was common (63, 65, 67, 71, 73). Such responses to symptoms made it difficult to gauge physical condition and led to function decline/decreased mobility that often went unnoticed (50). Patients may be unlikely to seek care when adaptations disable evaluation of deterioration.

Seeking professional care was a response largely provoked by fear. Patients often did not seek care until symptoms became intolerable (52, 56, 57, 60, 68, 73, 75). Frightening attacks of acute breathlessness were the most common reason patients sought professional care (50, 52, 57, 75).

> *"It feels like you are getting the last drop of air around you, and you are doing everything you can do to get air in"* (52)

For a number of patients, fear of death motivated care-seeking behaviours (52, 73).

> *"One night while I was sitting watching TV my heart started racing, it kept getting faster and faster and my breathing got shorter and shorter, I told my husband to get me to the emergency room fast… I thought I was going to die"* (52)

The perception of being a burden to others acted as a barrier to seeking care. Fear of bothering physicians, especially in the evening, led patients to delay seeking care for nocturnal symptoms(60).

> *''…well, all these things seem to happen in the middle of the night so I don't call doctors''*(60)

When symptoms were perceived as minor, patients were reluctant to call for help (52). Some patients avoided voicing concerns to doctors or nurses until their symptoms were severe, as anything less was perceived as unjustified (50).

Talking to others, including clergy, psychologists and family, helped patients cope with the burden of living with HF and provided a sense of security and support. However, some felt the need to cope with HF alone, as keeping things private was a desirable trait in some sociocultural contexts (54, 56) or was perceived as a way of protecting loved ones by "putting on a front" (65). Patients were also generally unwilling to discuss issues pertaining to emotional turmoil and sexual health with HCPs as they were deemed too private. Patients described being more open with their feelings with trusted social supports (54, 71).

Patients also responded to symptoms using alternative methods of coping such as physiotherapy, spirituality, music, deep breathing, walking, and other exercises to help build further capacity for physical activity (50, 54, 64, 66, 71, 72).

### 3.6.8 Appraisal

Patients evaluated whether their choice of coping was an effective or ineffective way of restoring a sense of equilibrium, as in the SRM. When coping methods were perceived as effective, patients chose to continue with the strategy, or seek an alternative if ineffective. This was problematic in instances where patients had adapted daily routine to accommodate symptoms, and led relatively 'normal' lives by restricting activities. This was perceived as a highly effective coping strategy and therefore patients continued to limit activity, were unable to recognise worsening condition to seek timely care, and thus experienced acute exacerbations unexpectedly (50).

Patients often recognised that *'wait and see'* strategies used to cope with HF had been ineffective only upon reflection, when patients had been hospitalised for HF symptoms.

> *"I know I probably should've called earlier during this last bout, but I kept thinking I would start feeling better, but it just got worse"* (52)

Patients were more likely to recognise a 'danger' situation upon reflection of events leading to emergency hospitalisation. For example, the following patient became aware that he had ignored early warning signs upon reflection of a number of evenings spent sleepless due to breathlessness (60).

> *''It had been coming on over a period of time…there were little signals, like there has been a couple of nights when I would lay down and I actually couldn't sleep, you know, I couldn't really breath properly and I would have to sit up and those are the warning, the early warning signals that you kind of choose to ignore''* (60)

Upon reflection of delayed hospital presentations, patients recognised that their avoidance strategies were ineffective in preventing hospitalisation, which may prompt patients to choose an alternative strategy in the future.

### 3.6.9 External appraisals, previous care-seeking experiences, and financial, system and provider related barriers

Factors influencing decisions to seek professional care that were not accounted for in the SRM included patients' appraisals of previous care-seeking experiences, perceived system and provider barriers to accessing care, and the influence of external appraisals. External appraisals may take the form of friends, family and HCPs noticing worsening conditions when symptoms went unnoticed by patients (60, 68).

> *"My wife and family noticed the worsening, Home care personnel recommended me to seek acute care"* (68)

It was not uncommon for others to help appraise a patient's health situation when patients were uncertain (60, 64). In a number of cases, family support played a vital role in the recognition and appraisal of symptoms and prompted care seeking behaviour when necessary (60).

#### *Previous care-seeking experiences*

Informed by previous experience, some patients were reluctant to call for help or see their doctors for fear of being sent into hospital unnecessarily.

> *"You ring the emergency doctor, they ask what the problem is, next thing the ambulance is here and you are in hospital...I think, 'Do I really need to be here?'* (61)

One patient noted her reluctance to call the ambulance in case symptoms resolved by the time they arrived, as had occurred in the past, describing the scenario as a *"catch 22"* (64). Previous negative hospital experiences provided further reason to avoid seeking care, with patients preferring to suffer with symptoms at home as a result (52, 73).

> *"I hate the hospital, I would rather tough it out as long as I can at home"* (52)
>
> *"I felt wretched—I didn't care quite seriously if I died—I felt wretched—stuck in that little ward—that CELL! God!"* (73)

Patients also described previous negative hospital experiences with unskilled HCPs and expressed a sense of frustration and loss of confidence (64). Previous experience may shape perceptions of professional care and seeking care, and guide action. If the experiences are negative as in these cases, it may potentially impact future decisions to call for help.

### *Perceived system and provider barriers to accessing care*

Poor coordination between primary and secondary care services (49, 61, 69), and long wait times (60, 69) meant patients were left unsure of who to call in an emergency situation, and in some cases actually motivated patients to present to the ED.

> *"I rang GP who said to ring hospital, rang hospital and was told they couldn't do anything, you have to ring GP"* (61)

Patients reported consciously allowing their condition to deteriorate merely to avoid the confusion associated with ambulatory care, preferring instead emergency care in the ED (69).

> *''In the time it takes to call them, I'm in good hands in the ER''* (60)

When patients were unable to get appointments or have their phone calls returned instantly, they *"hit the panic button"* and opted for care in ED (69). In other cases, patients perceived the ability of local physicians was inadequate for HF specific management (57). Many noted a preference for doctors in the ER, with specialist HF knowledge. Confidence in ER doctors may drive patients to take deliberate action (or non-action) to receive care in the ED. Furthermore, the expense of seeking professional care was also reported as a reason why patients did not seek help earlier for worsening symptoms (57, 60, 68).

## 3.7 Discussion

This meta-synthesis of qualitative research in HF has facilitated a more comprehensive account of patient decision-making processes.

As suggested by Leventhal's SRM, a patient's emotional response and understanding of their condition (illness perceptions) influences coping decisions including the decision to seek professional care. Poor understanding of HF, its causes, long term consequences, trajectory, and controllability, left patients unsure of how to perceive their situation and respond appropriately.

These unclear representations were, in part, due to patients' own cognitive abilities, however, evidence also suggests patients had difficulty processing health information (59). This finding highlights the important consideration of health literacy; an area of growing interest in HF. A recent review has identified that approximately 39% of HF patients have low health literacy (23). Higher health literacy levels are consistently correlated with higher HF knowledge (23). Further investigation of the relationship between health literacy and decision-making, may be useful in the development of interventions to promote timely care-seeking for worsening HF symptoms. Results also showed that immigrants were more likely to be unaware of the cause of their condition and symptoms (68), thus suggesting the role of language barriers in patients' communication with providers (52, 64, 66). Therefore, use of medical terminology by HCPs, patients' cognitive deficits, and foreign languages may reduce the quality of patient/doctor communication and thus translate to gaps in knowledge and understandings of HF. Addressing these barriers to effective patient/doctor communication, with a focus on providing consistent, clear information using relatable language may help to bridge the knowledge gap for a large proportion of HF patients.

A major implication of unclear representations of HF was that the perceived seriousness of HF and symptoms were scarcely recognised (56, 60). This is evident through patients preferred coping methods (ie wait and see) in response to worsening symptoms, rather than seeking immediate professional care (52, 60, 75). Evidence also highlights the importance of support and empowerment. Not only did family members and informal carers provide a sense of security that helped patients cope with the burden of HF, but they also highlighted worsening symptoms and prompted care seeking (60, 64, 68). Patients must also recognise that they are in control of managing symptoms, making decisions about care, and must understand the cause and consequences of HF. Improving knowledge of HF, in addition to self-efficacy, will be more likely to result in a favorable outcome (timely care seeking).

Another finding was the influence of system/provider-related factors that were unaccounted for in the SRM, involving previous negative hospital experiences (52, 73), disorganised care (49, 61, 69), long wait times (60, 69), and even perceived negligence of GPs and nurses (57). These prevented access to timely care or discouraged patients from seeking professional help, despite having the will to manage their symptoms and sufficient knowledge to carry out necessary actions. Education alone is therefore unlikely to improve response to worsening symptoms, as external factors also influence patient decision-making. A chief example of this is in instances where patients are completely aware of their delay, but choose to allow symptoms to worsen so they can bypass the perceived inefficiencies of ambulatory care to receive immediate care in the ED (60, 69). These additional findings that are unaccounted for in the SRM should be considered in development of interventions to improve patient's response to worsening symptoms. Over half of HF patients delay seeking care for worsening symptoms, leading to acute exacerbations that require emergency hospitalisation (4). Understanding the full range of factors involved in timely care-seeking decisions and addressing these key issues may help reduce the rate of preventable hospitalisations, and thus improve survival, quality of life and reduce the economic burden of HF management enormously.

## 3.8 Conclusion

Findings from this metasynthesis extend the SRM to reflect a more comprehensive account of patients' decision-making. This information can be used to tailor education, communication and service initiatives to improve HF patient's responses to worsening symptoms, and assuage the negative effects associated with delay.

## 3.9 Epilogue

The meta-synthesis presented in this chapter has identified a range of factors impacting care-seeking in HF, many of which are in accordance with the SRM, and others not well-represented or unaccounted for previously. This meta-synthesis highlights the importance of previous healthcare experiences in care-seeking, which requires further investigation in an Australian HF population. Findings from this meta-synthesis also provide further rationale for investigating patient-provider communication in HF. This chapter reflects the literature at the time it was published in Heart Failure Reviews,(1) a leading international journal focused on HF, its pathogenesis and treatment. Additional literature published after the review period will be included in the discussion chapter to contextualise the findings. The next chapter details the methods used to further elucidate the role of these identified factors in care-seeking in an Australian HF population, and investigate patient-provider communication in HF.

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# Chapter 4
# Methods

## 4.1 Introduction

As demonstrated in Chapter 3, few studies that explore HF self-care and the experience of living with HF focus on care-seeking behaviour, specifically. Synthesis of the related literature revealed that an individual's decision to seek or avoid professional care is a complex process, much of which aligns with the principles of self-regulation. Chapter 3 also drew attention to factors that influence care-seeking that are not reflected within the Self-Regulation Model of illness behaviour (SRM) and require further investigation. The purpose of this chapter is to describe the rationale and processes involved in further elucidating the role of patient, provider and system-related factors in care-seeking in an Australian HF population, and determining how these factors are situated within or contribute to extension of our knowledge about the processes of self-regulation. This chapter also describes the processes involved in measuring factors known to impact health-related decisions in this population, and exploring patient preferences for HF information delivery and perceptions of patient-provider communication. This chapter will firstly explain the theoretical perspective guiding the study, and then describe the methodological approach used. The exploratory sequential mixed methods design of this study and steps taken to carry out the quantitative and qualitative phases will be described.

## 4.2 Theoretical perspective

This thesis adopts a pragmatic perspective, where the research problem, delayed care-seeking behaviour, is central, and multiple approaches are used to better understand the problem. Pragmatism originated from the work of Charles Sanders Peirce, William James, and John Dewey. The basic idea of pragmatism is that multiple research approaches can be mixed to offer the best chance of answering research questions. It attempts to consider multiple viewpoints, perspectives, positions and standpoints, including those of quantitative and qualitative research, and is thus often the preferred paradigm of mixed methods research.(1) Pragmatism rejects traditional dualism (e.g. objectivism vs. subjectivism, positivism vs. constructivism) and does not subscribe to a rigid philosophy.(2) A pragmatic worldview uses pluralistic approaches to better understand the research problem, also described as a 'what works' approach, where focus is centred around the research problem, rather than the methods used.(1) Under this paradigm, a researcher has the freedom to choose the methods, techniques, and procedures of research that best suit their aims and research questions.(2)

In keeping with a pragmatic approach, this study mixes a post-positivist approach (quantitative) with an interpretative phenomenological approach (qualitative). Using this specific qualitative methodology within a mixed methods framework has been termed mixed methods phenomenological research (MMPR).(3) MMPR was used in this thesis to provide a clearer understanding of care-seeking decisions in people with HF, which could not be provided using either approach alone. Mixed methods phenomenological research has only recently been formally conceptualised by Mayoh and Onuwuegbuzie, who define MMPR as:

> *"Research that combines phenomenological methods with methods grounded in an alternative paradigm within a single study"*(3)

There are several ontological and epistemological differences between post-positivist and phenomenological paradigms, however, the flexibility of phenomenological research(4) allows for its combination with more deductive, quantitative methods. In other words, despite seemingly contrasting worldviews, the two approaches can be integrated. Phenomenology is often described as a 'human science approach'.(5) Due to the scientific nature of phenomenology, there are methodological compatibilities between deductive quantitative methods and phenomenological methods.(3) Post-positivists advocate for the existence of an objective reality whereas interpretivists suggest multiple realities and a phenomenological approach emphasises the notion of subjective experience. There is a clear contrast between post-positivist and interpretative phenomenological approaches, however, the need to orient the phenomenon prior to investigating the phenomenon provides excellent justification for mixing these two contrasting approaches.(3) Orienting refers to understanding what key behaviours or experiences are before exploring these in-depth using interpretative phenomenological methods.(3) An initial orienting phase using quantitative methods can maximise the potential of an interpretative phenomenological approach.(3) This provides strong justification for the use of an initial quantitative phase followed by interpretative phenomenological methods in a sequential research design. A sequential exploratory design mixing quantitative and interpretative phenomenological approaches was adopted in this thesis and will be described later in this chapter.

## 4.3 Methodology

As described in the previous section, MMPR justifies the integration of interpretative phenomenology into a mixed methods framework despite the paradigmatic differences between post-positivist and phenomenological approaches.

The method of interpretative phenomenology is interpretative phenomenological analysis (IPA).(6) IPA stems from phenomenology and symbolic interactionism, which deems that people are not passive receivers of an objective reality, but rather that they understand and make sense of their world based on their own experiences and interactions with others.(7) IPA is phenomenological in that it focuses on participants' perceptions of their experience of an event rather than producing an objective statement of the event itself, through scrupulous examination of the participant's world and their personal experiences.(6) The approach is interpretative in that it acknowledges the active role of the researcher in the process of making sense of the participant's perspectives. IPA acknowledges that whilst the aim is to gain insight into the participant's world, it is inherently impossible to do so directly or completely. Researchers' own personal conceptions complicate fully understanding the world of the participant. The process, therefore, involves interpretive activity, occurring in two-stages, or a double hermeneutic, where the participants are trying to make sense of their world, and the researcher is trying to make sense of the participants trying to make sense of their world.(6)

IPA uses a combination of two interpretative stances: empathic hermeneutics and questioning hermeneutics. In other words, whilst this approach is focused on understanding what it is like from the participant's perspective, it also involves asking critical questions about the participant's perspective. For example, do I, as the researcher, have a sense of something going on here that the participant themselves may not be aware of?(6) IPA recognises that a person's thoughts or cognitions are not often presented clearly through transcripts, but aims to say something about their cognition through analytical processes.(8) Using both stances in the process of inquiry is likely to result in a more in-depth analysis and an unvarnished understanding of the person whose perspective is being examined.

The core tenet of the theoretical model adopted in this thesis (Leventhal's SRM) is to understand how people make sense of their world, which corresponds with the fundamental principles of phenomenology, and is thus appropriate for use in this thesis. Rather than solely focusing on outcomes of models using a traditional quantitative approach, IPA can be used to examine processes within models using a qualitative approach.(9) It must be acknowledged that the use of IPA in a pre-existing theoretical model may influence the information provided by participants and the interpretations of the researcher(7) Although aspects of the SRM were not used as pre-determined themes in the analysis of interview transcripts, findings were arranged into various aspects of the model after analysis at the writing up stage. Like Green and colleagues, who also used IPA and the SRM to explore illness representations in people with non-epileptic seizures,(10) themes that did not fit within the model were allowed to emerge and were described in relation to how they were linked with different aspects of the model.

This interpretative phenomenological approach was combined with a post-positivist quantitative approach using MMPR. A post-positivist approach supports objective reality, contrasting entirely with an interpretative phenomenological approach. However, as described in the previous section, quantitative methods can complement phenomenological methods due to the discovery-oriented nature of phenomenology.(3) MMPR was adopted in this thesis for orientation purposes, but also to provide a more holistic understanding of care-seeking through joint discussion of findings from each phase. The next section will provide justification for the use of mixed methods to explore care-seeking in HF, and describe the sequential exploratory design adopted in this thesis.

## 4.4 Research design

Mixed methods research involves the integration of quantitative and qualitative data to answer research questions. This approach includes the collection of both closed-ended responses (quantitative data) and open-ended responses (quantitative and qualitative data), analysis of both forms of data (each involving their own procedures to demonstrate rigour), and integration of the two.

Mixed methods is a relatively new approach to research that has emerged since the late 1980's and early 1990's, offering an alternative to using a single approach to enquiry (i.e. quantitative or qualitative).(11) The core assumption of mixed methods research, and a large part of its appeal in the social and behavioual sciences, is that a combination of qualitative and quantitative approaches provides a more complete understanding of a research problem than either approach alone.(2) A mixed methods approach to enquiry enables one approach to strengthen the other, allows one dataset to explore different types of questions than the other dataset, and enables one to help explain and build on the other. For example, during the data analysis stage, quantitative data can facilitate the assessment of generalisability of the qualitative data and shed new light on qualitative findings. The integration of quantitative and qualitative data, therefore, provides a more comprehensive understanding of complex research problems, such as the one proposed in this thesis.

As highlighted in Chapters 2 and 3, making decisions to seek or avoid professional care for HF symptoms is a complex decision-making process involving practices of self-regulation. The authors of the Self-Regulation Model stress the importance of adopting a systems-oriented approach to account for contextual factors that impact on these processes. Leventhal and colleagues suggest that a single methodology is not sufficient to capture the complexities of self-regulatory processes, and instead recommend the use of multiple methods to explore the impact of specific factors on proximate and intermediate outcomes and final endpoints.(12) In accordance with Leventhal and colleagues, both types of data are essential to explore how patients with HF self-regulate and respond to their symptoms. A mixed methods approach is, therefore, necessary to answer the research questions indicated in Chapter 1. Final endpoints (ie delayed care-seeking) could not be captured quantitatively because: 1) a true measure of delay would require measurement of each of its three semi-independent stages (appraisal delay, illness delay, and utlitisation delay); 2) there is no standard measure available for delayed care-seeking; and 3) measurement relies on retrospective account. Whilst delay was not measured as an outcome for these reasons, qualitative data was able to provide insight into the processes involved that may contribute to delay. The quantitative data was able to orient the proceeding qualitative phase, and the joint discussion of qualitative and quantitative findings provide a more comprehensive understanding of care-seeking than either approach alone.

In this study, qualitative and quantitative approaches are combined to enhance the strengths and minimise weaknesses of each approach in isolation. A qualitative approach elicits information that quantitative data is unable to capture (i.e. a nuanced account of and meanings associated with patient experiences). The weakness of using this approach alone, however, is that it does not take into consideration objective measures of knowledge, health literacy, illness perceptions, affective symptoms and self-efficacy, which are known to influence behaviour and can help focus phenomenological enquiry. The initial quantitative phase (self-report questionnaires) was used to inform the phenomenological focus within the proceeding qualitative phase. For example, how participants responded on the questionnaires helped guide questions asked in the interviews. Furthermore, the quantitative findings were used to complement interpretative phenomenological methods by providing greater insight into the context in which care-seeking decisions were being made through the joint discussion of findings from both phases. The quantitative data thus helps orient the phenomenon and consider the context in which the phenomenon (delayed care-seeking) occurs. The methods were combined for the purpose of development,(13) whereby the results from one method help inform another. The specific MMPR design (sequential exploratory mixed methods phenomenological research design) used in this thesis will be described in the next section.

### 4.4.1 Mixed methods study design

Mixed methods studies use distinct designs that detail the timing or schedule of quantitative and qualitative data collection and the emphasis, or weight given, for each data set. Mixed methods studies can be informed by philosophical assumptions and/or theoretical frameworks, some of which may be explicit or implicit.(2)

This study used an exploratory sequential mixed methods phenomenological approach whereby enquiry commenced with a qualitative phase, followed by a quantitative phase, and ended with another qualitative (phenomenological) phase (Figure 4.1). This mixed methods study design was sequential in that data collection and analysis for each phase was consecutive and findings from each phase informed the subsequent stage.

Figure 4.1 Exploratory sequential study design

The exploratory sequential design had a qualitative (phenomenological) emphasis (QUAL/quan) and explicit use of the Self-Regulation Model of illness behavior (SRM). The two 'QUAL' phases of the study were the meta-synthesis of the existing qualitative literature (Phase 1) and in-depth semi-structured interviews with patients with HF (Phase 3). The quantitative or 'quan' phase of the study (Phase 2) included collecting patient clinical and demographic information and cross-sectional self-report questionnaires assessing key variables identified as important factors in health-related decisions in HF based on the self-care literature, the SRM, and results of the meta-synthesis. Each phase of the study had its own purpose and answered different types of research questions, collectively facilitating a greater understanding of care-seeking in HF. Results from each dataset are integrated (see section 4.4.7) through the joint discussion of findings from each phase, which are presented in Chapter 8.

*Phase 1*

The purpose of the initial qualitative phase (the meta-synthesis presented in Chapter 3) was to gain a thorough understanding of the scope of the problem (delayed care-seeking in HF), and direct subsequent research questions. The qualitative meta-synthesis identified patient, provider and system-related factors that influence care-seeking in a global HF population and drew attention to areas amenable to intervention, such as patient understanding and knowledge of HF and patient-provider communication. These findings informed selection of variables to be measured in the quantitative phase and highlighted the importance of patient, provider, and system-related factors that required exploration in the qualitative phase to provide a comprehensive understanding of care-seeking in an Australian HF population. The research questions that guided the study are:

1. What are the factors that influence care-seeking in HF?
2. How do Australian patients with HF perceive and understand their health condition and symptoms?

3. In what way do patient, provider, and system factors influence care-seeking decisions in an Australian HF population?
4. What are Australian patients' perceptions of and preferences for HF information delivery and patient-provider communication?
5. How do Australian patients with HF make decisions to seek or avoid professional care in the context of illness perceptions, self-efficacy, affective symptoms and health literacy?
6. What are Australian patient's perceptions and preferences for HF information delivery and patient-provider communication in the context of health literacy and HF knowledge?

The first research question was answered in the phase 1 meta-synthesis of international HF literature. The methods depicting the meta-synthesis process are found in Chapter 3. The second research question was addressed by a quantitative phase, while the third and fourth questions were addressed by the final phenomenological (qualitative) phase of this study. The fifth and sixth research questions are answered through the integration of quantitative and qualitative phases of the study, wherein qualitative findings are examined in the context of quantitative findings. The results of the integration are presented in Chapter 8, describing a more extensive understanding of care-seeking decisions and HF educational needs than each phase alone.

*Phase 2*

The purpose of the quantitative phase was to collect clinical and demographic information of the HF study population and measure key variables identified as important factors in health-related decisions in HF. This included patients' perceptions of their illness (i.e. their understanding of HF) and measurable factors that are likely to impact on how these perceptions are formed (e.g. factors reflecting patients' executive function such as health literacy, disease-specific knowledge, and affective symptoms). According to the SRM, emotional response to a perceived health threat informs coping choices, and thus provides a rationale for measuring anxious and depressive symptoms in this population. As described in Chapter 1, the self-care literature also stresses the role of self-efficacy in self-management decisions. Variables explored in this quantitative phase included findings from the meta-synthesis reflecting measurable factors, aligned with the established self-care literature and corresponded with the SRM. Participants' responses to the self-report questionnaires were also used to focus the interview question in the proceeding phenomenological phase. For example, if a participant perceived low levels of personal control over their condition, as reflected by the Brief Illness Perception Questionnaire,(14) they were probed about this specifically to help understand how this may impact decisions to seek or avoid professional care.

### *Phase 3*

Factors identified in the meta-synthesis that were previously unaccounted for in the SRM and had not been captured in the quantitative phase (e.g. patients' previous healthcare experiences) were explored further in the final qualitative phase. As noted, responses from the Brief Illness Perception Questionnaire(14) were also further elucidated in this qualitative phase through semi-structured in-depth interviews, and thus, built upon the quantitative data.

This phase highlighted patients' perspectives of the decision-making process through eliciting information about previous care-seeking experiences. Not only did this qualitative phase allow new ideas to emerge, but it provided insight into how key factors operate to impact on decisions to seek or avoid professional care, addressing the third research question. The meta-synthesis identified patient-provider communication as a problem area in HF, which subsequently impacted on patient knowledge and understanding of their condition. Furthermore, health literacy is a paramount outcome in HF education (see Chapter 1) and is an independent predictor of self-care behaviour.(15) Perceived barriers around HF communication and information delivery, as well as patient preferences, were also elicited in this qualitative phase, providing clear targets for intervention, and addressing the fourth research question.

A description of the methods of Phase 2 (quantitative) and Phase 3 (qualitative) are detailed in the next section.

### 4.4.2 Study setting and population

The study presented in this thesis was conducted at St. Vincent's Hospital in Sydney, Australia. St. Vincent's Hospital is located in the inner city Sydney suburb of Darlinghurst, and is a large teaching hospital comprised of 379 beds. St. Vincent's is a Centre of Excellence for cardiology and is recognised as the state and national leader of cardiac service provision, including cardiac transplantation. It is the oldest heart transplantation unit in Australia and therefore, patients with HF are often referred to St. Vincent's from across the state and Australia-wide, resulting in an array of patients with varying demographic and sometimes unique and severe clinical characteristics.

The study in this thesis was part of a larger cohort study (Living And in the Community with symptom burden with chronic hEart failure (LACE)), conducted at St. Vincent's Hospital. Participants involved were those who had experienced at least one previous HF hospitalisation, were symptomatic, and agreed to participate in the study. Inclusion and exclusion criteria are detailed in section 4.4.3. Participants came from an array of cultural and socioeconomic backgrounds, living in both rural and metropolitan areas from across the country. This parent study proposed to measure symptom burden experienced by people with HF, and outcomes at 30 days and six months. Baseline data and symptoms were reported upon recruitment and participants were followed up for six months to gather all-cause mortality and all-cause hospitalisation data. All data collected as part of the larger study (including all baseline data collected using a case report form, follow-up data, and all questionnaires) can be found in Appendix 2 and Appendix 3.

The focus of the current study was to explore the underlying processes involved in individuals' decisions to seek professional care for worsening HF symptoms. To measure variables that reflected the specific aims of this thesis, questionnaires were added to the parent study measures. To elicit patient experiences of care-seeking, preferences for HF information delivery, and perceptions of patient-provider communication, an additional qualitative study was undertaken. Only participants recruited into the larger LACE study after these amendments had been made were included in the thesis study. Consequently, only cross-sectional self-report questionnaire data were used for the purpose of this thesis, as the resulting sample size was not large enough to explore the impact of additional variables on 30-day and six-month outcomes.

### 4.4.3 Participant recruitment

Participants were recruited into the study from June 2015 – August 2016 using inpatient lists from the cardiothoracic ward at St. Vincent's Hospital, Sydney. Patients were required to meet the following inclusion criteria for the parent study to be considered eligible for the current study:

1. Diagnosis of HF
2. Symptomatic (New York Heart Association class II-IV)(16)
3. At least one previous HF-related hospitalisation
4. Sufficient English language reading and speaking skills to ensure completion of questionnaires and participation in interview
5. Ability to provide written informed consent

Following identification of potentially eligible participants on inpatient lists, the researcher examined medical records and patient notes to determine if they met all eligibility criteria. In accordance with the Cardiac Society of Australia and New Zealand (CSANZ) definition of HF(17) (structural/functional abnormality of the heart + characteristic HF symptoms), patients' most recent echocardiographic reports were examined to check for structural and/or functional abnormality of the heart indicative of HF, and cross-checked with medical records and patient notes to ensure HF diagnosis. Presence of HF symptoms and evidence of at least one previous HF-related admission were also ascertained from patient notes. Details were confirmed with the patient when information was missing or inconsistent in the notes. Patients were excluded if they were either unable to provide informed consent or had documented dementia. The research provided eligible patients with both verbal and written explanations of the study and the opportunity to ask questions about the study.

A selection of participants were invited to participate in semi-structured in-depth interviews to discuss a range of topics to be detailed in the qualitative data collection section. Participation in this qualitative portion of the study involved a separate consent process whereby the researcher directly approached participants already enrolled into the study and invited them to participate in an interview. At this stage, potential interviewees were already familiar with the researcher, as she recruited them into the study initially. In initial recruitment process, she introduced herself as a researcher working as part of a research team at St Vincent's Hospital Sydney. Potential interviewees were thus already familiar with her role at the interview recruitment stage. The researcher explained that the purpose of the interview was to understand how they manage symptoms and make decisions to seek professional care. Participants were also told about where the interview would take place (either at the bedside, in a private interview room, or over the phone, if discharged), how long it would take (30-60 minutes), and the nature of the interview (semi-structured with some topics pre-determined, yet conversational). The researcher also sought permission to audio-record the interview and explained how the data would be managed and used. This included transcription of the audio-recording involving a process of de-identification (participant numbers replaced names and pseudonyms used in-text), and secure storage of data to ensure participant anonymity and confidentiality. The researcher also explained that participants were free to withdraw from involvement in the study at any time if desired.

Interviewees were a convenience sample of LACE participants recruited post-amendment, including those who expressed an interest in talking about their previous healthcare experiences. The participant had to have the physical capacity to participate in a conversation for up to an hour without significant deterioration (e.g. breathlessness and fatigue). Importantly, participants had to have the time and willingness to speak at length in a busy clinical setting (e.g. no tests scheduled during that time frame, they were awake, with no doctors or visitors in attendance).

### 4.4.4 Quantitative data collection and study measures

As part of the parent LACE study, a range of information including current medications, biochemistry and haematology results were collected from medical records, however, this chapter details the information relevant to this thesis only which does not include these variables. Patient demographics, medical history, physical assessment, and HF profile were collected using a case report form for all participants who provided written informed consent. Details regarding all data included in this form can be found in Appendix 2.

A battery of self-report questionnaires and screening tools were then completed by participants. These measures included the Short Test Of Functional Health Literacy for Adults (S-TOFHLA), (18) Brief Illness Perception Questionnaire (B-IPQ), (14) Dutch Heart Failure Knowledge Scale (DHFKS), (19) Edmonton Symptom Assessment System (ESAS)(20), Kansas City Cardiomyopathy Questionnaire (KCCQ)(21), Patient Health Questionnaire-9 (PHQ-9)(22), and the short form of the Depression, Anxiety, and Stress Scale (DASS-21)(23), all of which have been validated and used in HF research. The S-TOFHLA, DHFKS, and B-IPQ, were additions made to the original LACE protocol for the purpose of this study. All participants completed questionnaires themselves, except in cases where participants had difficulty reading or writing (e.g. did not have glasses or were experiencing hand tremors), where the researcher read out questions and recorded the participant’s responses. The researcher also administered the S-TOFHLA for all participants. Questionnaires and other study measures are detailed below.

### *Short Test of Functional Health Literacy for Adults (S-TOFHLA)*

The Short Test Of Functional Health Literacy for Adults (S-TOFHLA) is a timed test used to assess patients' ability to read and understand health-related material. (18) The full version, the TOFHLA, takes 22 minutes to complete and includes 50 reading and comprehension items and 17 numeracy items. (24) The short version was used in this study, consisting of 36 reading and comprehension items, and is administered in seven minutes or less.

The S-TOFHLA requires patients to complete two passages: preparation for an upper gastrointestinal series which is written at a 4th grade level and patients' rights and responsibilities of a Medicaid application, written at a 10th grade level. The Anglicised version of the S-TOFHLA, developed by Barber, Buchbinder and Osborne (2009), was used in this study to ensure the tool was relevant to an Australian population. In the Anglicised version, the second passage is modified to describe applying for Sickness Allowance rather than Medicaid. Other modifications include minor changes in wording to reflect the Australian vernacular.

Every 5th-7th word is omitted from each passage, comprising 36 items in total. Patients must select the correct word that belongs in the omitted spaces from a set of four options. Each item is worth one point, giving a total score out of 36. Based on total score, patients are categorised as having either inadequate (0-16), marginal (17-22) or adequate (23-36) levels of health literacy.

### *Brief Illness Perception Questionnaire (B-IPQ)*

The Brief Illness Perception Questionnaire (B-IPQ) is a nine-item scale that enables rapid assessment of illness perceptions, including cognitive and emotional representations of illness. (14) The original IPQ uses a five-point Likert scale to assess the five dimensions of cognitive illness representations according to Leventhal's SRM. In the B-IPQ, five items assess cognitive representation (one item for each dimension), two items assess emotional representation, and one item assesses illness comprehension. Patients rate each item on a 0-10 numeric rating scale.

The last item assesses causal representation and requires patients to list the three most important perceived causal factors related to their illness.

The open-ended responses of the last item are grouped into categories based on the nature of the perceived cause (e.g. hereditary, lifestyle, stress). High scores on each of the numeric items translate to a perceived increase in each respective dimension measured.

### *Translated Dutch Heart Failure Knowledge Scale (DHFKS)*

The translated Dutch Heart Failure Knowledge Scale (DHFKS) is a 15-item self-report questionnaire that is used to measure patients' general knowledge of HF, understanding of treatment, and symptoms.(19) Each multiple-choice question requires patients to choose from three options, one of which is correct. Four items assess general knowledge, six items test knowledge of treatment including diet, fluid restriction and activity, and five items assess symptom awareness and symptom recognition. The total score indicates level of HF knowledge, ranging from 0 (no knowledge) to 15 (optimal knowledge).

### *Edmonton Symptom Assessment System (ESAS)*

The Edmonton Symptom Assessment System (ESAS)(20) is a nine-item self-report assessment tool commonly used in palliative care and has been validated in HF.(25) Each item represents a symptom common to HF including pain, fatigue, nausea, depression, anxiety, drowsiness, loss of appetite, well-being and breathlessness.(20) Patients rate the current severity of each symptom from 0 to 10 (0= no symptom, 10= worst possible symptom). The zero to ten numerical rating scales indicate the magnitude of each symptom at that point in time. A score of zero indicated the symptom was not present, while ten indicated the participant was experiencing the worst possible magnitude of that symptom. Total ESAS score can be calculated to indicate overall symptom burden. The brevity and ease of administration of the ESAS renders it a highly suitable measurement tool for this elderly patient population in a busy clinical setting.

### *Kansas City Cardiomyopathy Questionnaire (KCCQ)*

The Kansas City Cardiomyopathy Questionnaire (KCCQ) is a 23-item assessment tool used to measure health related quality of life and is specifically designed for patients with HF.(21) It covers various domains of health-related quality of life including physical limitation, symptoms, self-efficacy, social interference, and quality of life. The KCCQ is a self-report tool using a Likert scale, providing an overall score (mean score of all domains combined) ranging from 0-100 (0 = lowest possible health status i.e. poorest, 100 = highest possible health status i.e. best). Lower overall summary scores at baseline have been strongly associated with increased risk of mortality within a year.(26) Furthermore, scoring below 50 has been identified as an independent predictor of the onset of depressive symptoms in patients with HF.(27) The KCCQ is a validated measure of health-related quality of life, exhibits greater sensitivity than the Minnesota Living with Heart Failure questionnaire(28) and 36-item Short-Form health survey(29), and has been used effectively in patients with HF and previous myocardial infarction.(21, 30)

### *9-item Patient Health Questionnaire (PHQ-9)*

The 9-item patient health questionnaire (PHQ-9) is a self-report tool representing nine symptoms common to depression and is recommended by the American Heart Association for detecting depressive symptoms in cardiovascular disease.(31) Items are scored on a 0 to 3 scale (0=not at all, 1= several days, 2= more than half the days, 3= nearly every day) indicating frequency of the symptom over the past two weeks. The first two items measure the most prominent symptoms of depression; anhedonia and dysphoria. At least one of the two initial questions, measuring anhedonia and dysphoria, respectively, must be scored highly for a diagnosis of depression.(22) Major depression is suspected if more than five of the nine symptoms, inclusive of anhedonia or dysphoria, have been present ‘more than half the days’ in the past two weeks.(32) The final item ‘thoughts that you would be better off dead or hurting yourself in some way’ is registered as positive for depressive symptoms if present at all.(32)

It is important to note that positive scoring alone does not indicate a clinical diagnosis of depression, but rather the presence of depressive symptoms. Total PHQ-9 score determines severity of depressive symptoms. If a patient screened positive for depressive symptoms, their primary treating team was notified of the results and these were documented in the patient's medical record.

### *Depression Anxiety Stress Scale (DASS)*

The Depression Anxiety Stress Scale (DASS) measures anxiety, stress, and depression using three scales (one subscale for each state), each with 14 items.(23) Level of anxiety only was assessed using the anxiety subscale of the tool, which measures autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious effects. A short version, the DASS-21 was used in the LACE study, with seven items per subscale. The anxiety subscale only was used for the purpose of this study, as depressive symptoms were measured by the PHQ-9, which is the American Heart Association recommended tool for detecting depressive symptoms in cardiovascular disease. In the anxiety subscale of the DASS-21, participants were required to use a four-point severity/frequency scale to reflect the frequency of their anxiety over the last week. The DASS-21 has been shown to be a valid measure of anxiety, stress and depression. (33)

### *Socio-economic indexes for areas (SEIFA)*

Socio-Economic Indexes For Areas (SEIFA) have been developed by the Australian Bureau of Statistics (ABS)(34) to rank geographic areas in Australia according to relative socioeconomic advantage and disadvantage. The indices were developed using nationwide census data using household income, highest educational attainment, and occupation to rank geographic areas across Australia based on the socio-economic conditions in that area. The present study used the index of relative socioeconomic advantage and disadvantage (IRSAD) to reflect the relative socio-economic advantage and disadvantage of participants, based on the area (postcode) of Australia in which they live. This measure was included in the current study given the relationship between health literacy and socioeconomic status, with lower health literacy more common amongst populations with lower socioeconomic status.(35)

SEIFA indices were calculated using the spreadsheets available on the ABS website, where every postcode in Australia corresponds with a SEIFA score. Each postcode has a score, a rank, a decile, and a percentile. For the purpose of this study, the corresponding decile for each participant's postcode was reported, where areas are ordered from the lowest scoring 10% of areas (1st decile) to the highest scoring 10% of areas (10th decile) in Australia. A high index score (i.e. 10th decile) represents high advantage and low disadvantage, and a lower index score represents relatively greater disadvantage and lack of advantage.

### *Charlson Comorbidity Index*

The Charlson Comorbidity Index (CCI)(36) was used to quantify participants' co-morbidity burden. The CCI is an index designed to estimate the relative risk of death based on the number and severity of co-morbidities.(36) This index does not account for all co-morbidities a person may have but instead assigns a weighted score to nineteen conditions that were shown in epidemiological studies to increase risk of death in longitudinal studies.(36) The sum of the index score is an indicator of disease burden and a predictor of death.(37) Conditions not considered prognostically significant included previous conditions that had been entirely resolved, such as history of pneumonia.(36)

Since its development in 1986, the Charlson index has been widely used in longitudinal studies as a prognostic indicator, and validated in various patient populations including cancer, end stage kidney disease and ischaemic stroke.(36, 38-40) Results from these studies confirm the relationship between co-morbidity and risk of death within ten years. Co-morbidities have not only been linked with mortality, but also functional status and quality of life.(41)

### *New York Heart Association (NYHA) classification*

Physicians and researchers often assess the stage of HF with the New York Heart Association (NYHA) classification system (Table 4.1); a valid measure of functional status which is used internationally to grade the severity of HF. (16) Patients are classified on a four-point scale from mild (classes I and II) to moderate (class III) to severe (class IV), based on the level of physical activity able to be undertaken before symptoms appear. As seen in Table 4.1, NYHA class I patients do not experience any physical restrictions such as breathlessness, fatigue, cough or palpitations upon physical exertion, whereas NYHA class IV patients suffer severe discomfort, even at rest.

Table 4.1 New York Heart Association (NYHA) functional classification (adapted from The Criteria Committee of the New York Heart Association, 1964)(16)

| NYHA Classification | Description |
|---|---|
| **Class I (asymptomatic)** | • No limitation of physical activity<br>• Ordinary physical activity does not cause undue fatigue, palpitations, or breathlessness |
| **Class II (mild)** | • Slight limitation of physical activity<br>• Comfortable at rest but ordinary physical activity results in fatigue, palpitations, or breathlessness |
| **Class III (moderate)** | • Marked limitation of physical activity<br>• Comfortable at rest but less than ordinary physical activity results in fatigue palpitations, or breathlessness |
| **Class IV (severe)** | • Unable to carry out physical activity without discomfort<br>• Symptoms at rest<br>• If any physical activity is undertaken, discomfort is increased |

### *Australia-modified Karnofsky Performance Status (AKPS)*

The Australia-modified version of the Karnofsky Performace Status (AKPS)(42) is an eleven-level scale ranging from 0 (dead) to 100 (no complaints or evidence of disease) to measure patient functioning. The AKPS incorporates aspects of the original Karnofsky Performance Status (KPS)(43), widely used for measuring functional status in cancer patients,(44-46) and the Thorne-Modified Performance Status (TKPS) which is better suited for home hospice patients.(47) The AKPS, unifies the two aforementioned assessment tools into a single scale with a more general approach in order to enhance usability in various clinical settings.(42) Table 4.2 highlights the similarities and differences between the KPS, TKPS and AKPS functional categories. For the purpose of this study, participants' functional capacity was assessed according to the AKPS.

Table 4.2 Comparison of the KPS, TKPS and AKPS score indicators (adapted from Abernethy et al, 2005)(42)

| Score | Karnofsky Performance Status (KPS) | Thorne-modified Karnofsky Performance Status (TKPS) | Australia-modified Karnofsky Performance Status (AKPS) |
|---|---|---|---|
| **100** | Normal; no complaints; no evidence of disease | Normal; no complaints; no evidence of disease | Normal; no complaints; no evidence of disease |
| **90** | Able to carry on normal activity; minor signs or symptoms | Able to carry on normal activity; minor signs or symptoms | Able to carry on normal activity; minor signs or symptoms |
| **80** | Normal activity with effort; some signs or symptoms of disease | Normal activity with effort; some signs or symptoms of disease | Normal activity with effort; some signs or symptoms of disease |
| **70** | Cares for self; unable to carry on normal activity or to do active work | Cares for self; unable to carry on normal activity or to do active work | Cares for self; unable to carry on normal activity or to do active work |
| **60** | Requires occasional assistance but is able to care for most of his needs | Requires professional visits less than once a week | Requires occasional assistance but is able to care for most of his needs |
| **50** | Requires considerable assistance and frequent medical care | Requires professional visits more than once a week | Requires considerable assistance and frequent medical care |
| **40** | Disabled; requires special care and assistance | In bed more than 50% of the time | In bed more than 50% of the time |
| **30** | Severely disabled; hospitalisation necessary; active supportive treatment is necessary | Almost completely bedfast | Almost completely bedfast |
| **20** | Very sick; hospitalisation necessary; active supportive treatment is necessary | Totally bedfast and requiring extensive nursing care by professionals and/or family | Totally bedfast and requiring extensive nursing care by professionals and/or family |
| **10** | Moribund; fatal processes progressing rapidly | Comatose or barely arousable | Comatose or barely arousable |
| **0** | Dead | Dead | Dead |

#### *Frailty*

Frailty was measured using the frailty instrument (SHARE-FI) from the Survey of Health, Ageing and Retirement in Europe (SHARE) trial.(48) This simple to use instrument requires only a single physical measure (hand-grip strength with a dynamometer). The other domains of frailty (exhaustion, weight loss, slowness and low activity) are measured using 1 question per domain. The domains of frailty are in keeping with the Fried Frailty Index,(49) which provides a standardised definition for frailty in older adults.

### 4.4.5 Qualitative data collection

Semi-structured in-depth interviews were conducted with 15 participants to ascertain information about previous care-seeking experiences, perceptions of HF and its symptoms, perceived system- and provider-related factors influencing decisions to seek professional care, and perceptions of patient-provider communication and HF information delivery. As previously noted, these interview topics were informed by themes that emerged from the meta-synthesis and key components of the SRM, with a focus on understanding patients' representations of their condition, symptoms and events in order to remain in keeping with the methodology (IPA) and the conceptual framework adopted by this thesis (SRM).

Interviews were primarily conducted in-person at St Vincent's Hospital (n=11) either in a private interview room on the cardiology ward or at the bedside when patients were less mobile (i.e. on IV dobutamine). Four interviews were conducted over the telephone in cases where participants had been recruited for interview in hospital, but were discharged before the opportunity to conduct the interview arose. Interviews lasted from 31-95 minutes, were audio-recorded, and transcribed verbatim.

An interview schedule (Appendix 4) was used to guide this qualitative data collection, informed by the SRM and themes that emerged from the meta-synthesis. Interviews started with broad, open-ended questions about experiences with HF symptoms pre-hospitalisation. Questions became more specific to the research questions as the interviews progressed. Open-ended probes were used to clarify statements and encourage disclosure of in-depth accounts of care-seeking experiences and perceptions of patient-provider communication. For example, if participants recounted an event that led to hospitalisation, they were asked follow-up questions such as '*how did that make you feel?*' and *'what were you thinking about at that time?'* Furthermore, if participants expressed vague feelings or perceptions of events, the researcher probed with questions designed to elicit more detail, such as *'you said X, what do you mean by that?*' or *'can you tell me more about how you felt X?'* The researcher also checked for accuracy of her interpretations with participants as the interview progressed. The researcher periodically summarised accounts of what participants said and how they felt and asked if these interpretations were correct. This offered the opportunity for participants to either confirm the researcher's interpretation of their telling of events, or clarify their meanings. This enabled the researcher to check that her own interpretations were in line with participants' perceptions of those events. Member checking during interviews was carried out to facilitate credibility of findings. Following preliminary analysis of the first ten interviews, it was found that little data reflected perceived system- and provider-related factors that influenced decision-making. The interview guide was slightly amended to better elicit patients' experiences relating to perceived system and provider-related barriers to seeking/accessing care. Select questions relating to illness perceptions were tailored for each participant based on responses from the B-IPQ. Interviews were ceased if participants were unable to continue due to symptoms or emotional distress. In these instances, participants were reminded that they did not have to continue if it was making them feel physically or emotionally uncomfortable, and were given the option to resume the interview at a later time, or to end their involvement altogether. In cases where participants were emotionally overwhelmed, they showed incredible strength and perseverance. None of the interviews were terminated due to physical or emotional stress, however, interviews were paused momentarily in some cases.

Reflexive accounts were written by the researcher immediately following each interview to enhance rigour and check for bias.(50) Each reflexive account included personal thoughts and opinions about the major ideas that emerged from the participant's story, and thoughts about the interaction and rapport between the researcher and the interviewee (i.e. how the interview went, practical issues that may have arisen during interviews such as interruptions, recorder malfunction) which may have affected data collected. The researcher reviewed these notes repeatedly throughout the data collection process in an attempt to refine her technique in subsequent interviews. Reflexive accounts were also used to ensure the phenomenon of care-seeking was encountered 'freshly and described precisely as perceived'(51) rather than allow prior knowledge of the topic and the SRM entirely interfere with interpretation of participants accounts. In other words, reflexive accounts were also used for bracketing. Bracketing is a method of rigour used in phenomenological studies to enhance validity whereby the researcher attempts to hold prior knowledge and beliefs about the phenomena being investigated in suspension in order to perceive it more clearly.(52) Having knowledge of the principles of self-regulation, and having used it to explain findings from the meta-synthesis in Chapter 3, the researcher was careful not to impose the model upon the interviews or analysis of transcripts, particularly since it had already been identified that this model did not fully account for all factors contributing to care-seeking decisions. Whilst the SRM was a useful tool to help make sense of how people behave in the context of illness, participants were the main drivers of interviews and questions were kept open-ended and non-directive to facilitate the participant's ability to tell their own story in their own words.(53) Despite efforts to remain unbiased, however, the researchers previous exposure to and knowledge of the model may have impacted interviews. Frequent review of reflexive accounts during analysis was used to mitigate the impact of prior knowledge of the topic and of the model on interpretation of participants' experiences.

Data collection and analysis occurred simultaneously. The researcher completed transcription of audio recordings as soon as possible following the interviews and de-identified them. The researcher engaged in preliminary analyses of transcripts (see *qualitative analysis* section 4.4.6) and when it appeared that no new information was emerging from transcripts following mapping of findings (see *A master list of themes for the group* section, see Writing up), it was felt that data saturation was reached and recruitment for interviews ended. This occurred after 15 interviews. It was deemed appropriate by the researcher in conjunction with the supervision team to finalise interviews at this stage because conducting more interviews than necessary in this chronically ill population would cause undue responder burden.

### 4.4.6 Data analysis

#### *Quantitative analysis*

Quantitative data were analysed using IBM Statistical Package for the Social Sciences (SPSS) Version 24 for Mac (IBM Corporation, Somers, NY). Descriptive statistics were used to summarise clinical and demographic variables of the study population and questionnaire results. Mean and standard deviation were reported for normally distributed data, whilst median and interquartile ranges were reported for non-normally distributed data. Frequencies were reported as percentages.

Open-ended responses from the B-IPQ (perceived cause item) were coded into groups where different terms indicated the same concept (e.g. hypertension and high blood pressure). Responses were also grouped into broader categories to reflect more general trends in perceived cause (e.g. poor diet, lack of exercise, alcohol and smoking were categorised as lifestyle factors). Groupings were discussed and checked with the supervisory team until all categories were agreed upon.

#### *Qualitative analysis*

Analysis of interviews was undertaken using methods consistent with interpretative phenomenological analysis (IPA).(6) Theory was consistently applied throughout the research process,(54) as the SRM was used to construct the interview schedule and report findings. The SRM was not, however, used as a strict framework to guide analysis to prevent 'squeezing' data to fit the theory.(54) To avoid a force-fitting the model and analogous to the methods used by Taylor and colleagues,(55) analysis of transcripts was inductive, but findings were mapped onto aspects of the SRM following analysis. Emergent themes from interviews were mapped at two stages (see *master list of themes for the group*) and themes that emerged from interviews that fit within the model were organised into features of the SRM following analysis (see *Writing up* section). Audio files were uploaded and transcribed verbatim using NVivo for Mac version 10.2.1, however, analysis was undertaken using Microsoft Word for ease of use.

### *Generating initial themes*

Analysis was an iterative process in that steps were carried out for each transcript and repeated rounds of analysis undertaken. Transcripts were exported to a Word document and read multiple times to establish familiarity with each account. Following multiple readings of each transcript, initial notes were made, using the comment function, to annotate the significance of what the participant said. Note-taking occurred one transcript at a time. These notes, or 'codes', included attempts at summarising/paraphrasing what the participant said, association or links that came to mind, and preliminary interpretations.(6) At this point, reflexive accounts were re-read to further contextualise and aid in interpretation of the participant's world, and help give meaning where it was unclear. Other foci included the ways in which participants spoke (including the language that was used); and ideas about the participant's personality.(56) This was an important step as IPA takes an interpretative stance of questioning hermeneutics (see section 4.3), and thus, noting, for example, how participants spoke in addition to what they said allowed for understanding of things in the transcript that might have not been overt.

Following this initial note-taking process, or 'coding', initial themes were developed for each transcript.(56) This process involved going back to the beginning of the transcript and transforming initial notes into emerging themes.(56) This process involved a higher level of abstraction than the initial more descriptive note-taking stage, meaning that emerging themes were at a high enough level to allow for theoretical connections within and across transcripts, but were still grounded in the participants' words.(6) Emerging themes were listed at the bottom of each transcript.

*Looking for connections*

Once a list of initial themes had been identified for a transcript, connections were made between them.(56) In the attempt to create order from the ideas that emerged from the transcript at this stage, themes reflecting the same concept were clustered together, and themes reflecting a similar concept were grouped into new larger categories.(56)

*Table of themes*

Smith and Osborne(56) suggest that at this stage of analysis, a master table or list of themes be created to identify each sub-theme that corresponds with each superordinate theme, complete with excerpts from the transcript to reduce bias and ensure the theme is represented in the transcript.(56) In this stage of analysis, processes akin to the development of a master list were carried out (Table 4.3). An explanation was added to each of the larger categories generated in the previous step, which included information about what the category reflected, including its associated sub-themes. These explanations included direct examples from the text that were attached to ensure the larger theme was reflected in the transcript.

Team discussion occurred during interviews to enhance rigour and credibility of findings, where two supervisors separately read and coded a selection of transcripts, a process called independent parallel coding.(57) It should be noted that the supervisory team consisted of one researcher with a background in HF and one in health psychology, both offering different perspectives of the participants' accounts. Thoughts about emergent themes were discussed as a group to check for consistency of interpretation. Disagreements were discussed until consensus was reached.

Table 4.3 Example of the development of a master list for themes

| Example from transcript | Explanation of theme | Theme |
|---|---|---|
| *'You know, maybe you get called to the emergency department or something like that, and then you got all the doctors there saying 'oh you know you can't'...'oh you shouldn't be on this', and they take you off it and you get back to...(your cardiologist) and he says 'who took you off this?!' and I said well, they told me to go off it...'you can't go off that!'. You know, its just...that second person can cause insurmountable problems, so I would rather deal with the one person.'* | Receiving care from the same provider long-term is perceived to minimise potentially harmful changes in patient management. Involving additional members to care team is perceived to complicate management rather than enhance feelings of support. The participant recognises the lack of effective communication between HCP's, which can interfere with care, and contributed to her preference to maintain continuity with known provider. | Preference for continuity |

*Continuing analysis with other cases*

The process of analysis, including coding, the generation of initial themes and larger categories, and development of a master list of themes with explanations and examples, was continued for each interview transcript.(56) Themes generated from the previous transcript helped orient themes for the next, whilst allowing for the generation of new ideas and themes as they emerged.(56) Special attention was paid to ways in which accounts were similar and different between participants with the aim to respect convergences and divergences in the data.(6)

*A master list of themes for the group*

A conceptual map was developed for each theme to reflect the experience of care-seeking and patient-provider communication across all transcripts. Master themes for the first nine transcripts were mapped in collaboration with one supervisor, which provided another opportunity to check that main ideas emerging from interviews were consistent. Through this mapping exercise, it became apparent how master themes from each interview could be connected to become larger overarching ideas with associated sub-categories. Findings were mapped a second time after all 15 interview transcripts had been analysed. The second mapping phase yielded results more refined than the first, and reflected new ideas that emerged from the remaining six transcripts. This final mapping phase was undertaken in collaboration with both supervisors to ensure coherence of ideas and credibility of findings.

### *Writing up*

Analysis was expanded in the writing phase, where final overarching themes were written using examples from the data to describe the meanings inherent in the participant's experience. This stage involved translating the themes into a narrative account where the themes were explained, demonstrated using examples, and nuanced.(6) As noted, the SRM was not used as a strict framework to guide analysis, however, themes that emerged from interviews that fit within the model were organised into features of the SRM at the writing up stage to avoid 'squeezing' data into the model during analysis.(54) Findings reflecting patient-level factors that contributed to care-seeking decisions were presented in relation to aspects of the SRM, as in the meta-synthesis in Chapter 3. As noted in Chapter 3, the SRM did not explain care-seeking entirely. Interviews with Australian patients with HF, too, revealed other factors that largely influenced care-seeking that were unaccounted for in the model. Along with themes that did fit within the SRM, themes that did not fit were also described. Provider- and system-related factors that did not fit within the SRM were described separately, as were perceptions of HF knowledge, preference for HF information delivery, and perceptions of patient-provider communication.

The researcher was also careful to avoid reporting bias by searching for negative cases relating to the development of insights as well as describing accounts supporting these insights.(58) Both types of cases were portrayed in the writing up stage. To facilitate transferability, narrative accounts were thick and descriptive to illustrate context in which the phenomenon occurred, so that others who may want to apply findings to a different population can make judgements about how/if they fit by taking context into consideration.(58)

### 4.4.7 Integration

Integration of quantitative and qualitative data occurred in two ways. Firstly, the 'following a thread' method was used,(59) where results from the quantitative dataset were further elucidated in interviews (i.e. responses on the BIPQ were elaborated on in the interviews – see interview guide in Appendix 4). As described at the beginning of this chapter, in MMPR it is appropriate to use an initial quantitative phase for orienting the phenomenon before exploring it in-depth using interpretative phenomenological methods.(3) One dataset helped build upon the other. Secondly, during the writing of the discussion(2)(Chapter 8), findings from each phase were integrated to gather a holistic understanding of care-seeking in HF and patients' HF education needs. Interview findings were considered in the context of self-report questionnaires, to help explain unexpected results and understand how care-seeking operates in the context of various known factors to answer the fifth research question of this thesis: *How do Australian patients with HF make decisions to seek or avoid professional care in the context of illness perceptions, self-efficacy, affective symptoms and health literacy?* Self-report questionnaires were compared with interview findings to also ascertain a clearer understanding of patient care-seeking in HF and information needs (55) to answer the final research question of this thesis: *What are Australian patient's perceptions and preferences for HF information delivery and patient-provider communication in the context of health literacy and HF knowledge?* Data were considered collectively, rather than individually, to answer the research questions of this thesis. Both types of data were examined to see if one helped explain, provide context or negate the other. Potential reasons for inconsistencies were explored (e.g. high HF knowledge scores despite ongoing confusion about various aspects of HF). Within the discussion of findings, qualitative and quantitative data are integrated and discussed in relation to the theoretical model outlined in Chapter 3.

## 4.5 Ethical Considerations

This study complied with the National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research.(60) Respect is central to the values and principles set out in the National Statement involving regard for patient welfare, beliefs, perceptions, customs and cultural heritage, as well as respect for patient privacy and confidentiality. Details of the study were provided verbally and via written explanation (Appendix 5, Appendix 6) before patients were asked to provide consent. If further clarification was necessary, patients were given the opportunity to raise questions with the researcher. Participants were reminded that participation was voluntary and they could withdraw from the study at any time without penalty. Neither their care nor relationship with staff was affected by withdrawal from the study. In addition, permission was sought to audio-record interviews in the qualitative portion of this study.

The parent study (LACE) was approved by St Vincent's Hospital, Sydney, (HREC 12/052) and the University of Technology Sydney Human Research Ethics Committees (2012-120R) (Appendix 7). Additional questionnaires added to the thesis research study were approved by these committees. Short versions of each of the questionnaires were administered to minimise responder burden. Other ethical considerations included potential discomfort caused by blood pressure measurement (for LACE study), and psychological or emotional distress that may have occurred as a result of answering some of the questionnaires, screening tools, or during interviews. It was considered that patients may have potentially become distressed if they screened positive for depressive or anxiety symptoms, or become aware of conditions previously unknown to them. In these particular cases, results were reported to the medical team. If required, participants were able to access a counsellor, although no participant needed to see a counsellor as a result of participating in this study. Despite these provisions, these risks were considered low.

### 4.5.1 Data management, storage, and retention

Data was managed appropriately to ensure confidentiality of patient information and maintain ethical research conduct. The researcher transcribed all interview recordings, removing all identifying information, which included participant names, names of treating healthcare providers, and hospitals (other than St. Vincent's). The audio-recorder was stored in a locked cabinet in a locked research office at St. Vincent's Hospital Sydney, and all recordings were erased from the device following transcription. Participant names were replaced with participant numbers and pseudonyms replaced names of treating doctors upon transcription. All questionnaire data and data collected on the CRF were also de-identified, with subject identification numbers replacing participants' names, and no identifying information collected (e.g. transplant recipient). Paper copies of the forms were stored in locked cabinets in the locked office at St. Vincent's Hospital Sydney, accessible only to researchers and supervisors conducting studies at the site. All data will be retained for a period of five years from the completion of the study.(61)

### 4.5.2 Positioning of the researcher

Engaging in qualitative research requires interpretations that are inherently influenced by a researcher's own biases. Engaging in reflexive practices requires the researcher to position herself within her work and to remain in dialogue with research practice, participants, and methodologies.(50) Reflexivity in research leads us to question how interpretations arise and how personal interests and standpoints affect the research process.(50) As Richardson notes, the researcher emerges *'not as an individual creative scholar, a knowing subject who discovers, but more as a material body through whom a narrative structure unfolds'*.(62) Understanding the positioning of the researcher is therefore essential in conducting rigorous qualitative research, and requires recognition of the influence and power they may bring upon the interview.(50)

The interviewer was a PhD candidate with a Medical Science (Honours) degree and prior clinical research experience in a HF population. Prior to study commencement, participants had no relationship with the researcher, as she was uninvolved with their care. She was an outsider to the hospital/healthcare system and participants were aware of her role as a researcher and not a clinician. This position as an outsider seemed particularly advantageous, as interviews often involved disclosure of previous healthcare experiences that were negative or traumatic. Her role was to listen and elicit information about patient perspectives, which was highly welcomed by most patients during their long stay in hospital. Rapport developed quickly, as participants valued the opportunity to express their thoughts and feelings at a time that was often frightening and lonely. As noted in section 4.4.5, reflexive accounts were used to ensure the researcher's prior knowledge of care-seeking in HF and the principles of self-regulation did not dominate interpretation of participants' accounts. This prior knowledge was bracketed so that the phenomenon of care-seeking could be described freshly. The researcher had no personal experience with the topic of care-seeking in HF, however, delayed care-seeking was not a new concept, having engaged in the behaviour herself and witnessed close family members also engage in avoidance coping. Anxieties about seeking professional care for even minor issues were familiar and somewhat normalised. These previous personal experiences and thoughts about how delayed care-seeking is rationalised were also set aside, in order to clearly understand the phenomenon of delayed care-seeking in HF. Furthermore, the researcher's personal interest in understanding the mechanics of human behaviour should be made explicit. The researcher is psychologically-minded in that she is interested in the way people think and make decisions about taking care of themselves. These interests facilitated close engagement with the research process and data.

## 4.6 Conclusions

This chapter described the sequential exploratory mixed methods design used in this thesis with explicit use of the SRM and an emphasis on the qualitative approach to understand the complexities involved in the decision-making processes underlying care-seeking in HF. Findings from the meta-synthesis (Chapter 3), the SRM (Chapter 2), and the existing HF self-care literature guided the selection of variables explored and the interview guide, but analysis of interviews remained inductive so as not to force-fit the model. The next chapter will present results from the self-report questionnaires and the clinical and demographic characteristics of the study population.

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# Chapter 5
# Quantitative results

## 5.1 Introduction

The findings presented in this chapter contribute to answering the second research question of this thesis: *How do Australian patients with HF perceive and understand their health condition and symptoms?* This chapter presents the quantitative findings of this study, including the clinical and demographic characteristics of the study population and results from the self-report questionnaires.

## 5.2 Participant characteristics

A total of seventy-two inpatients were recruited into the study (see Table 5.1). Mean age of the cohort was 61±15 years, with ages ranging from 21 to 91 years. Most participants were male (68%) and did not live alone (72%). Participants were predominantly Caucasian (70%). SEIFA score for 21% (n=15) of participants fell into the 10th decile (Figure 5.1), meaning these participants lived in the most advantaged/least disadvantaged 10% of areas in Australia. The majority of the population lived in a major city (65%), as defined by the Australian Statistical Geography Standard (ASGS) remoteness classification.(1)

Participants were managing an average of 6±2 co-morbidities in total. Amongst the most common were heart rhythm disorders (67%), hypertension (50%), coronary artery disease (42%), and diabetes mellitus (35%).

Most participants were categorised as either NYHA class II (45%) or NYHA class III (45%), yet 11% fell into the NYHA class IV category, indicating some participants were experiencing severely debilitating symptoms even at rest. The median Australia-modified Karnofsky Performance Status score (60) suggested that participants required occasional assistance but were able to care for most of their own needs (2). Mean BMI (28.6± 8.0 kg/m$^2$) was within the 'pre-obese' range (25.0-30.0 kg/m$^2$)(3), and median length of stay in hospital (during the time they were recruited) was 11 days, ranging from two to 88 days.

Table 5.1 Socio-demographic and clinical variables of the study population

| Participant characteristics | N = 72<br>Mean ± SD or n (%) |
|---|---|
| **Demographics** | |
| Age (years) | 61 ± 15 |
| Male | 49 (68%) |
| Remoteness | |
| Major city | 47 (65%) |
| Inner regional | 16 (22%) |
| Outer regional | 9 (13%) |
| Lives alone | 20 (28%) |
| Caucasian | 51 (70%) |
| English spoken at home | 67 (93%) |
| **Risk factor profile** | |
| Smoking status [a] | |
| Smoking history | 48 (67%) |
| Frailty [b] | |
| Non-frail | 20 (30%) |
| Pre-frail | 9 (15%) |
| Frail | 35 (55%) |
| Medical history | |
| Arrhythmias | 48 (67%) |
| Hypertension | 36 (50%) |
| Coronary artery disease | 30 (42%) |
| Diabetes mellitus (type I and II) | 26 (36%) |
| Renal disease | 22 (31%) |
| Respiratory disease | 17 (24%) |
| Depression | 13 (18%) |
| Total number of co-morbidities | 6 ± 2 |
| Charlson co-morbidity index (median, IQR) | 2.0 (2.0, 4.0) |
| **Heart failure profile** | |
| Ischaemic aetiology of HF [c] | 32 (48%) |
| LVEF | |
| HFREF (LVEF<50) | 53 (74%) |
| NYHA classification | |
| Class II | 31 (45%) |
| Class III | 27 (45%) |
| Class IV | 8 (11%) |
| **Clinical presentation/profile** | |
| Length of stay (days) (median, IQR) | 11 (5.3,20.0) |
| AKPS [e] (median, IQR) | 60 (50.0, 70.0) |
| Body mass index | 28.6 ± 8.0 |

**Legend:** HF = heart failure, TIA = Transient ischaemic attack, LVEF = left ventricular ejection fraction, HFREF = heart failure with reduced ejection fraction, HFPEF = heart failure with preserved ejection fraction, NYHA = New York Heart Association, AKPS = Australia-modified Karnofsky performance status, IQR = interquartile range, N = sample size, SD = standard deviation

[a] n=71, [b] n=67, [c] n=67, [d] n=65, [e] n=69

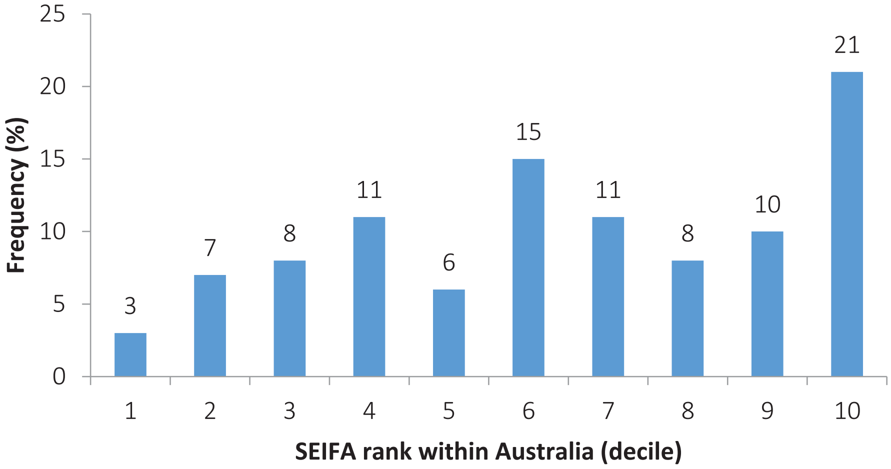

Figure 5.1 Proportion of participants within each SEIFA decile indicating relative socio-economic advantage and disadvantage compared with other areas in Australia

## 5.3 Living with heart failure

### 5.3.1 Symptom burden

Figure 5.2 depicts the average perceived severity at the time of assessment, represented by mean score out of ten for each ESAS item. Errors bars indicate the standard deviation for each item. Mean total ESAS score was 29.5±15.2. As illustrated in Figure 5.2, participants perceived wellbeing, tiredness, shortness of breath, and poor appetite as the most severe and burdensome symptoms. Mean ESAS score for each of these symptoms reached clinically significant levels (more than or equal to four), which would require further attention in routine clinical practice(4).

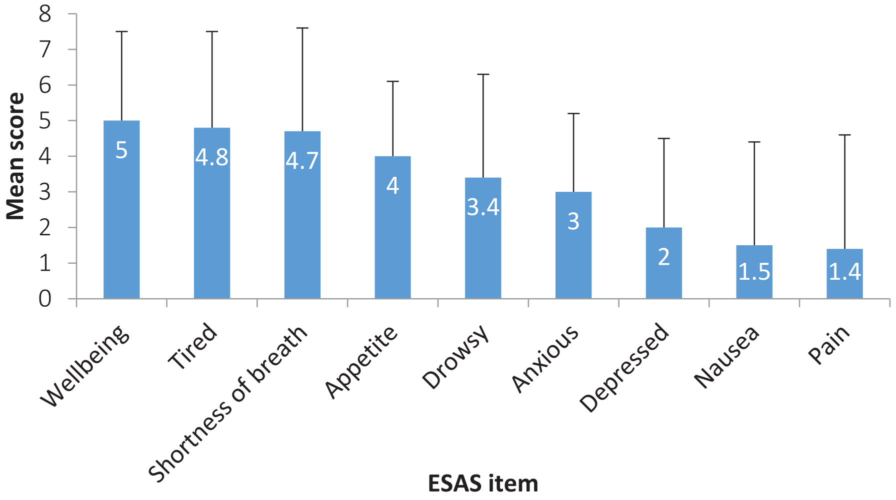

Figure 5.2 Perceived severity of symptoms illustrated by mean ESAS symptoms scores

### 5.3.2 Anxiety and depressive symptoms

Anxiety and depressive symptoms experienced in the last one-two weeks were further explored using the anxiety subscale of the DASS-21 and the PHQ-9, respectively. Figure 5.3 illustrates the distribution of anxious symptoms according to DASS categories, ranging from not anxious to symptoms indicating extremely severe anxiety. Results indicated that almost three quarters of participants were experiencing symptoms of anxiety (n=48, 74%), ranging from mild to extremely severe anxiety over the last week (Figure 5.3).

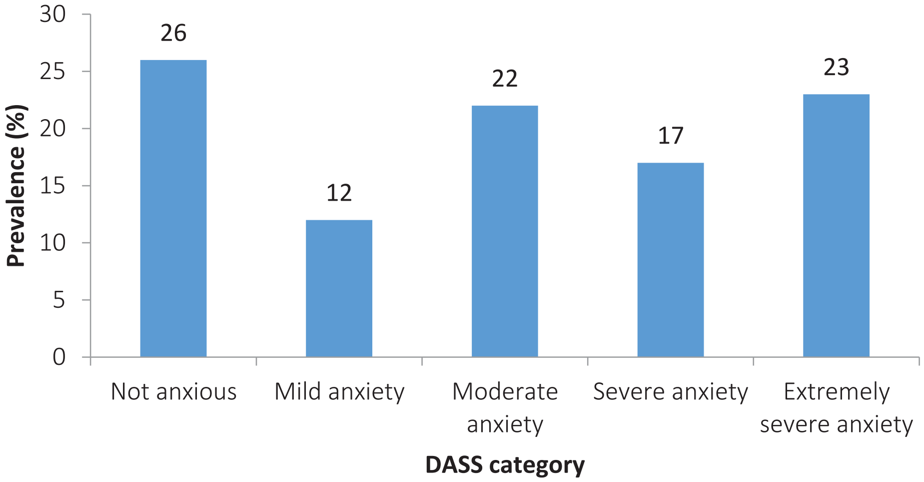

Figure 5.3 Prevalence of anxious symptoms categorised by severity, according to the anxiety sub-scale of the DASS-21

Similarly, the PHQ-9 reflected much higher prevalence of depressive symptoms than the ESAS. Figure 5.4 illustrates the prevalence of mild, moderate, moderately severe and severe depressive symptoms experienced over the last two weeks in this cohort, as measured by the PHQ-9. Sixty-two percent of participants (n=41) screened positive for depressive symptoms, ranging from moderate to severe (Figure 5.4). Screening positive for depressive symptoms (PHQ-9 score of ten or above) does not indicate a clinical diagnosis of depression, however, it is often used as a screening cut-off score and the point at which treatment is recommended in clinical practice (5). The remainder of participants (n=25, 38%) either experienced no depressive symptoms, or mild depressive symptoms, which typically would not prompt further attention in clinical practice.

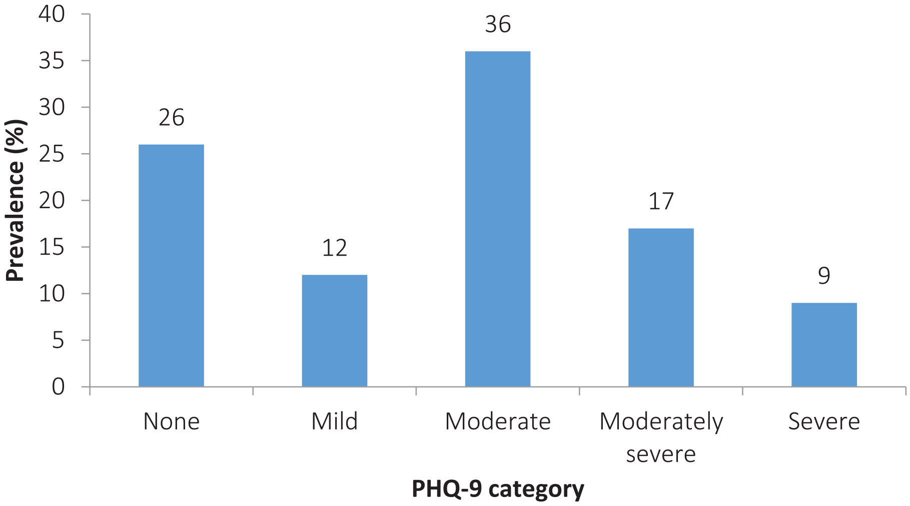

Figure 5.4 Prevalence of depressive symptoms, categorised by severity, ranging from none to severe according to the PHQ-9

### 5.3.3 Health status

The KCCQ was used to assess participants' health status. Its ten scales measure physical limitation and symptoms (frequency, severity, and recent change over time), as well as social interference, self-efficacy, and quality of life. The boxplots in Figure 5.5 illustrate the distribution of scores for each of the discrete scales measured by the KCCQ, whilst Figure 5.6 depicts results for the scales reflecting composite scores. The horizontal line traversing each box represents median score for each scale with sections above and below the line representing upper and lower quartiles, respectively. The whiskers represent maximum and minimum values. The circles outside of the maximum or minimum values represent outliers. Each domain is a 100-point scale, where values closer to 100 indicate better health status.

Social limitation and quality of life were scored the lowest of all scales Figure 5.6. Median score for social limitation was 18.8 on the 100-point scale, indicating that these participants' interpersonal relationships were severely compromised due to their condition. Similarly for quality of life, median score (25.0) reflected the detrimental impact of heart failure on these participants' interpersonal relationships and overarching state of mind. Self-efficacy was scored the highest (75.0) suggesting that participants believed they could manage their care and easily find answers to their questions.

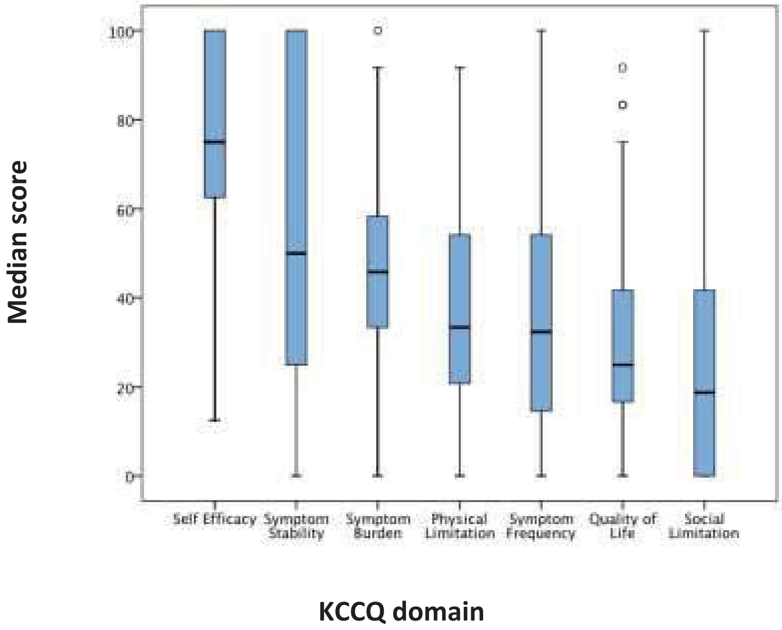

Figure 5.5 Boxplots for each discrete scale of the KCCQ illustrating median score, interquartile range, maximum and minimum values, and outliers

Results for the composite scores reflected the poor overall health status of participants. As illustrated by the boxplots in Figure 5.6, median score for all three scales were below 50, with the overall summary score (combined measure of all the discrete scales) being the lowest, at 33 on this 100-point scale.

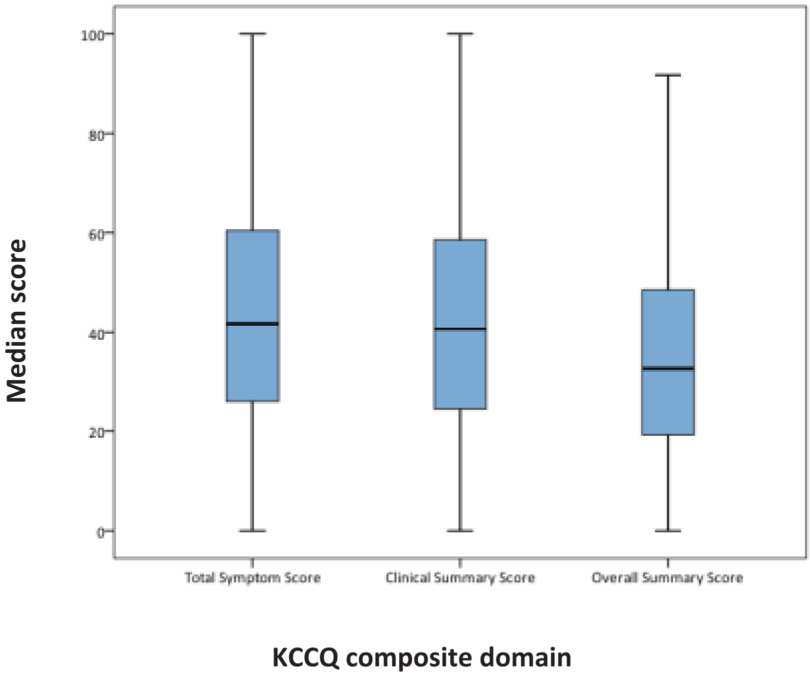

Figure 5.6 Boxplots for composite domains of the KCCQ illustrating median, interquartile range, maximum and minimum values

## 5.4 Understanding of heart failure and symptoms

The following section describes what participants understand about their HF. This section is concerned with HF only, and does not include perceptions and understanding of comorbidities. In addition to HF knowledge, participants' ability to understand and use health information was also explored using a functional health literacy assessment. Additionally, this section details how participants perceive their condition (HF), including their cognitive and emotional representations of illness, which are likely to contribute to care-seeking decisions, as specified by the Self-Regulation Model of illness behavior.

Exploring participants' knowledge of HF, health literacy skills, and illness representations allows us to gain insight into how patients perceive their condition and symptoms, addressing the second research question of this thesis.

### 5.4.1 Heart failure knowledge

Results from the DHFKS reflected good overall heart failure knowledge with a mean score of 12.3±1.9 out of a possible 15. Figure 5.7 illustrates the proportion of participants that answered correctly for each of the items on the scale. Each item on the DHFKS represents an important aspect of heart failure knowledge and self-care in general. Almost all participants understood why they were prescribed diuretics (n=62, 97%), and recognised the importance of remaining adherent with heart failure medications (n=62, 97%).

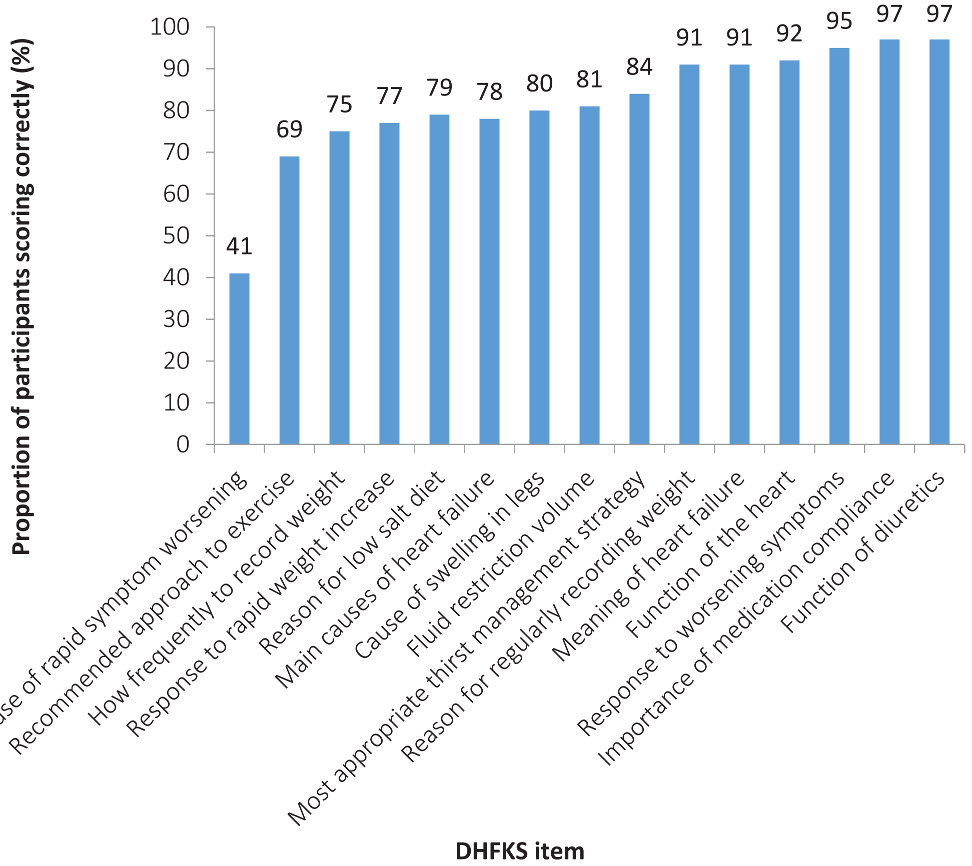

Figure 5.7 Percentage of participants choosing the correct answer for each item of the DHFKS

The following charts illustrate how participants responded to items specifically relating to care-seeking and symptom appraisal.

Whilst participants performed very well overall, the only item that most people answered incorrectly was related to perceived cause of symptom exacerbation. Figure 5.8 illustrates how participants responded to question six on the DHFKS - *What can cause a rapid worsening of heart failure symptoms?* The light blue bars indicate the proportion of people who chose an incorrect multiple-choice answer, whilst the dark blue indicates the proportion of people who answered correctly. As shown in Figure 5.8, over half of participants misattributed rapid worsening of heart failure symptoms to either a high-fat diet (n=24, 38%), or lack of exercise (n=13, 21%). Only 43% (n=26) of participants were able to correctly link rapid symptom onset to a cold or flu. Of all topics covered in the DHFKS, participants performed the worst on this question, indicating that participants are most confused about identifying factors that may cause a rapid worsening of heart failure symptoms.

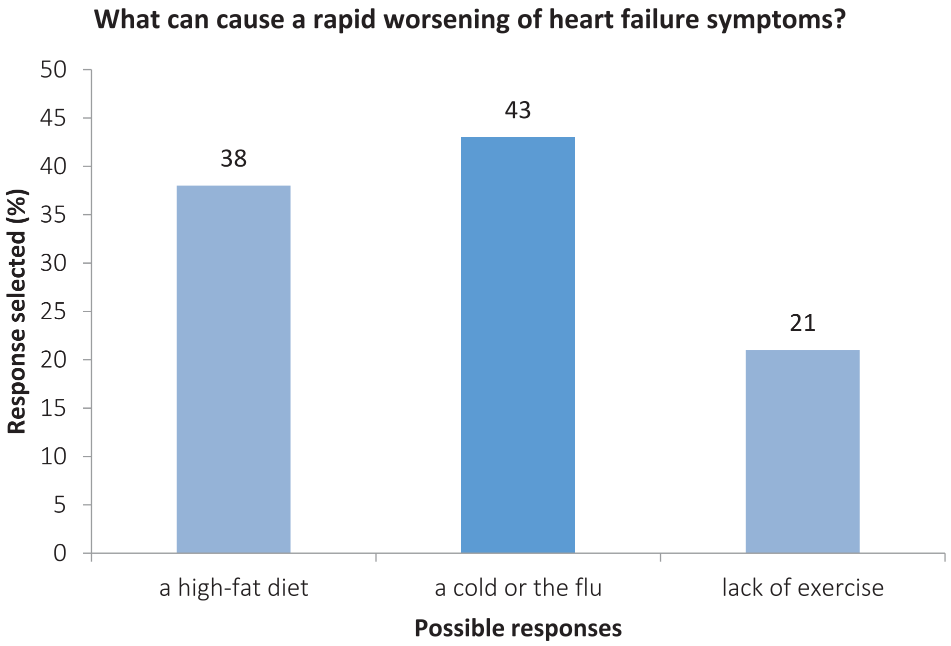

Figure 5.8 Percentage of participants who selected each multiple-choice answer in response to a question about the cause rapid of symptom exacerbation

A question about symptom attribution required participants to make the link between peripheral oedema and fluid retention (Figure 5.9). Figure 5.9 illustrates how participants responded to question eight on the DHFKS – *Why can legs swell up when you have heart failure?* The light blue bars indicate the proportion of people that chose either of the two incorrect answers, and the dark blue bar indicates the proportion of people who answered correctly. Whilst most participants answered correctly (n=51, 80%), 20% (n=13) did not correctly link fluid retention and symptoms of leg swelling.

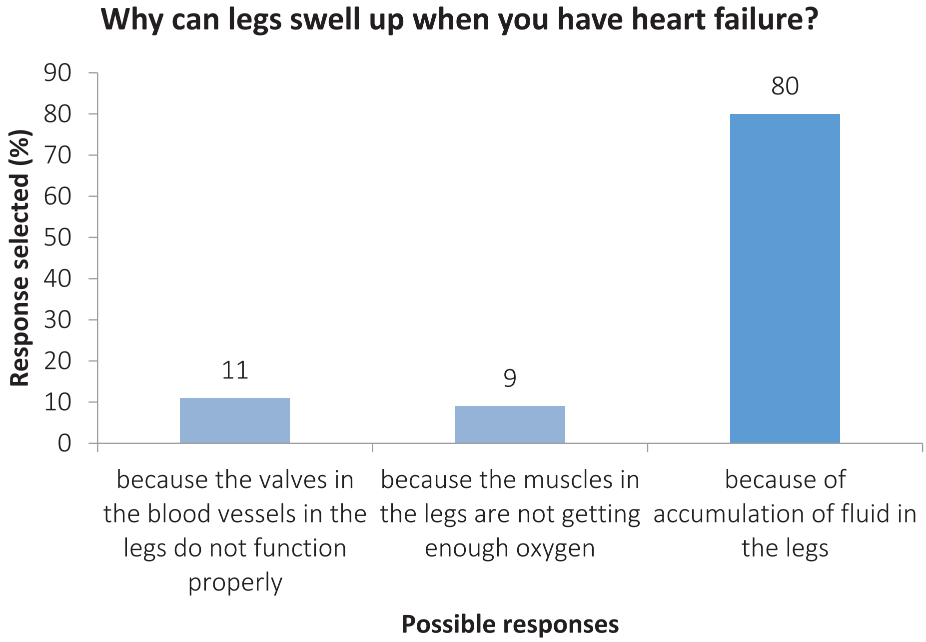

Figure 5.9 Percentage of participants who selected each multiple-choice answer in response to a question about the cause of leg swelling

Two questions on the scale pertained to care-seeking directly. The first of these questions asked participants to think about how they would respond to a rapid change in weight (Figure 5.10). Figure 5.10 illustrates how participants responded to question 14 on the DHFKS – *Which statement about weight increase and heart failure is true?* The light blue bars indicate the proportion of people who chose the incorrect multiple-choice response, and the dark blue bar indicates the proportion of people who chose the correct answer. Whilst most participants agreed that they should make immediate contact with their doctor or nurse (n=49, 77%), 17% (n=11) reported that they should wait until the next check-up, and 6% (n=4) were seemingly unaware of the cause of rapid weight gain, indicating that they should merely eat less food in response. Whilst most did score correctly for this item, it was the 4th lowest scoring question.

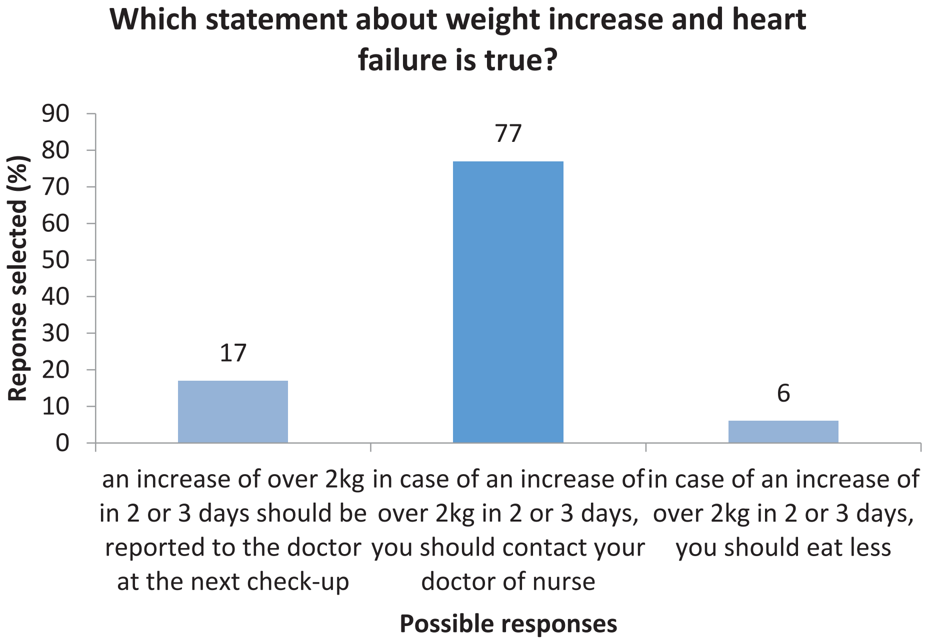

Figure 5.10 Proportion of participants who selected each multiple-choice answer in response to a question about how to most appropriately respond to rapid weight increase

The second item of the scale relating specifically to care-seeking behaviour revealed that 95% (n=61) of people would contact their doctor or nurse immediately in case of increased shortness of breath or swollen legs (Figure 5.11). Figure 5.11 depicts how participants responded to question five on the DHFKS – *What is the best thing to do in case of increased shortness of breath or swollen legs?* The light blue bars indicate the proportion of people who selected the incorrect responses, whilst the dark blue bar indicates the proportion who chose the correct answer.

Only 3% (n=2) stated that they would wait until the next check-up, a considerably lower proportion than the previous question about care-seeking where 17% (n=11) thought it would be best to delay until their scheduled check-up if they noticed a rapid increase in weight. There was more confusion about the urgency of professional care when participants were required to interpret the meaning of weight changes.

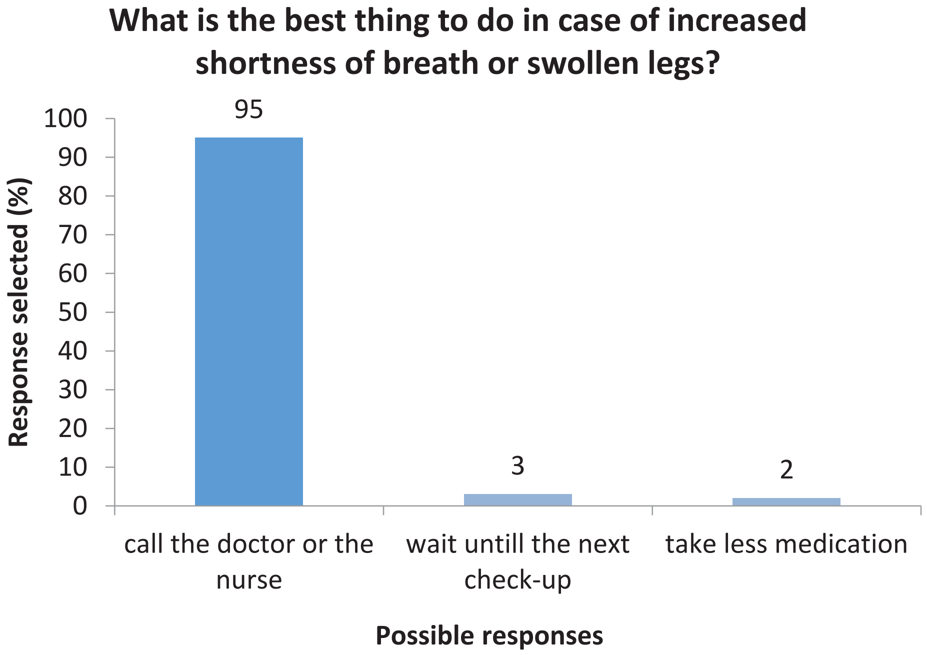

Figure 5.11 Proportion of participants who selected each multiple-choice item in response to a question about how to respond to worsening symptoms

In terms of symptom recognition and response, this was the item on which participants performed best, indicating that if people do recognise symptoms of breathlessness or swollen legs, they know that they should call for help immediately.

### 5.4.2 Health literacy

Total S-TOFHLA score was used to classify participants as adequate, inadequate, or marginal in terms of functional health literacy. Figure 5.12 illustrates the proportion of participants in functional health literacy classifications as defined by the S-TOFHLA. As depicted in Figure 5.12, three-quarters of participants (n=45) were classified as having adequate health literacy, whilst 25% (n=15) were classified as having either inadequate or marginal health literacy skills. This indicates that whilst a large proportion of participants did have adequate health literacy skills, a quarter of participants would still struggle to understand and use health information.

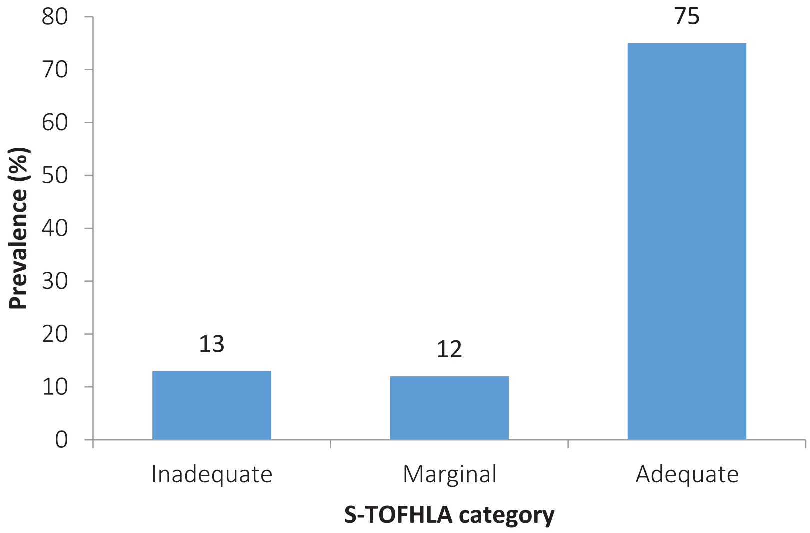

Figure 5.12 Prevalence of adequate, marginal, and inadequate health literacy as measured by the S-TOFHLA

### 5.4.3 Illness perceptions

The B-IPQ was used to measure participants' cognitive and emotional representations of their illness. Five items of the B-IPQ assess cognitive illness representations including: perceived consequences (item 1), timeline (item 2), personal control (item 3), treatment control (item 4), and identity (item 5). Two items assess emotional representations including: concern (item 6), and emotional response (item 8), and one item measures perceived illness comprehensibility (item 7). Items were ranked on a ten-point scale, where a score closer to ten reflected an increase in the dimension measured (e.g. a score of 9 on the timeline item indicates the perception that HF will last a long time, whereas a score of 9 on the personal control item indicates perceived high levels of personal control).

As seen in Table 5.2, participants were largely aware that their condition would last forever, indicating that they understood the chronicity of their illness. They were also very concerned about their illness, perceived its consequences on daily life were extensive, and perceived they had little control. Whilst personal control was scored relatively low, treatment control was scored comparatively high, indicating that participants perceived that treatment could help their condition a great deal. Participants also felt as though they understood their condition relatively well, and did not feel as though they were severely emotionally affected by it.

Table 5.2 Median score and interquartile range for each 10-point scale of the B-IPQ reflecting cognitive illness representations, emotional representations, and illness comprehensibility

| B-IPQ item | Median score (IQR) |
|---|---|
| **Consequences** | |
| *1. How much does your illness affect your life?* | 8 (6.5, 9.0) |
| **Timeline** | |
| *2. How long do you think your illness will continue?* | 10 (7.75, 10.0) |
| **Personal control** | |
| *3. How much control do you feel you have over your illness?* | 4 (1.0, 6.0) |
| **Treatment control** | |
| *4. How much do you think your treatment can help your illness?* | 8 (6.0, 10.0) |
| **Identity** | |
| *5. How much do you experience symptoms from your illness?* | 7 (6.0, 8.0) |
| **Concern** | |
| *6. How concerned are you about your illness?* | 9 (6.0, 10.0) |
| **Comprehensibility** | |
| *7. How well do you feel your understand your illness?* | 8 (7.0, 9.75) |
| **Emotional response** | |
| *8. How much does your illness affect you emotionally? (E.g. does it make you angry, scared, upset or depressed?)* | 5 (4.0, 8.0) |

**Legend:** B-IPQ = Brief illness perception questionnaire, IQR = interquartile range

The final item of the B-IPQ assessed causal representation with an open-ended question (item 9). Participants were asked to list the three most important factors that they believed contributed to their illness. Participants listed between one and three factors. The most common responses were: diet, lack of activity, and genetic factors (Figure 5.13). Participants identified a total of 55 different factors, reflecting the wide variety of perceptions about causality of heart failure. Figure 5.13 depicts the frequency of a variety of responses noted on item 9 of the B-IPQ. The most common perceived causes (factors mentioned more than twice) are shown in this chart (Figure 5.13).

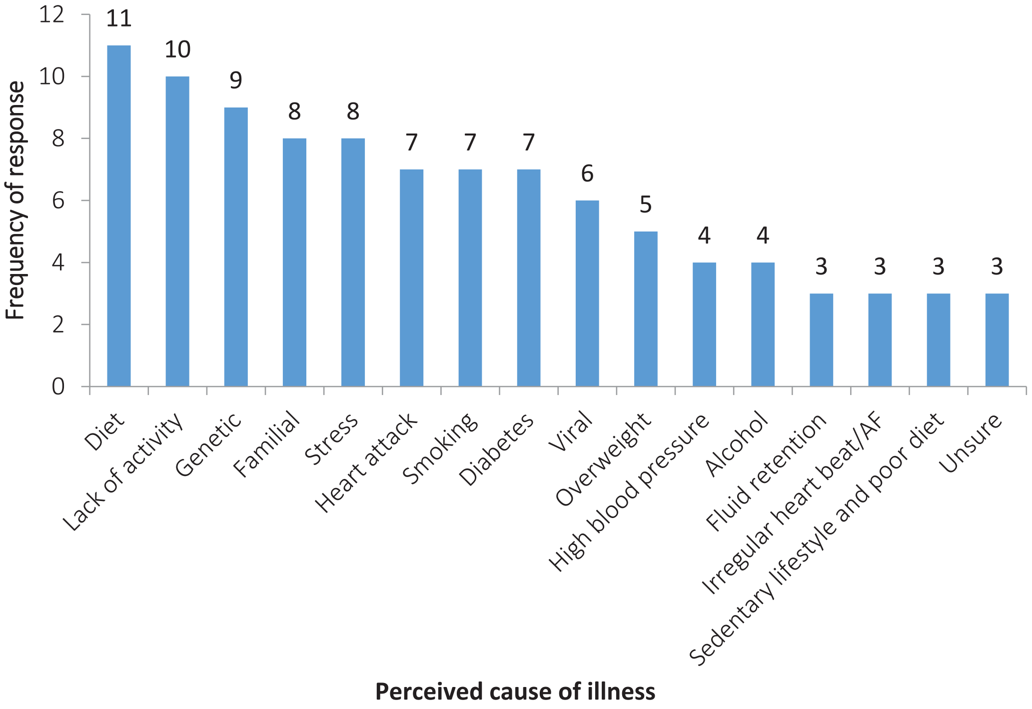

Figure 5.13 Perceived cause of illness as identified by participants

Responses were also grouped into broader categories to explore more general trends in perceived cause. Table 5.3 illustrates how causal factors identified by participants were grouped into larger categories, and illustrates the frequency of responses for each category. As shown in Table 5.3, each of the 55 different responses were coded to form 13 categories, which were discussed and agreed upon with the supervisory team.

As illustrated in Table 5.3, it is clear that participants were most likely to attribute their condition to lifestyle factors than any other type of factor. This was mentioned 35 times, which was 15 times greater than the next most popular type of response. The second most common type of response was a non-modifiable cause, followed closely by a cardiac event, such as previous myocardial infarction (MI) or cardiac co-morbidity (eg. coronary artery disease or hypertension).

Stress/life event/work and having a respiratory illness were also common responses, mentioned on 12 and 10 occasions, respectively. Fluid retention (3 times) and non-compliance (3 times) were less commonly noted as causal factors. Some other less common responses grouped as ‘other’ included fate (1 time), being unsure of cause (3 times), and a ‘downward spiral’ (1 time).

Table 5.3 Groupings of causal factors as identified by participants on item 9 of the B-IPQ and frequency of responses in these categories

| Category | Factors within group | Frequency of responses |
|---|---|---|
| **1. Lifestyle factors** | Diet, Lack of activity, Sedentary lifestyle and poor diet, Smoking, Alcohol | 35 |
| **2. Non-modifiable cause** | Congenital, Familial, Genetic, Inherited, Age | 20 |
| **3. Cardiac event/comorbidity** | Heart attack, High blood pressure, Irregular heart beat/AF, Peripartum cardiomyopathy, Pulmonary hypertension, Cardiomyopathy, Cardiac arrests, Pre-existing heart/lung problem | 19 |
| **4. Other illness/comorbidity** | DVT, Illness, Other illnesses (cancer), Depression, Gout, Renal failure, Diabetes, Liver problems, ALPS syndrome | 16 |
| **5. Stress/life event/work** | Forced to return to work when very sick, Stress, Work, Loss of business and house, Financial stress | 12 |
| **6. Respiratory illness** | Flu, Lung infection, pneumonia, virus | 10 |
| **7. Weight** | Obesity, Overweight | 7 |
| **8. Structural/functional abnormality of the heart** | Amyloid, Coronary artery blockage, Valvular defect, Lessened ability of the heart to pump, Death of the heart muscle | 6 |
| **9. Treatment** | Chemotherapy, Diuretics, Unfortunate stent mishap, Angioplastic procedures, Medication affecting kidneys | 6 |
| **10. Outcomes/symptoms** | Fatigue, Sleep apnoea, Fluid retention | 5 |
| **11. Other** | Unsure, Spiraled down, Fate-God | 5 |
| **12. Non-compliance** | Not listening to doctors, Non-compliance with medications | 3 |
| **13. Environmental factors (exposure to toxic chemicals)** | Working with polyeurothane, Exposure to chemicals on farm | 2 |

**Legend:** AF = atrial fibrillation, DVT = deep vein thrombosis

## 5.5 Conclusion

Participants in this HF cohort were young, suffering multiple comorbid conditions and highly symptomatic. These participants also suffered poor quality of life, social limitation and a high prevalence of anxiety and depressive symptoms. Participants overall had good HF knowledge, high levels of self-efficacy, and the majority had adequate health literacy. Despite good overall knowledge, participants struggled most with questions relating to symptom appraisal and response. The BIPQ also revealed participants felt they had little personal control over their condition and most commonly attributed their condition to lifestyle factors such as diet and lack of activity. The next chapter will describe interview findings pertaining to care-seeking in HF.

## 5.6 References

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# Chapter 6
# Qualitative results: The experience of care-seeking

The previous chapter presented the quantitative findings, including results from the self-report questionnaires, assessing variables known to impact health-related decisions and HF self-management. The qualitative findings provide further insight into the decision-making processes involved in care-seeking. This chapter will describe interview findings pertaining to care-seeking decisions to address the third research question of this thesis: *In what way do patient, provider, and system factors influence care-seeking decisions in an Australian HF population?* The first half of this chapter will detail patient-level factors influencing decisions to seek professional care, whilst the second half will address provider- and system-related barriers and facilitators of care-seeking. Concepts are explained using examples from transcripts, and described in relation to aspects of the self-regulation model of illness behaviour. Clinical and demographic characteristics of interviewees are also described, as well as qualitative results from this subset of LACE participants.

## 6.1 Characteristics and questionnaire results of interviewees

A subset of LACE participants took part in in-depth semi-structured interviews. This subset's clinical and demographic characteristics and questionnaire results appear in Table 6.1 and Table 6.2 to provide context to their interviews and to facilitate subsequent integration of qualitative and quantitative results (**Error! Reference source not found.**, **Error! Reference source not found.**). Of these fifteen participants, ten were male and their mean age was slightly younger than the entire cohort (58±10 vs. 61±15). All participants spoke mainly English at home and lived in areas of various socioeconomic conditions. SEIFA rank ranged from 2-8, with most interviewees falling in the 6th and 7th decile. Most participants lived in major cities, however, 40% lived in inner our outer regional areas of Australia. Corresponding with the entire cohort, interviewees were managing on average 6±2 co-morbidities. The most common co-morbidities were comparable to the larger study population.

Table 6.1 Socio-demographic and clinical variables of interviewees

| **Interviewee characteristics** | **N=15**<br>**Mean ± SD or n (%)** |
|---|---|
| **Demographics** | |
| Age (years) | 58 ± 10 |
| Male | 10 (67%) |
| Lives alone | 4 (27%) |
| Caucasian | 10 (67%) |
| English spoken at home | 15 (100%) |
| SEIFA rank within Australia | |
| 2nd decile | 2 (13%) |
| 4th decile | 3 (20%) |
| 6th decile | 4 (27%) |
| 7th decile | 4 (27%) |
| 8th decile | 2 (13%) |
| Remoteness | |
| Major city | 9 (60%) |
| Inner regional | 5 (33%) |
| Outer regional | 1 (7%) |
| **Risk factor profile** | |
| Smoking history | 10 (67%) |
| Frail | 9 (60%) |
| **Medical history** | |
| Arrhythmias | 7 (47%) |
| Coronary artery disease | 7 (47%) |
| Diabetes mellitus (type I and II) | 7 (47%) |
| Hypertension | 6 (40%) |
| Renal disease | 5 (33%) |
| Respiratory disease | 4 (27%) |
| Stroke/TIA | 3 (20%) |
| Cancer | 3 (20%) |
| Depression | 3 (20%) |
| Total number of co-morbidities | 6 ± 2 |
| Charlson co-morbidity index | 3.3 ±1.8 |
| **Heart failure profile** | |
| HFREF (LVEF<50) | 12 (80%) |
| NYHA classification | |
| Class II | 7 (47%) |
| Class III | 8 (53%) |
| **Clinical presentation/profile** | |
| Length of stay (median, IQR) | 11 (4,19) |
| AKPS (median, IQR) | 60 (50,70) |
| Body mass index (median, IQR) | 25.6 (24.2, 27.8) |

**Legend:** HF = heart failure, TIA = Transient ischaemic attack, LVEF = left ventricular ejection fraction, HFREF = heart failure with reduced ejection fraction, HFPEF = heart failure with preserved ejection fraction, NYHA = New York Heart Association, AKPS = Australia-modified Karnofsky performance status, IQR = interquartile range, N = sample size, SD = standard deviation

Corresponding with the larger cohort, questionnaire results revealed that interviewees had good overall knowledge of HF (median score 12/15). Over two-thirds had adequate health literacy (n=10, 67%), which was slightly lower than the prevalence of adequate health literacy in the larger cohort (n=45, 75%). Self-efficacy was higher in this subset of participants compared to the larger cohort (87.5 vs. 75.0). Sixty-seven percent of participants screened positive for depressive symptoms (PHQ-9 score of 10 or above, which equates to moderate depressive symptoms or above), which was about the same in the larger cohort (62%). Two-thirds of participants were experiencing symptoms of anxiety (n=10, 66%), which was slightly lower than the proportion of participants experiencing anxiety in the larger cohort (n=48, 74%).

Table 6.2 Questionnaire results of interviewees

| **Questionnaire results** | **N=15**<br>**Median, IQR or n (%)** |
|---|---|
| Total DHFKS | 12 (10,14) |
| Health literacy | |
| Adequate | 10 (67%) |
| Marginal/inadequate | 5 (33%) |
| Self-efficacy (median, IQR)[a] | 87.5 (50,100) |
| Depressive symptoms[a] | |
| None | 3 (20%) |
| Mild | 1 (7%) |
| Moderate | 6 (40%) |
| Moderately severe | 4 (27%) |
| Anxiety symptoms[a] | |
| Not anxious | 5 (33%) |
| Mild anxiety | 2 (13%) |
| Moderate anxiety | 2 (13%) |
| Severe anxiety | 2 (13%) |
| Extremely severe anxiety | 3 (20%) |

**Legend**: DHFKS = Dutch heart failure knowledge Scale, IQR = Interquartile range, n = sample size

[a] n = 14

Following this introduction of interview participants, the remainder of this chapter will focus on their perspectives of previous care-seeking experiences and factors that contributed to their decision-making.

## 6.2 Patient-level factors influencing professional care-seeking

Patient-level factors that impacted on participants' decisions to seek professional care aligned with the principles of self-regulation. For this reason, the SRM was used to organise findings following analysis of transcripts. The use of this model and eliciting patient experience through interviews and IPA illuminates the patient's perspective. Hearing the voices of participants is key in understanding how they make sense of their world and how contextual factors unique to the individual impact decisions to seek professional care. **Error! Reference source not found.** is presented here again as a reminder of the stages involved in coping with illness, as stated in the Self-Regulation Model of illness behavior (SRM).

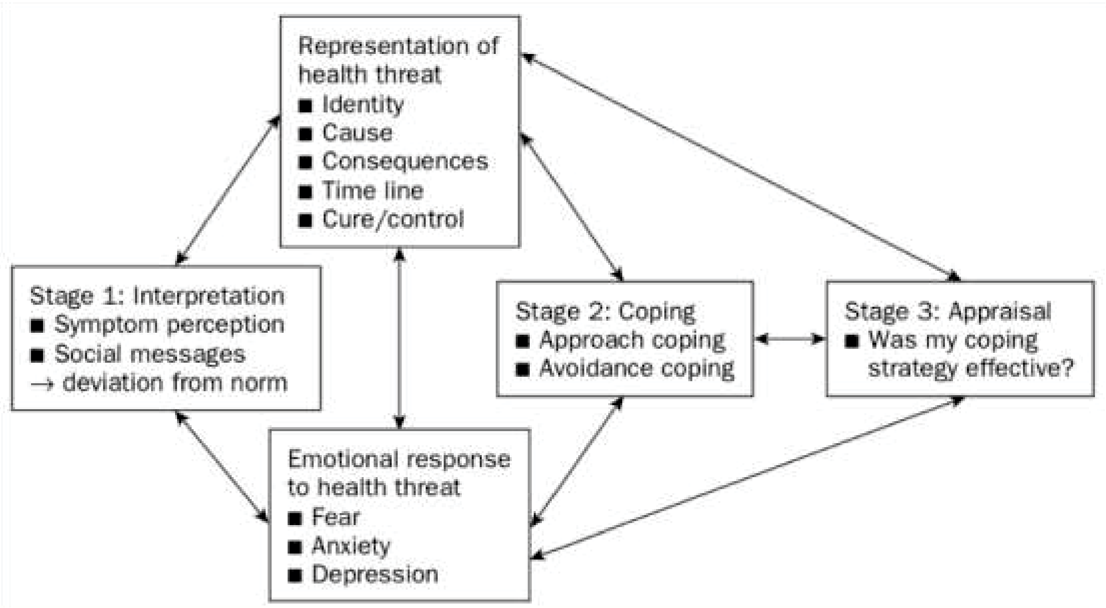

Figure 6.1 Leventhal's SRM

### 6.2.1 Interpretation of symptoms

According to Leventhal and colleagues, self-regulatory processes are triggered when a change is detected from a person's experience of what is 'normal'. People then construct cognitive and emotional representations of what this change means and how it makes them feel. These representations inform how they decide to cope with the health threat in the effort to regain normalcy. Whether the chosen coping strategy involves approach coping strategies (e.g. care-seeking), or avoidance coping (e.g. delay in care-seeking), a change from normal needs to be detected first to initiate self-regulatory processes. This section describes this first step in the process, which highlights some participants' inability to detect changes from a healthy state due to what they conceive as normal.

### *New versus old symptoms: tolerance impacts perceptions of normality*

People with HF live with restrictive symptoms every day. What they conceive as 'normal' often encompasses daily breathlessness, fatigue, and oedema making it difficult for them to engage in activities requiring low-level physical exertion. Whilst compromised mobility poses a major threat to a sense of independence and quality of life, recognising symptom onset is also a challenge for people who have grown accustomed to feeling fatigued and breathless daily. Living with restrictive symptoms also means that most patients accommodate their routines by pacing or restricting physical movement to cope. Whilst this enables them to maintain daily activities, it also makes it difficult for them to recognise deterioration reflected by worsening symptoms. Inability to detect onset of HF symptoms or to appraise them as nothing out of the ordinary puts patients at risk of unexpected acute symptom exacerbation requiring emergency hospitalisation. Recognising symptoms early and taking appropriate action is fundamental to avoid hospitalisaiton, re-hospitalsation, and can potentially decrease length of stay in hospital when treatment is necessary. Symptom recognition and appraisal is a vital precursor to timely care-seeking.

As patients suffer with symptoms for many years, sensations such as breathlessness and fatigue are perceived as less severe over time. One participant equated the dampening effect of HF symptoms to chronic back pain. She explained how HF symptoms were perceived as severe at first, prompting frequent episodes of professional care, but explained how this differed from her current appraisal of HF symptoms.

> *'.....a little bit I think, and you sort of go to the doctor's all the time but then as you get it more and more, and I mean I've had it for years now, you sort of tolerate it more I think. You know, its like when you've got a backache when it first comes on you think 'oh wow, that really strong pain', but when its been there for months and months you sort of get used to it, you know.'* (Participant 3, female)

She described the reduced sensitivity as symptoms becoming less of a shock. The severity and frequency of symptoms, as well as their limiting consequences seemed so far from what was normal to begin with, however, over time, she was less disturbed by symptoms, as they became part of what she now considered normal.

> *'Things that in the beginning are a shock to you because you can't do things, they become quite normal for you, you know.'* (Participant 3, female)

Another participant explained how breathlessness was perceived as being *'a morning thing'*. He became so accustomed to feeling breathless every morning, that he simply attributed it to being morning, thus, normalising the sensation. He did not think symptoms were related to illness and did not recognise that lying flat for hours whilst sleeping was contributing to worsening symptoms. He noted that symptoms did get better as the day progressed, but did not realise that this was because he was standing and the fluid was no longer obstructing his breathing.

In contrast, when people recognised that physical sensations fell outside the realm of what they were used to, or what they perceived as 'normal', an appraisal process was triggered where these new unfamiliar symptoms were perceived as a cause for concern and led to professional care-seeking. New unknown symptoms often led to feelings of fear and panic that facilitated care-seeking. For example, one participant described how in the lead-up to hospitalisation, he experienced unfamiliar sensations that were out of the ordinary, which caused alarm bells to ring.

> *'Well I just thought this is not right, I can't breathe. I'm normally...ok, early in the morning when I do wake up, because I do shift work, sometimes I can't breathe. I haven't got the general pattern of breathing but as the day progresses it gets better. But that particular morning I knew there was something wrong because that was the first time that I could feel that my stomach...the top of my stomach was getting hard.'* (Participant 12, male)

He described that his symptoms were not the usual morning breathlessness that he was used to experiencing, but were accompanied by an unfamiliar feeling of hardening of the stomach.

> *'...the Tuesday morning that I woke up and I couldn't breathe. It was all on my chest, my stomach, high up stomach was hard and that's when I rang then nurse and we took it from there by her ringing the doctor to drain all the liquid, or the fluid on my lungs.'* (Participant 12, male)

He also described that his symptoms hadn't been as severe or generalised before, which led him to believe something was wrong and that action was required.

> *'I hadn't felt that. I hadn't gone that far before. As I said, I can put up with the not being able to breath as much, but this was a different sensation'* (Participant 12, male)

## 6.3 Cognitive representations and emotional responses to heart failure symptoms

Cognitive representations reflect meanings given to the health threat (HF symptoms) including its identity, perceived cause, timeline (i.e. chronicity), physical and social consequences, and beliefs about its curability/controllability. Findings illustrate uncertainty and misconceptions in many of these areas, and a sense of cognitive dissonance between how participants perceived themselves and how they perceived their condition. This often led to a highly emotional response which drove coping in many cases towards avoidance strategies and denial. Cognitive representations of HF symptoms and associated emotional responses will be described in this section.

### *Identity*

#### *Painful symptoms prompt care-seeking*

Participants understood the concept of pain as dangerous and worthy of immediate care based on its identity as being heart attack related. For many participants, symptoms of pain, notably chest pain, led to immediate care-seeking. Participants were easily able to identify this sensation as heart-related because the pain emanated from the effected organ, and was often associated with heart attack. Participants understood the related dangers of heart attack clearly. They understood chest pain as a hallmark of heart attack, leading to fear of its well-known consequences, and thus sought immediate care.

> *'(It's severe enough to call an ambulance) when you get someone stabbing you with each heartbeat. You feel someone is stabbing you in the chest and being your shoulder on your heart side… Its scared, you get scared. You think, I'm having a heart attack. But when it doesn't have a pain, you can ask my wife, it doesn't worry me. But even if my breathing tight, but, when I have pain with the heartbeat or stabbing pain and it doesn't go away and this arm you know you feel tingling in the...yeah, I don't wait. I just go to hospital.''* (Participant 14, male)

One participant explained her struggle to interpret flu-like symptoms (breathlessness and fatigue) as heart-related - a stark contrast to her ability to interpret symptoms of heart attack.

> *'So its only...after the first heart attack I know what a heart attack feels like so I would just go straight to hospital. If its like flu, you just...I'm going to the GP I don't go to the hospital because I think its something different. I don't automatically go 'oh I've got a heart problem I need to go for that'* (Participant 13, female)

Symptoms such as breathlessness and fatigue took greater skill to correctly attribute to the heart. With experience and knowledge, however, many participants were able to conceive that their breathlessness was due to fluid retention caused by the heart. Nonetheless, this was not as common as immediate appraisal of pain as a problem. Almost all participants described a sense of urgency to seek care in the event of painful symptoms. Many participants described an overwhelming sense of pain as the main factor driving them to hospital.

> *'When the pain is just too much and I, you know, I just can't...its just too much for me. I just ring the ambulance or jump in a car and get to hospital.'*(Participant 11, male)
>
> *'Chest pains. Massive chest pains. It was getting worse and worse to the point where I couldn't handle it no more and gave in and came in and seen them and look where I am!'* (Participant 10, male)

Severe pain was less easily tolerated than other symptoms. For the following man, pain was perceived as more severe than breathlessness, taking a greater physical toll on his body, and prompted care-seeking more often than any other symptom.

> *'Oh, (I would seek care for) shortness of breath. But that doesn't...you know, sometimes they give me oxygen, but not as much as the pain. That's the one that really knocks me around.'* (Participant 11, male)

When symptoms were not painful, they were endured for longer and not often perceived as threatening, which led to delayed care-seeking (longer illness delay stage).

> *'I just sit and wait and see what's going to happen (when feeling breathless, light-headed, or clammy). Like, if that sort of starts, without the pain, I'll just...like if I'm just...relaxing...I would just lay on the lounge and wait and see what happens'* (Participant 2, male)

Participants commonly perceived that only painful symptoms warranted professional care. The identity of pain as a dangerous symptom, unlike fatigue and breathlessness, contributed to this perception. In the following example, this man explains how he associates pain with hospitalisation and thus other symptoms such as breathlessness didn't seem severe enough to warrant medical attention.

> *‘But not enough...it doesn't hurt. No pain so it doesn't feel like...I associate hospitals with pain.’* (Participant 1, male)

### *Threat to identity: image of cardiovascular risk incongruent with self-perception*

For many participants, HF symptoms posed as a major threat to personal identity. As will be described in the perception of burden section, simply asking for help challenged the self-concept of some participants, as reaching out to others was often perceived as a sign of weakness. Furthermore, participants’ representation or image of heart disease and the meaning of symptoms did not always correspond with how participants’ perceived themselves and acted as a threat to their identity. Preconceived ideas about the defining characteristics of someone with heart disease (i.e. old, unfit, and overweight) complicated symptoms appraisal (appraisal delay) and often led to denial and the desire to avoid communication with others (including providers) about illness. Many participants were not able to relate to their image of heart disease, especially the younger male participants, and did not expect to experience symptoms indicating heart dysfunction, particularly if they had been fit, strong and independent their entire lives. These participants did not expect to be faced with a chronic heart condition given that their self-concept did not fit their meaning and image of a sick person. As a result, these participants often coped with the reality of their diagnosis and its required management by using denial and avoidance.

For example, one participant described the shocking reality of his diagnosis, as he did not identify with the prototype of who he thought a patient with HF should be.

> *‘I just didn't believe it. I just...that’s just....gotta be wrong, you know. Because I thought it was...someone if you smoke a lot, and you're overweight, and you're over 60 sort of thing. So I just didn't believe it. And then, once I found out 'OK, well now I'll deal with it and then just get o...then forget about it'* (Participant 1, male)

Inconsistency or cognitive dissonance between how this participant perceived himself and someone with heart disease caused a sense of shock, which influenced his chosen coping strategy. Not fitting the mold of who a patient with HF was challenged his self-concept and left him feeling emotionally shaken and vulnerable. He chose to cope with these emotions by ignoring his condition and remaining in denial. The incongruence between his physical capacity and diagnosis led to him not seeking help.

Another participant expressed aversion towards medical devices due to their negative connotation. He associated device therapy with being old, which as a middle-aged man, was not what he wanted to feel.

> *‘And really, I don't want to have any medical devices especially a pacemaker...its makes me feel... old. It makes me feel old. And usually you associate pacemakers and these things with the heart with older people. But then I think that’s older people (inaudible) but I guess, you know, I don't want to feel old. And it does restrict your lifestyle to an extent, having a pacemaker.’* (Participant 9, male)

Once again, this participant described pre-conceived ideas about the type of person he thought would need such therapy. This image was one that he struggled to relate with, and thus expressed a strong desire to avoid this type of treatment due to his fear of feeling old.

In some cases, incongruence between these preconceptions and self-concept complicated symptom appraisal. This participant explained that he did not expect his symptoms to be indicative of serious physical deterioration, as he was accustomed to doing physical work as part of his job.

> *‘No (I didn’t expect it), like you go out and you know, you're tying on chains, ropes, straps, everything else like that. You um.... changing tyres… you're doing everything, you know.* ’(Participant 2, male)

This participant struggled to accept the sick person identity due to previous perceptions of being fit and active, which in this case, contributed to appraisal delay where he was unable to link his symptoms with illness.

This struggle with self-concept is further exemplified in the following example where reduced physical capacity led to feelings of frustration. Living with HF symptoms affects the lives of patients daily. It forces them to adjust their daily routine to accommodate symptoms, move at a slower pace, give up physical hobbies and work, and increasingly rely on others. As expected, frustration ensues and comparing themselves with others' physical capabilities made participants increasingly frustrated. Observing similarly aged healthy people influenced perceptions of what participants 'should' be able to do. For example, the following participant struggled with his self-concept when comparing his friends' physical abilities to his own. He questioned why he was the one struggling when the other men were overweight and unfit.

> *'...I'd get frustrated a lot, that I was getting puffed. And the last couple of years when I was getting puffed, say playing golf, where you know my friends are overweight..."what the hell?" you know. You know, they're walking along and I can't...and I need to stop, or they're...I keep powering along...and...it's just not right (laughs) So, and they used to play sport but they just haven't looked after themselves as much, you know, as I have.'* (Participant 1, male)

Again, preconceived ideas about heart disease complicates symptom appraisal, making it difficult for participants to link their symptoms to a deteriorating heart, particularly when comparing their own characteristics to those around them who seemingly personify cardiovascular risk. The participants did not self-identify as the type to be suffering from a heart condition.

### Cause

#### *Symptoms not linked with illness*

Symptom appraisal played a key role in how severe symptoms were perceived. When participants were able to link their symptoms with worsening heart function, these were perceived as serious and needed to be addressed immediately. Failure to attribute symptoms to HF, or misattributing them to more benign causes, often caused participants to ignore these sensations and delay care-seeking. When symptoms were not perceived as serious, participants did not feel a sense of urgency or motivation to act. In some instances, symptoms were thought to be part of the natural ageing process and/or not linked with the heart at all which led to delayed care-seeking.

> *'(No, I wouldn't call for help) because the way I put it with meself, um 'oh you getting bloody old now, you're running out of breath'. Alright, because I'm 72. So um, you just getting breathless, and that's all I put it down to.'* (Participant 5, male)

The inability to link symptoms with the heart meant that symptoms were not perceived as threatening. They were not viewed as something that needed to be dealt with urgently, and with professional intervention. Attributing HF symptoms to a less threatening cause led patients to adopt alternative coping strategies, such as resting to alleviate symptoms.

> *'No (I wouldn't seek care), I would have just said oh I'm just tired and I'm just at home. I'll ride it and have a shower, have a bath, relax.'* (Participant 9, male)

#### *Comorbid conditions (past or present) complicate symptom appraisal*

Co-morbid conditions with overlapping symptoms also complicated symptom appraisal, making it more difficult to link symptoms to HF. For example, given this participant's history with cancer, his initial response was to assume symptoms were cancer-related, or due to the side effects of cancer treatment. His problem-solving thereafter was based on this assumption.

> *'About half way through the game I was totally puffed out. I thought this is the first time in my entire life I've been so tired and exhausted. And due to the cancer, I mean I'm still...*

> *I haven't started remission as yet so I'm still being treated for cancer. All the side effects and....I was totally exhausted and I started to vomit and I knew then. Vomiting is the number one sign that I should be in hospital.'* (Participant 9, male)

Similarly, another participant initially assumed that his breathlessness was due to asthma, which he had suffered with in the past as a child.

> *'I was getting like asthma attacks and I thought they were asthma attacks and I went to Nepean hospital and said...I hadn't had asthma since I was a kid. And I took up swimming and lost the asthma and the last asthma attack I had was when I was in year 11.'* (Participant 15, male)

He explained that whilst he now knows his symptoms are not indicative of asthma, the symptoms still feel very similar.

> *'Well yes I know that now it's not asthma. It's still very much like asthma. Asthma-like symptoms, yeah.'* (Participant 15, male)

Constipation was noted as another factor contributing to complicated symptom appraisal, as it became difficult to determine whether weight gain was due to fluid retention and thus linked with the heart, or whether it was due to constipation.

> *'... go on the scale and...our biggest enemy is constipation. It doesn't help. Because you don't know what is your symptoms there, if its bloated, or not being able to breathe because of the heart.'* (Participant 14, male)

### *Previous experience with physical injury and capacity inform symptom appraisal*

Interviews revealed that previous experience with physical injury and capacity also informed attribution and initial management of symptoms. For two younger male participants, in particular, symptoms were often attributed to lack of fitness. They were therefore dealt with by being 'pushed through', as they had done when playing sports.

> *'…what I noticed on the touch footy field...when you play touch you know you get tired, and what I used to do was, you just push through it. And you get to a level where you get tired and puffed but you just keep going and sort of get out to this sort of medium happy equilibrium where you are puffed but you can keep running.'* (Participant 1, male)

When asked about how this impacted his appraisal of breathlessness, he acknowledged the influence that his previous training has had on his interpretation and response to symptoms.

> *'I thought...I'm used to getting...pushing yourself. You get puffed you know its not...it means probably you haven't...you're not as fit as you should be. That's the way I've always looked at it - if you're getting puffed, you need to improve your training.'* (Participant 1, male)

#### *Past experience with symptoms facilitates confidence in appraisal*

The potential danger of attributing familiar symptoms as 'normal' has already been described, however, in some cases, the familiarity of symptoms acted as a facilitator of rapid symptom appraisal. In these instances, when symptoms had been experienced previously, participants were less doubtful in attributing the physical sensations to its proper cause. They were able to identify the cause of symptoms and its implications with greater confidence. Participants were able to draw from memory of the sensations itself, imagery, emotions from when the symptom had occurred previously, and conceptual beliefs about the meaning of the symptom. Given that executive function was intact and participants had the ability to draw from memory of these levels of processing, rapid appraisal of symptoms ensued as a result, shortening the length of illness delay and appraisal delay. In the following example, the participant was able to draw from previous experience to identify that the specific sensation of pain was a sign of heart attack despite having attributed this exact sensation to RSI previously. Memory of the concrete physical sensations, the conceptual beliefs, emotions and imagery attached to this previous experience enabled him to push the alternative explanation out of his mind and accurately link these sensations to heart attack. He explains the uncertainty around making sense of what had happened the first few times he experienced heart attack symptoms, but now understands because of his experience what those sensations mean.

> *'.... the actual first heart attack, well, when I was diagnosed, because I think there was probably at least 2 or 3 that I had before I got myself off to hospital (laughter). You know, because you just don't realise that that's what you are looking at, you know, and at the time I was a truck driver and, bad combination, like you are getting...what you know NOW is like angina pain and everything else coming from the heart, but you just think its like RSI or something like that.'* (Participant 2, male)

Similarly, another participant explained how previous experience with heart attack symptoms when pregnant facilitated rapid symptom appraisal and response. Due to this previous experience, she was able to evaluate heart attack symptoms with confidence, which enabled her to formulate an action plan to seek immediate professional care without uncertainty.

> *'…then the third time with the dissection I did (go) into hospital, but I knew I was having a partial...I was having a heart attack so I knew the symptoms and we just went straight there. But it wasn't bad, nothing like the first time. So I knew enough to go (chuckles) But this viral one, no. I just thought I had the flu'* (Participant 13, female)

Whilst she was able to quickly recognise symptoms of heart attack, she drew attention to her struggle to make judgments about symptoms relating to her viral cardiomyopathy, often misattributing them to the flu and therefore not perceiving them as serious. Despite her previous experiences with HF symptoms, she was not able to assign an appropriate label or cause to them, and therefore adopted a 'wait and see' attitude.

### *Consequences*

#### *Interference: persistent symptoms perceived as a threat to quality of life prompts care-seeking*

Participants described a threshold, in a sense, in which symptoms became so intolerable that they made the decision to seek professional care. This threshold was different for each individual. Some described this to be point where there was no other choice but to seek professional care, whilst for others, this threshold was much earlier. In all cases, participants described what motivated them to seek care in terms of interference. When participants continued to experience burdensome symptoms and perceived they were unable to cope with the symptoms themselves, professional intervention was sought. It should be noted, that in some cases, despite not knowing what was causing symptoms, participants turned to professionals to help formulate an action plan. Unclear representations did not necessary mean that the symptoms were overlooked. If they interfered with daily life enough, and occurred frequently, professional care was sought.

In this example, it is evident that despite not knowing what was causing symptom exacerbations, professional advice was sought on how to manage them as they were occurring frequently and disrupting this participant's daily life.

> *'So went back up to Brisbane, the second and third one came in about, well, about 3 months later, and then about 2, 2 days, 2 weeks apart, and then we just...that's when I started talking to the doctors you know, what do I do, you know, because this is happening, you know. (Participant 2, male)*

Coping with the physical discomfort of severe pedal oedema, ascites, and fatigue had negative implications on this participant's quality of life to the point where dressing herself became a massive struggle. When her quality of life was compromised due to these persistent symptoms beyond what she was able to cope with, she was prompted to seek professional care.

> *'Yeah, so when things become so so difficult, and you know...you think to yourself, 'I can't carry on like this', because every day is getting worse and I think I have to go to the doctor….'* (Participant 3, female)

This illustrates that when these consequences could not be sustained, and the losses in both the realms of functional capacity and quality of life demand attention, the decision is made for professional intervention. Persistent symptoms such as breathlessness or unabated flu symptoms that interfered with daily activities likewise were perceived threatening to quality of life and prompted care-seeking.

Interference with routines also facilitated symptom recognition. In one example, a participant realised he was starting to require more sleep to effectively carry out his shift work without fatigue. He explained that he now needed seven hours of sleep as opposed to four hours. Noticing fatigue was likely facilitated by the interference to his shift work.

### *Perception of being a burden: reluctance to seek care*

A major social consequence of worsening HF symptoms was perception of being a burden. In the majority of cases, professional care-seeking was perceived as a last resort. Only when symptoms were perceived as severe to the point where they became both physically and psychologically overwhelming did participants call for help. Many participants described a fear of burdening others that stood in the way of seeking care in times of need. The sense of burden was not only felt in relation to providers, but also families, and the health system. Views about when and who should utilise health services underpinned participants' decisions to seek professional care when symptoms worsened. All too often, participants were averse to seeking care because they perceived their condition was not bad enough to warrant professional care. Fear of being a burden to others was also linked with a sense of pride and desire to remain independent. The desire to maintain self-sufficiency did not align with asking for help. A number of participants struggled to do so for fear or being a burden to others, but also for fear of being perceived as weak or being labelled a hypochondriac. This again highlights a sense of cognitive dissonance in these participants, which corroborates with findings previously detailed in the identity section.

Participants described wanting to avoid 'being a burden' to providers for a number of reasons. The following participant, for example, took great pride in her independence and as a general rule, avoided asking for help in situations that she perceived she could manage herself. She expressed a great sense of responsibility to handle her own problems, and as a result, only used professional services as a last resort.

> *'No (I didn't call for help), I didn't want anybody else cleaning up my business!'* (Participant 7, female)

A sense of pride in not calling on medical professionals for assistance delayed care-seeking. Anything less than very severe symptoms were perceived as an unjustified reason to ask for help.

> *'Yeah. It is a last resort for me when I call them. I don't call them for nothing. No, it is a last resort for me. Every time I've called the ambulance, its pretty well justified.'* (Participant 7, female)

This attitude towards care-seeking seemed to be congruent with her stoic personality. This participant took pride in not asking for help, and expressed a sense of contempt for those who did utilise health services.

> *'…there wouldn't be so much pressure on hospitals or anything else if people stop and thought about things for a while instead of grabbing the ambulance at every little pain. I mean I've seen them in there with colds, just pure colds. And I thought, you arseholes, you can fix that up yourself. Why would you come to a hospital to get something for a cold? They probably can't give them anything for it anyway. You just gotta get over it yourself…. I've seen the way they use the hospitals and I refuse to use hospitals that way. We weren't meant to use the hospitals that way.'* (Participant 7, female)

She viewed professional care, namely calling for the ambulance and hospitalisation, as an overreaction in most cases, and perceived that those who did utilise these health services were a burden to providers and the health system. This quote also illustrates her lack of confidence in formal health services to provide adequate care. It should be noted that throughout the interview with Participant 7, it became clear that she had very little faith in the medical profession, repeatedly expressing distrust in their competence, and thus frequently expressed her belief in the superiority of self-management and self-reliance.

Another reason that participants described hesitation to seek care and ‘burden’ health providers related to their perceived busy schedules. Participants openly acknowledged their providers’ time constraints, and for the most part, were highly satisfied with the support and attention they received given perceived busyness. Being aware of the high demands of their providers’ jobs, however, was often a reason cited by participants for avoiding calling for professional help when symptoms worsened. For example, the following participant described his fear of being a nuisance to health professionals by seeking care, expressing his inclination to ignore symptoms rather than burden his providers about concerns which he fears they will not validate.

> *‘Like going to, like being a nuisance to, showing up to a doctors office and saying "I feel this and this and what’s wrong with me", and they'll say "oh, you'll be right". Um, (pauses for a while). OK, sorry.’* (Participant 6, male)

He fears being told there is nothing wrong with him, and inconveniencing others for what he perceives as no reason. This overlaps with his fear or being labeled a hypochondriac and fear of being told nothing is wrong, impacting his sense of masculinity and challenging his self-concept.

> *‘I try to avoid...I'm not the type...I'm not a hypochondriac so to speak, you know, I don't go for the slightest of things to the, to the doctor. The only time the doctor will see me is when I've chucked a sickie and I want him to sign a sick form...off the record (laughs)’* (Participant 6, male)

Fear of being a burden to others in general, including loved ones, was a recurrent theme, particularly for those who were struggling with their loss of functional ability and independence. Furthermore, frequent hospitalisation is a part of living with HF, a consequence affecting both patients and their families. The impact of their chronic condition on loved ones was something participants took into consideration when making decisions about going to hospital.

> *'…(Its not involving) you only. Me. My wife have to change everything. The kids, they always in the hospital with me. Whatever plan they have...see you don't want to ruin it for them so you avoid going there.'* (Participant 14, male)

The desire to remain as independent as possible was incongruent with asking for help. One participant described his inclination to avoid involving others or burdening others with his personal concerns. This attitude towards seeking help was particularly strong as he described himself as the type of person who likes to help others and therefore struggled to ask for help himself.

> *'I just wish no one had to look after me. Or help me. I'm the one that likes to help. But... I do, if I'm good at something and someone needs a hand or anything, I'll help them. It doesn't always get me anywhere but I do it anyway. That's another thing.'* (Participant 10, male)

This caused friction between what he needed (help), and his personal identity of always being the helper. Asking for help was therefore perceived as a threat to his identity.

> *'Oh always (reluctant to receive help from others). Always have. Always have. If I can do it, no matter how painful or difficult, I'll do it. But I won't ask anyone for help (chuckles) I'm laughing, but its true! (Participant 10, male)*

This quote suggests that pushing through difficulties alone and not wanting to burden others was coherent with his personality. In addition, he expressed a strong need to contribute to his family, who had consistently supported him throughout his life. He felt as though he should have been the one helping them, suggesting a sense of guilt, and therefore struggled to take a more dependent role.

> *'I can help them, and I do, but I always feel like I could do more. You know like contribute, even to working, instead of them helping me, I should be helping them. I'm talking about me mum...my late father...its too late now for that. Anyway. They've always helped me. They always used to bring me here. It got to a point where I wouldn't let them come with me anymore.' (Participant 10, male)*

Sadly, his limitations did not allow him to fulfill this desire, however, he felt the least he could do was take care of his own affairs and drive to hospital on his own when needed. He explained that he aimed to remain independent in this way until he was no longer physically able to.

> *'I don't want anyone...I don't want anyone to have to go out of their way...I shouldn't say that.... what's a good word.... I don't want to be a burden on anyone. While I can take myself in, its all good.'* (Participant 10, male)

This may be problematic as the desire to avoid involving others may be so strong that despite having no other choice in instances of acute symptom exacerbation, patients may delay seeking-care just to satisfy their need to avoid being dependent.

Other participants expressed a very similar fear of burdening others, having strong links with a sense of pride and personality of not wanting to ask for help. As a single mum who took pride in her independence, this participant described her struggle to let go and ask others for help.

> *'(I am fearful of being a burden to) Everyone! Everyone, because I look after the whole kit and caboodle, and for me its a case of having to learn to go beyond that and go 'can you help me please?' and believe me when you are standing up here you know, and to come all the way down here at street level and say can you help me, I can't tell you how hard that is.'* (Participant 8, female)

Participants were also aware of their personal impact on the health care system. Burdening the health system was another factor taken in to consideration when making decisions about seeking professional care.

> *'I don't like inconveniencing services that I'm getting for free. And I've really tried to work it out myself before I'll call them***.'** (Participant 7, female)

This quote illustrates how fear of burdening the health system provided further reason to avoid utilitsing health services, which may lead to delayed care-seeking. From this participant's perspective, exhausting all self-management options was essential before the decision to seek professional care was deemed appropriate.

In a more detailed example, it became evident how awareness of healthcare expenditure was a key part of this decision making.

> *'I got a, an invoice from NSW ambulance for $360 or something and I had that a few times, and I'm thinking, that was only 15 mins away and its costs me, it costs, you know, people, $360, and then there was another couple of other invoices that came in and I'm thinking wow, thats ahh...and so THEN I started to become aware of how much... when I come here for instance, all the tests and things like that um, if they weren't for free, as such, I'd be dead. You know, you put my situation in America, forget it. You know, where you have to pay for every single...like the test and all the, you know, all the fancy equipment that they use and stuff, no way! So that makes me very much aware.'* (Participant 8, female)

Receiving invoices detailing the cost of just one aspect of this participant's care (hospitalisation) drew attention to the high overall cost of keeping this patient with HF alive. This became a fundamental part of making decisions about whether professional care was absolutely necessary, or whether costly health services could be avoided. Her personal impact on health care expenditure was a harsh reality that caused this participant to think twice about seeking professional care. She explained that asking for help became even more difficult when she became aware of the cost.

> *'Yes, but more so when I go to hospital because I know how much it costs and how expensive it is, and everything like that.'* (Participant 8, female)

#### *Putting health on the backburner: competing responsibilities take precedence over heart failure self management*

Due to competing responsibilities such as work, family, and caregiving roles, health was often put on the backburner. In these cases, the management of personal health was not a priority, which led to decreased symptom vigilance and delayed care-seeking. For example, one participant explained that despite being advised to follow up with a cardiologist after suffering an exacerbation at work almost ten years ago, he delayed making contact with specialist services for 2 years. He explained that he was trying to balance work, building his house, and family roles, which led to delayed care-seeking. His health was put on the back burner for 2 years due to these competing responsibilities.

> *'They took me to the nurse and they did an ECG on me and found something irregular, the ambulance was, came and picked me up, took me to St George Hospital then, observed me overnight, and thought that I should seek help by going to a cardiologist at the time. That was in 2007. With my life extremely busy at the time, raising 3 kids, and working, and doing over time, and building a home, um, completely didn't continue to look at following it up.'* (Participant 6, male)

He also explained that at work, he felt he was able to 'control' how he felt, and only noticed symptoms once he has arrived home. Once again, this demonstrates how competing priorities can lead to decreased symptom vigilance, where perceived 'control' of symptoms may, in reality, be disregard of them. Symptoms that go unnoticed at work increases the risk of symptom exacerbation at work, which did occur in the case of this participant in the aforementioned 2007 instance. He recognised a pattern of symptoms, which coincidentally corresponded with his work schedule.  When he did notice symptoms, he responded by taking rest. This may be because he attributed symptoms to stress rather than his underlying heart condition.

> *'OK, my daily activities, the mornings are always hard for me, to get up in the morning. That's fine. While I'm at work, fine, although, I feel pressure and the stress gets to me. Round about the afternoon, round about finishing time, I've gone home, that's when my batteries are sort of exhausted. And, so I'll lie down. I can't sleep, I won't sleep, I don't have that ability to be able to sleep in the afternoon for some reason. I'll have a cat nap, and that's enough for me.'* (Participant 6, male)

It became clear that managing HF was not prioritised for some participants. The maintenance of work or family roles were perceived as more important. Another participant described his diligence to work, pushing symptoms aside to complete work tasks. Despite suffering symptoms and being told device management was necessary, he did not hesitate to keep up with work related travel, and maintain his self-concept as a man of his word.

> *'Umm so I come back down umm, then I had an appointment with me heart specialist, then I, we deci(ded) me an me sister said oh we'll go down to Albury because there was another conference on down there, and I had to take some stuff down to em. And um I got down there, I just sat in the car, didn't feel like moving. And we went up to where the conference was and went in and handed the stuff over to em that I promised 12 months ago I would bring down. And they were surprised because no one ever does that. Um then I went down, back, we went down to Wagga, and during the night I get up, and I said "I don't feel well, I think you better take me down to the hospital" and that was it...' (Participant 5, male)*

Being able to uphold a promise was clearly important to this participant, and held more weight over any health-related concerns. In this instance, he pushed himself to the conference to uphold his word and ended up in hospital as a result.

Another participant compiled a list of competing responsibilities, all contributing to her hesitation to seek care.

> *‘I'm hesitant because I don't want them to think I'm being a hypochondriac. I am hesitant because I don't want to be a burden to other people. I am hesitant because who is going to feed my dog and cat…but that sort of thing...I delay, I think well you know, if anything happens Snoopy will be here, or if anything happens I can't leave Snoopy because, you know, no one will be around to feed him or something like that’* (Participant 8, female)

Together with fear of being a burden and fear that providers would not validate health concerns, this participant explained how her responsibilities as a dog owner who lives alone influences her decision making process. These were all factors that she considered when making decisions about seeking professional care, and in some cases led to delayed care seeking when the benefit of seeking care didn’t seem worth the risk of her dog going hungry, for example. These are equally important things to consider when understanding factors that may impact patients’ decisions to seek or avoid professional care.

### *Timeline*

#### *Symptoms perceived as an acute problem – informed by pattern of symptom onset*

The challenge of correctly attributing symptoms to HF has been described in the ‘Cause’ section, noting various barriers to symptom appraisal which made it difficult for participants to link their symptoms with illness, and furthermore, to link them with HF. In other cases, HF symptoms were linked with illness, but perceived as an acute problem. For one participant, the chronicity of her condition was not realised, as she only suffered symptoms when she had a cold or flu, which created confusion in symptom appraisal. Due to this pattern of symptom onset, she did not link these symptoms to an underlying chronic disease, and instead perceived them as an acute problem. She therefore had difficulty interpreting symptoms as serious.

> *‘Well I've had the shortness of breath since I had the virus and it only gets worse when I have a cold so you just think...it just affects you that way, you don't think, oh heart problem.’ (Participant 13, female)*

This example illustrates how symptoms are perceived as less threatening if participants do not recognise that they indicate underlying chronic disease. Immediate action is therefore not prompted, and a passive response is chosen.

### *Cure/control*

#### *Perceived curability: loss of hope versus the will to persevere impacts attitudes towards care-seeking*

Being aware of the limited curability and controllability of HF led to loss of hope in some participants. This caused participants to question the purpose of remaining diligent with appointments and self-care maintenance and self-care management activities. For example, the following participant expressed a sense of hopelessness in knowing that nothing short of surgery would cure him, and even then, recognised that it would only prolong his life rather than fix the problem.

> *'I know with whatever happens, whatever treatment or operation, I'm still not going to be like, say my friends that can do anything. That I know. It makes it a bit hard but you know, like I said before, from what I understand it just prolongs your life. You still got to come in here and check-ups and ohh. Sometimes you wonder, what's the point, if you know what I mean.' (Participant 10, male)*

Another participant described how perceived futility of HF management impacted his decisions to seek professional care.

> *'(waited to call for help) A number of times. A number of times because I know that when I go into hospital, they'll put the cannula in my arm and give me morphine and send me home the next day but nothing has actually happened in trying to fix what I have and that sort of annoys me.' (Participant 11, male)*

For this participant, knowing HF can't be 'fixed' led to delayed care-seeking on a number of occasions. Whilst he acknowledged the ability of formal health care to effectively manage symptoms such as pain, he expressed a sense of frustration with the underlying thought that nothing was being done to reverse his condition. This participant perceived that that the only thing that would ‘fix’ him is transplantation, and viewed professional care for worsening symptoms as a band-aid solution, successful in treating acute exacerbations, but not doing much for his chronic condition.

For other participants, looking to the future and the will to live through significant events helped them persevere through negative experiences and uphold self-management responsibilities. One participant explained that despite her previous negative experiences, her will to live and spend time with her grandchildren helps her cope and keeps her going.

> *‘Well, I have a choice. Either I die, here (hospital), and I'm not prepared to, I want to get this Christmas in because I want to see my grandchildren, I haven't seen them in 2 years, and they're coming down this Christmas. And that’s all I want to do, get through this Christmas and January because it’s my grandson’s 6th birthday.’* (Participant 7, female)

In another example, the will to live life and return to full-time work motivated a participant to carry on with self-care maintenance and self-care management practices to help him lose the weight required to become a suitable candidate for transplantation. He explained that he is *‘fighting for another 25 years’* and wants to keep working.

> *‘I'll get this off (referring to excess body weight which classified him as obese) and I'll get that new kicker down the road. So that’s my battle. That’s my goal. So I'm fighting for that. It better help. Actually, fighting for another 25 years. That’s what I'm fighting for. Yeah, if I hit that, I'll be quite happy. And I definitely want to get back to work. I think I'm...I want to work full-time in radio so.’* (Participant 15, male)

#### *Locus of control: being active or passive impacts orientation towards care-seeking*

Not only did beliefs about whether HF could be cured or controlled impact care-seeking decisions, but also the role participants perceived they had in controlling their condition. Some participants expressed a strong desire to play an active role in their care, some were happy to play a passive role by entirely relinquishing control to trusted providers, and others expressed mixed feelings. Once again, orientation towards being active or passive was often related to how participants perceived themselves. The decision to take ownership of their condition and the degree of personal control participants felt they had about making decisions about their care impacted their attitudes towards care-seeking.

In some cases, longstanding relationships with providers involving trust and respect meant that participants relied entirely on them for support, advice, and their expertise when making decisions about care. For one participant, her long-time cardiologist, who provided an unparalleled sense of 24-hour support, became the sole driver of self-care management practices and decision-making. Control was given up willingly, facilitated by confidence in the ability of this provider. In terms of seeking professional care, this can be advantageous as positive interpersonal relationships with providers can overcome perceived system and provider-related barriers to seeking professional help, which will be discussed in the second half of this chapter. In these cases, patients do not hesitate to call their trusted physician when in need. As soon as this participant noticed her symptoms were getting worse, she did not hesitate to call her cardiologist immediately. Her cardiologist then decided upon the appropriate management strategy. For this participant, utmost respect for the medical profession meant that she left medical decisions entirely in her doctor’s hands. In her perception, her role was ‘patient’.

> *‘Well, I've got to leave it up to the doctors. I can't...I'm here, I've just gotta go with what they say. So, and I've just got to trust them, that’s it. I know when I'm in good hands, and you've just got to leave them to do it. They know more than me, and I'm not going to tell them their job, so, I'm just here as a patient (laughter).’* (Participant 4, female)

On the other hand, another participant described a new-found sense of control after attending a cardiac rehabilitation program, forming the opinion that it is imperative to take ownership of your condition in order to cope and make it easier to live with. She described how engaging in self-care maintenance and self-care management practices helped her maintain a sense of control and independence.

> *'I can control; low salt diet, fluid restriction, a little bit of exercise depending on how I'm feeling and what's happened at that stage, and changes to my lifestyle. I've really learnt, you know...cooking is the most boring thing ever, but now especially since its only for 1, I don't cook too much, so I've re-learnt these things...that gives me control of my condition*.' (Participant 8, female)

Taking ownership also meant she was not the type to blame others, instead taking responsibility for her own health.

> *'Yes, and I'm not one to say ' oh it's the nurse's fault, or it was the bloody pills' or, you know, whatever, you know*.' (Participant 8, female)

She was, however, aware of aspects of her condition that were not in her hands. She decided that the best she could do was to focus on what she could control to remain a good candidate for transplant.

> *'I can't control, you know, a deteriorating heart. I can't control when to have surgery, you know. If I don't control what I'm doing, to the betterment of my health as much as possible, then I won't get a heart and I will die in 12 months. That's the bottom line. Not maybe later on, you know, do a few healthy things and....no! That's the bottom line. You know, my heart is operating on 20% as it is. I mean, what else can I do?'* (Participant 8, female)

The attending cardiac rehabilitation nurse played a key role in this participant's shift in thinking and approach to self-management, reinforcing the message about the importance of being an actively engaged patient rather than a passive one. This message was also rooted in this participant's family upbringing and values, and is perhaps why this message resonated with her strongly.

> **'***I guess that for one thing, my parents taught me very well. But that's the kind of attitude that I have, and having all of those bits and pieces helps me to cope with what I have to cope with.' (Participant 8, female)*

Whilst many participants expressed a strong desire to take ownership of their condition and aimed to be the sole driver of deciding what was best for them, many still required affirmation from providers about the appropriateness of seeking professional care. Care-seeking decisions were an aspect of self-management that participants still struggled to take complete responsibility for, despite wanting to take ownership of their condition. Participants expressed the attitude that it was the doctor's decision whether or not hospitalisation was required, not the patient. One participant felt strongly about the way people should use medical services, adopting the belief that a referral from the doctor is required to receive care in hospital.

> *'…you go through your doctor to get in to the hospital. And that's how I did it.'* (Participant 7, female)

Affirmation from providers was essential when seeking professional care, particularly for this participant who took pride in her independence and condemned those that sought emergency care.

> *'Most people panic. I've got a neighbour who I've rung the bloody ambulance twice for, and said nothing wrong with her. She just wants attention.'* (Participant 7, female)

Another participant expressed similar views, describing the GP as the gatekeeper to accessing any professional healthcare service. She explained that first and foremost, she would make contact with her GP to check and confirm if her concerns warranted further care in hospital. Whilst she was responsible for making it to her regular GP appointments, she perceived that her

GP was responsible to make the decision whether it is appropriate or severe enough to be admitted to hospital. She assigned this responsibility to her GP.

> *'I usually go to the GP first. He usually will do a blood test or...and an ECG and based on that I've gone to hospital based on results. So that was when I had the viral attack. So based on what he said to me. Same with the next one so.' (Participant 13, female)*

This participant also described the difficulty she had in symptom appraisal and her need for more information to help her judge 'should I be concerned?' She used the GP's professional advice as a way of dealing with her own perceived inability to judge the severity of her symptoms. She relied on him to monitor symptoms and make judgments about whether or not care in hospital was required. This attitude was facilitated by her perception of the GP's superior knowledge and qualifications that she perceived were essential to make care-seeking decisions.

> *'So you sort of ride on the fact that they know more than you.' (Participant 13, female)*

### *Emotional response to heart failure and symptoms*

The emotional responses associated with illness representations and symptom perceptions have been described throughout the previous section. The following section describes more specifically, how unclear cognitive representations and uncertainty can lead to an active or passive response, depending on whether participants were optimistic about the outcome of symptoms, or experienced fear and anxiety about the unknown. This section also describes the crucial role of an emotional response to symptoms to prompt care-seeking.

#### *Hope: passively coping with unpredictable symptom trajectory*

Findings revealed that participants were uncertain about various aspects of illness representations. The unpredictable nature of HF symptoms made it even more difficult to establish certainty in terms of evaluating whether symptoms would resolve on their own, or continue to deteriorate. In this context of sporadic symptoms and uncertainty, many patients opt to 'wait and see' how symptoms develop by taking rest in response to worsening symptoms.

> *'….if I get up in the morning and I wander out here and have my breakfast and I go to have my shower, some mornings I can have my shower, wash my hair, and wash the shower and screen down. I feel good. Other days I can just about wash myself and I'm exhausted, and I think well today is not a good day so I just do nothing but rest that day.' (Participant 3, female)*

In this example, it is evident how the nature of HF symptoms can be problematic in terms of deciding what to do. When personal previous experience tells patients that symptoms are just as likely to get better the following day, as they are to get drastically worse, professional care is avoided. Hope that symptoms will dissipate encouraged delayed care-seeking behaviour. This highlights how the unpredictable nature of HF symptom trajectory can make symptom appraisal inherently challenging and can contribute to illness delay.

> *'Thinking oh, don't worry it'll get better…always think its going to get better. Even though we know it won't but we always hope it does. Actually, sometimes it does. It gets a little bit better and…you can handle it...' (Participant 10, male)*

The following example illustrates the role of uncertainty as a barrier to seeking care. A combination of not being able to determine the cause of symptoms, attribute symptoms to illness, and the inability to assess the likely trajectory of symptom onset led to a 'wait and see' response.

> 'About half way through the game I was totally puffed out. I thought this is the first time in my entire life I've been so tired and exhausted… *I said look, maybe I can override it, maybe I'll get better.' (Participant 9, male)*

Once again, hope facilitated this response when this participant was uncertain about the cause of symptoms and how they were likely to unfold. Despite feeling symptomatic and recognising symptoms were out of the ordinary, he adopted the attitude that he could perhaps push through the symptoms and avoid professional intervention.

### *Fear/anxiety: actively coping with uncertainty*

It should also be noted that in some cases, uncertainty acted as a motivator of care-seeking. Participants would opt to actively cope with uncertainty by seeking professional advice to clarify ambiguity about the cause of symptoms, or whether they were something to be concerned about. In attempts to clarify uncertainty, participants chose to seek professional care to not only treat the issue, but to satisfy their need to know and understand their condition. When these participants experienced incessant symptoms for which they could not provide an explanation themselves, they looked for answers from a trusted source, being the expert health professional. When the following participant could not comprehend why he kept getting pus (from central line) he decided to seek help from providers.

> *'Well I didn't think I'd have an infection. And uh I don't even know where the infection come from. That's the other thing which is a bit frightening. Did I get it here? Or did I get it, down home? Uh you know, once I found out it was an infection, the only problem was, where did it come from? And you know, they said I'm going to have to be on umm antibiotics for the next 2, 3 weeks. And that's probably 5 or 6 times a day.' (Participant 5, male)*

The infection he experienced was unexpected, and fear surrounding the cause and consequences of the infection prompted him to seek care.

For another participant, determining the precise cause of symptoms was very important, as he was highly motivated to self-manage to avoid hospitalisation. Knowing the cause of symptoms was imperative to make decisions about the most appropriate action to take. When this participant was, however, uncertain about why symptoms were occurring, he described a sense of panic and worry describing how *'anxiety - it get worse'*. He described how his plan of action when uncertain about how to appraise his symptoms was to call the cardiac rehabilitation nurse, with whom he had formed a strong trusting relationship.  Not only was calling for advice a way of coping with uncertainty, but also a very effective way of reducing panic.

> *‘I didn't panic when he tell me its alright and stop the fluid.’ (Participant 14, male)*

Coping with uncertainty and its associated anxiety by calling for professional help was perceived to be a very effective way of managing symptoms and a major reason why symptom management was effective in avoiding unnecessary hospitalisation.

> *‘When the heart people start looking after me and I did that operation, my nurse to be in contact with me all the time and every time I worry about something, I used to call him. And my doctor, because we've known each other for so long, he gave me his mobile so I could call him any time and unless they tell me you need the hospital, we manage it. Between the doctor and the nurse, we manage it. And it worked! We get better.’* (Participant 14, male)

This participant chose to actively cope with uncertainty by contacting his trusted health professionals due to the positive outcomes of previous experiences.

> *‘(Its been) Very helpful because you see, like this time, we end up in the hospital...I'm sure we would have end up in the hospital anyway, but he saved me ending up in hospital so many times.’ (Participant 14, male)*

This type of feedback appraisal informs subsequent decisions about how to reduce uncertainty and panic when symptoms worsen. As a result, the active coping method involving contact with health professionals is favoured, rather than a more passive ‘wait and see’ response.

The above examples highlight the importance of two key decisions on the path to professional care-seeking, and how uncertainty can either act as a motivator or a barrier to timely care-seeking. These two key decisions represent the first and second stages of delay: 1) whether the symptoms are indicative of illness (appraisal delay) and 2) whether they can be self-managed or require professional intervention (illness delay). These are the problem areas in HF that need to be addressed.

*Symptoms evoking fear and negative imagery prompt care-seeking*

Throughout interviews, participants described instances where they did seek professional care for symptoms in comparison to instances where they did not. A notable difference between these two scenarios was that when patients did seek care, physical symptoms were coupled with feelings of anxiety, dread, fear, and in some cases, powerful imagery. This combination of physical and psychological symptoms marked the point at which patients decided professional care was necessary.

For example, a combination of physical symptoms, such as breathlessness, coupled with feelings of anxiety prompted this participant to recognise something was wrong and seek professional care.

> *'I'll be feeling light headed, lack of breath, anxiety, weak.' (Participant 6, male)*

Emotive physical sensations prompted care-seeking for yet another participant, who described an overwhelming sense of dread when symptoms worsened. The powerful imagery associated with symptom exacerbation acted as compelling drivers of care-seeking decisions.

> *'Um I can feel when I'm (inaudible) and so that's a real ghastly feeling when it comes over you. The...a couple of times it feels like a...everything is sort of closing in around you. It's a real spooky feeling (laughter). Not much fun.'* (Participant 15, male)

For this participant, making judgments in relation to symptoms being 'bad enough' to seek care largely revolved around their ability to provoke strong emotions. Being 'bad enough' to go to hospital was described as:

> '(having that) *feeling. Like a real dread thing and its scary.'* (Participant 15, male)

This combination of physical sensations and emotions associated with negative imagery assisted in making future decisions about the precise moment during a symptom exacerbation when calling for an ambulance would be appropriate.

> *'Asthma like symptoms, yeah. And then (inaudible) hot and sweaty, and you get the like that dread type thing and then dark. It gets real dark (inaudible) black out. All that happens and then you ring 000. Before that dread. When you start sweating I reckon that 000 (inaudible).'* (Participant 15, male)

## 6.4 Coping

The chapter thus far has described participants' cognitive representations and emotional responses to HF symptoms, and how this impacted chosen coping strategies, including decisions to seek professional care. This section will describe how participants coped with their symptoms, drawing attention to the most common responses of: 'wait and see' due to uncertainty around the cause and consequences of symptoms; approach coping where participants described a sense of 'knowing' when they needed professional help; and avoidance coping where participants were in denial and thus avoided or delayed seeking care.

### *Coping with uncertainty*

As explained in the previous sections, participants commonly described feelings of uncertainty in response to symptom exacerbation. Uncertainty was described in relation to: 1) the cause of exacerbation; 2) whether it was illness-related; and 3) the likely consequences. When participants were uncertain about these crucial aspects of illness representations, they were not equipped with enough information to formulate an appropriate action plan to manage symptoms. Uncertainty acted as a barrier or facilitator of care-seeking depending on how participants decided to cope with it. Participants either responded actively by seeking professional care to clarify ambiguity; or responded passively, instead choosing to 'wait and see'. As described in the previous section, a passive response was linked with a sense of hopefulness and optimism that symptoms were not serious and would resolve on their own. In contrast, an active response was often linked with a sense of fear and anxiety about the unknown. Interview findings revealed that in most cases when uncertainty arose, patients would opt to ‘wait and see’ how symptoms developed. By monitoring the trajectory of symptoms over time, participants felt they could make better judgments about how to manage symptoms most appropriately, namely, deciding whether professional intervention was absolutely necessary. Furthermore, misattributing symptoms to a non-threatening cause, such as age, impacted the perceived severity of symptoms. The degree to which symptoms were perceived as threatening in turn influenced whether participants decided to act immediately, or adopt a more passive approach. These findings demonstrate how emotional and cognitive representations together impact how symptoms are managed or coped with, aligning with the core principles of the SRM.

### *Approach coping: sense of ‘knowing’ when to seek care*

Participants described various characteristics of symptoms that they perceived as threatening and prompted action. These characteristics included: new symptoms, painful symptoms, symptoms that evoked fear and imagery, and interference. A combination of these characteristics was described as a sense of ‘knowing’ when symptoms warranted professional care, when participants knew they should be alarmed. This perceptual sense of ‘knowing’ was generated by a combination of factors including previous experience, emotional responses, and problem solving strategies that led patients to believe they could no longer cope with symptoms on their own.

Participants often gauged the state of symptoms based on the degree of limitations they were experiencing. If various self-management strategies were employed to relieve the burden of symptoms, yet they remained an intrusion to daily activities, a decision was made to seek professional care. Many participants viewed calling for professional help as a last resort, only appropriate when all self-management practices failed.

> *'I couldn't get the breathing right, I was out on the balcony trying to gasp all the air in and it didn't work. Oh I try everything before I ring up for ambulance or doctors or anything. '* (Participant 7, female)

The following example illustrates how first testing out self-management strategies at home contributed to 'knowing' when professional intervention was necessary, through feedback appraisal.

> *'Well I suppose...I suppose if you go and sit down and you maybe will lean forward or sit up or something like that, and it starts to get better, well then you know its going to pass. If it doesn't improve with that method, you know its not going to get better. So I suppose that's my analogy as best I can (inaudible). I think, yeah, well see it's the same as walking. I know if I walk and my legs go weak and I get breathless, I've got to stop. I know if I stop and I wait, then I'm right to go again. So maybe its the same analogy, you just know what you do when you have a problem.' (Participant 4, female)*

Decisions were made about the appropriateness of professional care based on the effectiveness of symptom self-management. 'Knowing' when symptoms required professional intervention was centered on the failure to alleviate symptoms using known self-management strategies. One participant described the scenario where self-management strategies are no longer effective as a period of struggle. At this point of struggle, she developed a sense of 'knowing' professional help is needed.

> *'When I know I'm struggling. Yeah. When I know I'm struggling, I know I need help.' (Participant 4, female)*

This sense of 'knowing' professional care is required is further strengthened by the ability to correctly link signs and symptoms to HF. Again, participants seemed more alarmed by symptoms when they were able to link them with their heart. Of course symptoms such as chest pain were much more easily attributed to the heart, however, symptoms such as breathlessness, fatigue and oedema were more difficult to link with heart problems. For the following participant, a sense of 'knowing' symptoms were out of the ordinary and it was time to seek professional care was facilitated by a combination of severe symptoms, namely tightening in the chest.

> *'Palpitations and hard breathing and tight chest and I felt tight chest.... and really tightening the chest like a heavy weight squeezing me in. I knew...look, I knew I wasn't ok.' (Participant 9, male)*

Another participant described the frightening experience of a symptom exacerbation leaving her gasping for air that led to a sense of 'knowing' something was terribly wrong, and professional care was absolutely vital.

> *'Well, I was gasping and I knew that it wasn't good. So I rang the ambulance. Opened the door for them so they could get in, and I just collapsed into a chair then. I just couldn't breathe…. Well you know, if it was your breathing and you can't breathe (takes deep breath in) REALLY trying to gasp air in you, you really know something is wrong.'(Participant 7, female)*

Severe breathlessness was therefore perceived as a symptom that warranted professional help, despite this particular patient's aversion to interact with health services. The worrisome feeling of struggling to 'get any air' surpassed any negative perceptions of providers and services that generally led this participant to avoid seeking care.

> *'Oh well I, yeah, well I rang them. I'd been gasping like that from about 4 o' clock, and I, and I couldn't get any air and I knew something was wrong. Just knew it, you know.' (Participant 7, female)*

Another participant described a sense of 'knowing' when to take action, responding to worsening symptoms in a somewhat instinctual way. This participant had been living with a heart condition his entire life, having been born with a structural heart defect. He described his ability to feel when the sensations indicated danger, and perceived he was able to make appropriate decisions about what to do.

> *'Oh (I get symptoms like) shortness of breath. If I see I'm tired I normally stop and it's too hard. It's hard for me to explain. Its like I know what to do when things happen.' (Participant 10, male)*

A sense of 'knowing' when help is needed was a combination of being physically and mentally overwhelmed, and the consequences can no longer be sustained. The following participant described how she 'knows' when she needs help, which corresponded with her inability to carry out simple tasks, such as dressing.

> *'Ohhh when I'm really ...well I think you know inside you (that you need help) because you just feel so exhausted all the time that even if...look before I went into St Vincent's, even putting my undies on was an effort…but when you know that little simple things like putting your undies on is so hard, so hard...'* (Participant 3, female)

Despite her own personality erring on the side of stoicism, this participant felt she knew when to put that aside and seek professional help.

> *'So your body...you know yourself how you usually feel, and when you feel stuff then you don't mind struggling a bit, I don't mind struggling a bit, because I know I'm not well, but when it really, everything becomes such a big struggle then I know I have to go and get help, you know.'* (Participant 3, female)

Much like the previous section about how participants coped with uncertainty, these findings also demonstrate how decisions people make about how to cope with their symptoms are based on a combination of emotional and cognitive representations. A sense of 'knowing' was described as a feeling of being both psychologically and physically overwhelmed, which prompted approach coping strategies involving professional care-seeking.

### *Emotion focused coping: denial*

As described, many participants expressed a sense of cognitive dissonance towards accepting the reality of their health status. Many opted to reject the sick person identity, choosing to remain in denial about their condition altogether, or downplay its seriousness. This was a common response in younger participants who struggled to identify with the image of heart disease, and often led to avoidance coping strategies.

Coming to terms with being in poor health was particularly difficult for the following participant who had done his best to keep fit and active his entire life. His ‘normal’ prototype or self-perception was that of an athlete. He did not want to think about the possibility of illness jeopardising this prototype as he had always taken pride in his level of fitness and physical capabilities. Concrete stimuli of worsening symptoms could not be ignored, yet to cope with the intrusive sick person identity, he stopped himself from further conceptualising what these sensations meant. In the following excerpt, this participant describes his thought processes when symptoms were occurring, explaining his tendency to push them out of his mind in order to cope.

> *‘Well I just thought, I'm unfit firstly, that "God I'm unfit", that’s what I used to say to myself. And then I just thought, something’s wrong but I don't want to know about it. So, it’s just that block thing I was talking to you about earlier (spoke about how he blocked things out as he found it difficult to accept anything was wrong with him) so it was as if...um. So you're question was what did you think was causing your shortness of breath, I actually really didn't care. I didn't seem to want to know about it, just ignore it. It will go away. I was sort of brought up a bit that way, just tough it out.’ (Participant 1, male)*

As a result of this coping mechanism, symptom appraisal was interrupted and cognitive representations were unable to become fully formed. He did not allow himself to think about what was causing his symptoms. He was not in denial that there was a problem altogether, but wanted to remain in denial about being labelled a sick person who was suffering a serious chronic condition. For this participant, it was easier to attribute worsening breathlessness with lack of fitness. Furthermore, ignoring concrete physical sensations was reinforced by cultural context, as mentioned in the final sentence.

As a consequence, confiding in others about his concerns or any details of his condition was avoided at all costs. The example below illustrates how this impacted communication with friends and family.

> *‘...if I hear something bad about me, I don't want to hear it, you know. It's a bit like the stroke. I didn't want to hear the word stroke after I'd had a stroke. Just had enough, over it. Lets just move on, OK I had a stroke, let’s forget about it. You know friends and all...friends that care and that 'how are you going, how are you traveling' and the weird...that’s just a flaw in my personality or something, because...one of the...the hardest thing I find is talking about it. I hate talking about it.’ (Participant 1, male)*

This participant was aware of his inclination to push difficult thoughts out of his mind and explained how avoiding communication with others facilitated his denial. Interestingly, hearing the label of his condition was enough to trigger his emotions, which may potentially hinder communication with providers.

In another example, a ‘wait and see’ attitude was propelled by the notion that asking for help was a sign of weakness, again highlighting the cognitive dissonance between how participants perceive themselves, and representations of their condition.

> *‘Ok, but inside me I said, I'm tough. Maybe I can ride this. I'm big boy, you know, let’s not be at the hospital. But eventually I had to check in.’ (Participant 9, male)*

This participant described how he delayed seeking care to remain congruent with his ‘tough’ personality, but eventually had to be hospitalised. The perception of being tough was brought up in another instance where a participant was talking about his thought process in seeking care.

For another young male participant, a sense of duality interfered with symptom appraisal and decisions to seek professional care. This participant struggled to think of himself as a sick person. He perceived sickness as a sign of weakness and viewed the capacity of his heart almost external to his own physical capacity.

> *'Not physically (stressful), but obviously to the heart it was. So, you know, sometimes I take my physical ability for granted, that the heart can only do so much. You know what I'm saying. I, I feel so strong, you know, I feel so able to do things. Yet this thing (heart) says otherwise.' (Participant 6, male)*

A sense of duality in feeling strong, yet suffering a chronic illness challenged this participant's self-concept, making it difficult for him to attribute symptoms to illness, which resulted in delayed care-seeking.

> *'OK (I put off seeking care for 2 weeks). Only because of that reason. Because I felt so strong at that time of my life, and I'm 48 now, and it was in 2007, and like, I was, everything was happening in my life so a priority being something wrong with me, you know, was un… like I didn't feel that there could be anything wrong with me. That's what I was feeling at the time. When I was waking up in the middle of the night trying to catch my breath, obviously alarm bells are going off, but, you know, like I put up with it for 2 weeks thinking it's going to go away so. And maybe the fact that I couldn't afford to have anything be an obstacle in my life at that time. When I'm sort of at my peak, so to speak.' (Participant 6, male)*

Again, this participant was not able to ignore the physical sensations of breathlessness that kept him up at night, but akin to the other young patient with HF, he chose to ignore the underlying meaning and delayed seeking care. He did not attribute symptoms as a sign of illness as he *'felt so strong'* at that time in his life and could not comprehend that he could be affected by illness.

In the following example, care-seeking was perceived as ‘dobbing’ on one’s self (or turning oneself in or taddling), in a constant battle between weakness and perception of wellness. This participant was ambivalent about the reality of his diagnosis. Whilst he knew he was suffering a chronic condition and, in this case, required an ambulance, he was reluctant to admit to himself that he needed it. He described the decision to seek care as a negotiation between both sides, where one side (reality) was ‘dobbing in’ on the other (denial).

> *‘And by me saying "No, don't call the ambulance" its like, " Don't dob, don't dob!" (says in a whisper)… "Don't dob! (laughs) keep it between us!" (Participant 6, male)*

The participant explained that during this time, his defibrillator had fired and he urged his daughter not to call the ambulance, despite knowing that he should. The meaning of this event was too much for him, as he perceived it marked further dependence on others to come, which he had not been accustomed to his entire life.

> *‘Although I was asking her at the time, "Don't call the ambulance, don't call the ambulance...Ok, right after have been defibrillated and have sort of come to, I've um, "oh no" (strains as he says this), its just like, " come on man, I've been like this for 6 years...no, no!" Because I know now starts the deterioration, you know, like the worsening...Because my whole life is changing right now. I can't drive. I can't work. I'm dependent on people. I never had to do that. So my whole life is upside down, and at that time, after the defibrillation...."Nooo!"... that’s all I could think of. " (Participant 6, male)*

In direct reference to his denial, he describes how it influenced his attitudes towards remaining fully informed about his condition.

> *I'm my own worst enemy sometimes, because, sometime I don't want to know, do you know what I'm saying? Like, I don't want to know the truth, because maybe I'm too scared of the truth. You know, like, I still got so much to live for. You know, I don't want,*

> *like I feel like I'm trying to persuade myself "Its going to be alright" like you know, " You're ok!" "There's nothing wrong with you". My heart is saying otherwise, but you know. Maybe the reason why I've gone half way (on the questionnaire item) is because I only want to know half the truth. Do you know what I'm trying to say? I don't want to know the whole story.' (Participant 6, male)*

Struggles with identity ultimately informed decisions to interact with health services.

> *'I think it's, deep down psychologically, I don't want to accept the fact that there is anything wrong with me, and I don't want to go to those lengths of getting poked and poached again...' (Participant 6, male)*

Not wanting to accept the sick person role in combination with previous unpleasant experiences in hospital largely informed preference to avoid hospitalisation.

Not only did participants describe a preference to avoid hospitals, but any environment that would require interaction with sick people. For example, whilst the following participant expressed her desire to get more information about her condition, she also stated her reluctance to attend cardiac rehabilitation or any patient support groups available. Participation in these groups represented joining the 'club' of sick people, which she described her aversion to.

> *'…even like going to the um, the ICD, the device networks, sometimes you don't need to mix with people that might even be worse off than you (chuckles) I know that's a bit sad but. You know, I don't feel the need to join the club.'(Participant 13, female)*

This participant clearly struggled to accept a sick identity and did not want to 'mix' with other sick people. By not being open to attending these types of groups, she was not able to address gaps in knowledge. Although she described this aversion in the context of joining device networks, it could be assumed that her unwillingness to associate with other sick patients may have led to avoidance behaviours in terms of hospitalisation.

## 6.5 Appraisal of coping strategy

The SRM posits that self-regulatory processes occur in a constant feedback loop. Consequences of delay or timely care-seeking can thus impact representations of HF symptoms, and even emotional responses. The following section describes findings suggesting these feedback processes.

### *Learning from consequences facilitates positive attitudes towards future timely care-seeking*

As exemplified in the previous sections, a patient's previous experience with symptom exacerbation is likely to impact their decision to either cope with uncertainty actively (seek professional care and advice) or in a more passive manner (wait and see). The previous sections have touched on how past experiences with symptoms informed appraisal about its cause and likely trajectory. Participants' past experiences with delayed care-seeking also informed whether they would decide to seek immediate care in the future. When participants were aware of the consequences of not seeking timely care, they were less likely to consider delaying care-seeking when symptoms worsened. Becoming aware of the consequences generally occurred upon reflection on previous experience. Whilst knowing the consequences of delay facilitated favourable attitudes towards immediate care-seeking, such knowledge can not be assumed to translate to behaviours.

The following example illustrates how participants self-regulated using feedback appraisal to make decisions about when to seek care based on their previous experience. This participant explains his realisation of the consequences of delayed care-seeking, and now adopts more favourable attitudes towards seeking timely care in the future. He recognises, in hindsight, that he was lucky to survive, as he delayed treatment for 15 crucial hours. This participant realised the detrimental consequences of delay, recognising the importance of seeking care early.

> *'Actually, a few times what happened is when I was sick, when I was really sick, I didn't check into hospital for about 15 hours. That had an effect, I was lucky to make it because*

> *I didn't want to come into hospital…. but, I delayed it 15 hours. By the time I checked into hospital, that already caused the bowel obstruction.' (Participant 9, male)*

Similarly, the following woman learned from past experience that persistent symptoms that would not get better and professional intervention was necessary. Wanting to avoid being re-hospitalised shortly after discharge led to delayed care-seeking, further compounded by the notion that she had only just received a blood transfusion during her stay in hospital which made her feel like her concerns about feeling weak were not warranted.

> *'Well they said to me oh you know, you should have come in a couple of days ago and stuff. Like when my Hb was going down but I'm thinking, look, I was discharged on the Tuesday and they gave me blood the night before, so maybe I'm making a big deal about this because I'm feeling faint again and weak and everything like that, and then so that would go like Tuesday morning into Wednesday morning, Wednesday evening and then I finally think oh look stuff this, THEN I called the ambulance because I haven't gotten better. But THEN I've learnt along the way, the blood that I was getting was like putting blood in, you know, in a bucket with a hole in it. So I was back there in emergency 24 hours later. So, that was when I was really struggling with that was...'look its going to get better if I just rest, or if I just do this' but then it comes back'* (Participant 8, female)

This previous experience served as a lesson for her that symptoms should not be ignored, they will not get better, and that seeking help should not be avoided or delayed because of recent hospitalisation.

> *'Yeah, I'd do it straight away and I'd tell (as opposed to ask)… I'm not going to ask anymore.'* (Participant 8, female)

This participant took a firmer approach to expressing her need for help following her experiences, and in the future plans to take an active role by telling providers she needs help rather than asking providers whether care is warranted.

As explained in the perceived consequences section of this chapter, symptoms that interfered with daily living were often perceived as a threat to quality of life. Maintaining quality of life served as a great motivator to care-seeking for a number of participants. One participant, in particular, pointed out the importance of seeking help early to prevent symptoms from interfering with his life. This participant explained that in hindsight, he would have called for help earlier given that his current condition did not enable him to continue doing the things that he loved to do. His symptoms physically limited him in ways that affected him mentally. His sense of pride, his wellbeing, and general quality of life were all things he wished to preserve and believed he could have done so by seeking timely care.

> *'(I probably would have come down to hospital earlier) because it stopped me from doing a lot of stuff that I love doing. Umm, I got a house which I was renovating, and I had planned the way I want it done. Now, I gotta get someone to do it for me, but I got to supervise, but I can't physically work because I can't weld… I wanted to say, that's what I done to me house, and I done that meself' (Participant 5, male)*

## 6.6 Coherence

In Chapter 2 (conceptual chapter), it is explained that no single aspect of illness representations holds the key to behaviour change, but rather, behaviours depend on the stability of the self-regulatory system. Leventhal and colleagues suggest that the stability of the model is dependent on coherence; within self-regulatory processes themselves, with personality, and with cultural context and providers. The findings, thus far, have illustrated the difficulty participants had in building coherent models where each component fit with the others in perfect harmony due to the high level of uncertainty and misconceptions around HF symptoms. Findings have also exemplified lack of coherence or cognitive dissonance between representations of HF symptoms and how participants perceive themselves. This section will describe coherence between participants' representations (or meanings) and the representations of others (cultural context).

Coherence with providers will be described in the second half of this chapter, in the context of provider and system-related factors influencing care-seeking.

### 6.6.1 Other people facilitate symptom appraisal and care-seeking

Given the inclination of people living with HF to accept daily symptoms as 'normal', it was often others who identified worsening symptoms and recognised its links with a deteriorating heart. Others, including participants' spouses, trusted family members and friends, and even colleagues played an important role in care-seeking decisions. In the following examples, other people pointed out worsening symptoms that were unbeknownst to participants, or weren't perceived as 'that bad'. In either case, they either drew attention to symptoms that were unrecognised, or provided validation that participant's concerns were warranted and that action was necessary.

In many cases, HF self-management was a responsibility shared by the family and it was common for participants' husbands, wives, and children to help point out worsening symptoms and urge action.

> *'And the majority of the times, my wife will see me…that I'm so bad that she feels quite concerned that she will make that call to get an observation done' (Participant 6, male)*
>
> *'It was my wife's birthday and it was a lovely sunny day and I was getting the barbeque ready and drinks and my wife said you look terrible, you look shithouse. Sit down for a while and take it easy. And I said, I don't feel well. So we rang the ambulance.' (Participant 11, male)*

One participant explained that his preference to avoid seeking care was often overridden by his wife's concern. She urged him to be vigilant and to not to be lulled into a false sense of security in terms of symptom trajectory.

> *Yes. Like "here we go again" so to speak, you know. And I feel like, "oh let's just leave it, it will go away, it will be fine", you know. But my wife thinks otherwise, "No, its not going to, it might get worse". "Let just, you know, chase it up". Yeah.* (Participant 6, male)

Once again, the involvement of close family members in symptom appraisal and care-seeking decisions was very effective in overcoming barriers in relation to participants' perceptions of symptoms not being 'that bad'. When others pointed them out, participants were able to reconcile that their concerns were justified.

> *'"Dad, you're colouring, its terrible", "Dad, um, you're breathing heavy again", "Dad...."' (Participant 6, male)*

> *'You don't look...you wake up sometimes and they tell you your colour...I used to go and open the shop, we're talking only a couple of years ago, yeah they won't let me when my colour don't look good. They won't let me open the shop until I see my doctor.' (Participant 14, male)*

One participant described an instance where friends helped him recognise symptoms of heart attack, which resulted in subsequent care-seeking. The role of his friends in this example led to a shortened appraisal delay stage, facilitating the ability to rapidly recognise that symptoms were out of the ordinary and thus subsequently enabled him to link them with his heart condition.

> *'I had a heart attack after sailing at Kirribilli and I got off the boat and 2 of my mates who are sailors said Timmy you don't look very well. You look really pale and shithouse. I said yeah I don't very really well, I feel really painful. And they said look, don't worry about helping us unrigging the boat, just go up there and have a glass of water and sit on the...on the...at Kirribilli at the park. Anyway. So I sat on the seat and got my mobile phone out and rang the ambulance.' (Participant 11, male)*

The role of others in symptom recognition, appraisal, and care-seeking extended beyond friends and family in some cases. Participants' colleagues also helped identify signs of deterioration and prompted care-seeking when exacerbations occurred at work. One participant explained how he felt his colleagues were always there to *'keep and eye out'* for him, as they knew about his condition and associated symptoms.

For other participants however, care-seeking was a personal decision that did not involve others in any capacity. These participants relied solely on their own powers of deduction to make decisions about whether symptoms warranted professional care, as they felt like HF symptoms were a personal experience that family and friends *'can't see'*. (Participant 5, male)

### 6.6.2 A-priori action plan facilitates care-seeking

A number of participants described how a predetermined action plan used in the event of worsening symptoms helped them make timely decisions to seek professional care. This was a highly effective way of being able to cope with making decisions in a situation where panic, fear, and lack of oxygen often made it difficult to think clearly. An action plan or coping response was usually developed in conjunction with clinicians. A clear and easy to follow plan with little ambiguity could be carried out with a sense of autonomy. Disappointingly, it was more common for participants to have a specific action plan for pain rather than the entire host of symptoms that are indicative of a forthcoming HF exacerbation.

For example, the following participant had a clear plan for what to do when he experienced pain. The logic and simplicity behind these instructions facilitated long-term commitment to this advice.

> *'And they said well, you've got your GTN (nitroglycerin), if you get the pain, just um, take the GTN. Obviously the ambulance will get...take time to get to you so...if they're still not there in 10 minutes, take a second. And, that's the way I've worked it now ever since.' (Participant 2, male)*

The credibility of this advice was strengthened when there was coherence between multiple providers, which made the impact of the action plan even greater.

> *'As I said though, like, as they said (inaudible), everyone that I've talked to medically, they've just said exactly the same thing, its the right way to do it. Like, as soon as the pain comes on, take that first (inaudible) then ring an ambulance. Leave it 10 minutes, take a second one and just wait for them.' (Participant 2, male)*

Whilst having a specific action plan, reinforced by providers, sets an agenda for timely care-seeking, it also leaves patients unsure of how to respond when symptoms fall outside the boundaries of the specific action plan. When this participant experienced other symptoms outside of pain, no specific action was taken.

> *'I just sit and wait and see what's going to happen (when feeling breathless, light headed, or clammy). Like, if that sort of starts, without the pain, I'll just...like if I'm just...relaxing...I would just lay on the lounge and wait and see what happens.' (Participant 2, male)*

In a sense, this participant was just trying to do what the doctors had advised and maintain congruence with his providers' beliefs. In his experience, their advice had been highly effective and perceived as trustworthy. As they did not mention other symptoms to be alarmed about nor did they develop alternative action plans for breathlessness or fatigue, he had no reason to feel like action was necessary. Without explicit instruction from providers, deciding when action needs to be taken becomes a much more complex task. Without specific instruction, decision-making is dependent on patients' own problem solving abilities and the development of their own set of criteria for action.

As demonstrated, action plans were usually centred around coping with pain. In one particular case however, a HF-specific action plan was developed in conjunction with a cardiac rehabilitation nurse. The nurse provided this participant with a highly specific action plan when symptoms worsened. This action plan detailed exactly how the sensations felt, what they meant, what to do, and when to do it. Not only did the nurse provide her with an action plan, but she also explained what would happen if she didn't follow through with it.

> *'...look when you know that um that your body is um going into fluid overload is, in half an hour you get this feeling...you can hear the rumbling, that's fluid retention. You call the doctor straight away. Or go to the hospital or whatever but do something about it and don't sit on it, because it's just not going to go away. It'll get worse.'(Participant 8, female)*

Being provided with a specific action plan including information about what alarming symptoms felt like, what to do, and when to take action shortened the length of appraisal delay and illness delay.

### 6.6.3 Symptoms prevent care-seeking

In two instances, limited physical capacity led to avoidance behaviours. The following participant described how symptoms themselves, namely fatigue, acted as a barrier to seeking care. He explained that he instead adopted alternative coping strategies to help cope with symptoms, such as listening to music.

> *'Yeah, I mean one of the symptoms is you do get tired. Being tired to say look, I'm too tired to come in. It's a fair drive (to hospital). You just listen to music and hopefully you can override this.'* (Participant 9, male)

This participant explained how fatigue made it challenging to access care. He did not perceive that seeking professional care was worth the effort, however, he did negotiate with himself, trying to introduce reason to his argument by drawing attention to the seriousness of his condition. This self-negotiation is what helped him ultimately decide to seek professional care and not delay medical treatment any longer.

> *'I'm hoping listening to music will cure my ails but the fact is I need medical treatment. That's when I (realise) you know, I need to check in...I can't just...music is not going to get over heart failure because...its a serious illness, disease, heart failure. Look inside me I want to (inaudible) I need to do what I need to do which is check into hospital. Alright, sometimes I just don't want to do it. I'm just not in the mood to do...not in the mood due to laziness, its just because I feel lazy because I just can't be bothered. I'm so tired.' (Participant 9, male)*

## 6.7 Provider and system-related factors influencing professional care-seeking

The remainder of this chapter pertains to factors impacting care-seeking that come under the umbrella of previous healthcare experiences. This included participants' previous hospital experience, preference for provider continuity, and patient-provider interpersonal relationships.

Previous negative healthcare experiences were a great barrier to seeking care. Through traumatic healthcare experiences, a sense of fear was attached to seeking treatment, rather than the consequences of disease. For many participants, the perceived negative consequences of interacting with providers and the system outweighed the consequences of untreated symptom exacerbation.

Other participants had more positive views of the Australian health system. One participant described that nothing had ever stood in the way of getting care when needed, and perceived that Australians have the best medical system in the world. His positive patient-provider interactions and experiences in hospital led to this perception, however he realised that this may be different for different from others' experiences with doctors.

> *No (nothing has made it difficult to get help when I want it), not really. I think you know we've the best medical system in the world really. And the best hospital system in the*

> *world. Well that's only... from my point of view ok so I've always had good care, I've had doctors that are concerned about you.* (Participant 12, male)

These positive perceptions of the Australian health system facilitated interaction with it. This participant also expressed a sense of understanding for the nurses and staff working at the hospitals who often interrupt patients' sleep. He perceived that they were *'good staff'* and '*are only doing their jobs'* by waking patients every 2 hours. He did not view these experiences as negative, as many others had done, but rather, necessary as a part of providing optimal care.

The following section will describe provider and system-related factors that motivated interaction with health services, and also factors that led participants to avoid it.

### 6.7.1 Preference for continuity impacts care-seeking decisions

In the context of uncertainty, familiarity was highly sought after. Almost all participants described a desire to maintain relationships with select health providers or hospitals. Maintaining continuity of care meant participants could: be treated by long-term providers with whom they had already established trusting relationships; receive care at facilities that had easy access to their medical history (perception that they 'know' me); and avoid the consequences of being managed by too many people which may lead to perceived potentially harmful and unnecessary changes to treatment regimes. This impacted decisions to seek professional care, as when symptoms worsened and preferences for continuity could not be met, participants would delay seeking care. Maintaining continuity was perceived as more important than seeking immediate care. By whom and where the care was delivered took precedence over when it was provided.

#### *Maintaining continuity of care with hospitals*

A number of participants described how their preference to receive treatment at a specific hospital was part of their decision making process. In most cases, this preference was explained in relation to easy access of medical records. For example, the following participant described how her preference for continuity would lead to avoidance behaviours if getting to her hospital of choice was not a viable option at the time of symptom exacerbation.

> *'So as I said, I've been to (hospital X) and (hospital Y), and I'd still take (hospital Y) over (hospital X). Even when I get the ambulance I said 'If you can't take me to (hospital Y), I'm not going'. They look at me and they said ' Why?' and I said 'Because all my records are there' I said 'I've been going there for what, nearly 70 years, I think I was 4 years old when I went to (hospital Y).'* (Participant 7, female)

Again, preference for seeking care at a hospital where patient medical history is already known was perceived as highly important and played an important role in making decisions about seeking professional care.

> *'Yeah, that's the one thing I need...I can't seem to shake is that I need to check into St Vinnies instead of the local hospital, you know, because they don't know my...even though the other hospital can ask for my history, I just want to come here. By the time they get it, I'm already here.'* (Participant 9, male)

Another participant described his reluctance to call an ambulance if he was not taken to his preferred hospital. This reluctance tied into his preference for maintaining continuity with specific doctors, who were already familiar with his medical history and details of his case.

> *'No, (I wouldn't call the ambulance because they might take me to a different hospital) because they don't know me anymore. My doctor...if they change, you see how serious it is if they change anything, that could finish me, so. And that's a lot, that's a lot. See they work so hard to work out all the dose and my medicine here in a Webster Pack...'* (Participant 14, male)

This participant explains how he would no longer seek professional care at his local hospital, as they don't 'know' him anymore. His concerns were centered around new doctors making unnecessary changes to his treatment regime, which could potentially be harmful. Maintaining continuity with the same doctors at the same hospital was an important consideration when making decisions about seeking professional care. Preference for continuity led to avoidance behaviour in instances when continuity was not ensured.

### *Maintaining continuity of care with providers*

As previously mentioned, preference for hospitals was not only about easy access to medical records, but also aligned with preference for continuity of providers. Different hospitals meant different doctors. This was something participants wanted to avoid, as they were wary of the potential harm of involving too many different providers in their care. Potential harm was described in relation to doctors making unnecessary changes in patient management. Receiving care from the same provider(s) over time was perceived to minimise the risk of this occurring. Patients often recognised the lack of communication between the multiple providers looking after them. For example some patients were shocked to discover a component of their management had been changed unbeknownst to their primary care physician. It was often assumed that there were clear lines of communication between providers, although this was not the case.

For example, one participant explained that involving additional members to her care team would complicate management rather than make her feel better supported. She recognised the lack of effective communication between providers, which would likely interfere with her care plan. This led to her preference of being taken care of by a sole provider (her cardiologist).

> *'…when you get other people that are not in the loop that don't know what's happening interfering and thinking they know what they know and changing things around, which can cause insurmountable problems. So, I'm better off not to have a third person or a second person.'* (Participant 4, female)

The added confusion of additional members to the care team was a perception likely influenced by previous experience.

> *'You know, maybe you get called to the emergency department or something like that, and then you got all the doctors there saying 'oh you know you can't'...'oh you shouldn't be on this', and they take you off it and you get back to...to (cardiologist) and he says 'who took you off this?!' and I said well, they told me to go off it...'you can't go off that!'. You know, its just...yeah, that second person can cause insurmountable problems, so I would rather deal with the one person.'* (Participant 4, female)

For another participant, lack of continuity was a barrier to seeking care in hospital. Living rurally impacted this attitude, as this participant was aware that she would require hospital transfer to a distant city to receive appropriate care. The consequences of seeking emergency care for this rural-dwelling participant also meant new doctors. Maintaining continuity was important for her, as she described a sense of safety when dealing with providers with whom she had already built trusting relationships. She also perceived these long-term providers were better equipped to make decisions about how to effectively manage her condition, given their previous involvement in her care.

> *'I sort of think you build up a trust with your health professionals and its a bit like when you go, its not a reflection on the staff or anything, I just feel like I know he knows my history, I know that he knows what has worked for me in the past or what hasn't. So you're sort of reliant on that knowledge. So I would feel safer going to my GP and cardiologist.'*(Participant 13, female*)*

She explained her preference to seek care with known providers (her GP or cardiologist) rather than seek emergency care, however, she also understood the limitations of opting to seek care at her GP (perceived lack of specialist knowledge).

> *'I think its having a GP that understands your illness, or what inherent problems you have and try and cater for that. But they still don't know everything because they are not specialists, and I understand that but it, you know, it is the best way. I prefer to do that than just go straight to hospital and just be admitted and...'* (Participant 13, female)

This was problematic because whilst she was happy to keep up with appointments with known providers, in instances of acute symptom exacerbation, she would opt to avoid seeking care due to preference for continuity.

### 6.7.2 Previous hospital experience impacts care-seeking decisions

The most conspicuous message relayed by all participants was the desire to avoid hospitalisation at all costs. Previous experiences in hospitals were often traumatic and protracted. Furthermore, interactions with providers in hospital were not always positive, driving patients further away from seeking refuge in a place that was not deemed as safe.

#### *Previous traumatic experiences: emotional and physical turmoil*

This decision to avoid seeking care was not only impacted by participants' desire to maintain continuity with known providers, but also their desire to avoid being in hospital. For many participants, hospitalisation carried negative connotations involving incessant painful testing and emotional turmoil. For participants who chose to cope with HF though denial, hospitalisation served as a harsh reminder that they were ill. The thoughts and feelings evoked by memories of previous negative hospital experiences were enough to deter participants from seeking emergency care, even when necessary.

> *'Well I knew the doctor wasn't open and my GP and um...didn't want to go to the hospital...I hate the hospitals so...' (Participant 1, male)*

This participant's attitude towards seeking care in hospital was influenced by memories drawn from previous hospital experiences where he had suffered pneumonia (contracted in hospital).

The negative imagery and emotions associated with the experience, described as 'horrible', set the tone for hospitalisation in general.

> *'I just hate the idea of going into hospital.' (Participant 1, male)*

Another participant described a past experience in hospital with pneumonia as an unpleasant one involving frequent painful testing, which was to be avoided at all costs. Lack of continuity further impacted the unpleasantness of his stay.

> *'I had a really hard time in there because I was poked and picked and you know, because they didn't know my situation.'* (Participant 6, male)

These experiences informed subsequent decisions to seek professional care. Despite apparent satisfaction with the quality of care provided, the sheer experience of being in hospital was enough to dissuade this participant from interacting with the health system in the future.

> *Well, I try to avoid it (hospital) as much as I can. I know that after I leave from here, I feel well, like I feel right now. The doctors here are marvelous. They do a beautiful job of trying to help everyone in here. But I personally just try to avoid it, coming in here, not because I dislike it, its just that I don't like the, you know the...the pokiness, you know, and the stabbiness, and the changing of tablets and the, this and that.* (Participant 6, male)

Another participant described his experience of being in and out of hospital for many years as an ongoing 'saga' of traumatic experiences. These previous experiences, again, were not in direct relation to HF admissions, but strongly set the tone for interacting with the heath system. He described instances involving procedures that did not go as planned, one nearly ending his life and the other leaving him disfigured.

> *'And one of the angiograms, they ripped the artery as they were bringing out the whatever they were bringing out and I had to go up to intensive care and that was pretty exciting. Pretty, you know, didn't realise I was...it was pretty serious having all this blood*

> *pouring into my stomach and I remember one doctor said, we almost lost you there Jimmy, and I said, well I'm glad you didn't. So I've had all those sorts of things going on since 2008 and then I had the foot operation, which was an absolute disaster. I was in St Vincent's and all they had to do was straighten the toe and fix the toe and out in some plates and bolts and I ended up spending 6 weeks in hospital I got an infection and then the operation didn't turn out to be right and it was terrible. It was just hopeless and it has disfigured my foot for the rest of my life. You know I wasn't in tears but, you know, it was very...so that was another thing that just added to the whole...whole hospital, sort of, saga.' (Participant 11, male)*

Previous frightening and emotional experiences in hospital became painful reminders that led to avoidance behaviour. One participant described a particularly traumatic experience involving a code blue, which contributed to her preference to remove herself from the environment where these events had occurred, and where people around her may be suffering in the same way she was. These awful memories highlighting her awareness of vulnerability led to avoidance behaviours.

> *'You know, I've been actually through code blue myself so you sort of think (starts to cry) its not something you want to go through...because there's lots of people that do. So I definitely think the last time I'm a lot more...you get nervous about some of the procedures. (Participant 13, female)*

She was, however, aware that in some cases, she must negotiate with herself and seek professional care regardless of her disinclination towards being in the hospital environment.

> *'And then when you get paddles, which hurt quite a bit when they go off...you sort of think, usually apparently you forget all that but...I even remember the nurse hitting me on the chest and I'm thinking, gee that's a bit rough (laughs) I didn't really quite realise what she was doing. All I said to her afterwards...I said 'you just slapped me really hard*

> *on the chest!', I'm thinking, what did I do! (laughter) Well then we had like the defibrillator doing its thing. Its going off and then its...then they're doing the paddles as well so its like… and that's why on that particular experience I am sort of like a little bit head shy going forward, which you know, I was always...never you know like being in hospital or....I think that's just some people are like that. I'm sure a lot of people are like that. But in some cases you have to go with it..' (Participant 13, female)*

Avoiding interaction with hospitals was also part of feeling 'normal', despite suffering a chronic illness. For some participants, avoiding interaction with other sick people and providers facilitated emotion-focused coping by allowing them to remain in denial about being ill. Hospitalisation served as a reminder of being ill, and thus one participant described she would rather seek care at the GP instead of seeking emergency care in hospital.

> *'It's just part of feeling normal, I guess. You're not pandering to I'm sick, I need to go (to hospital), you know.' (Participant 13, female)*

These examples illustrate how previous traumatic experiences in hospital can lead to utilisation delay, where patients know that symptoms mean illness, but the benefit of seeking professional care in hospital does not outweigh the risk of another distressing experience. Whilst interacting with the health system triggered negative connotations for numerous participants, they acknowledged that in some instances the desire to avoid interaction must be put aside to benefit their health.

> *'I hate going to doctors to be honest. So I usually go only when I need to. But I've sort of had to put that aside and just turn up.' (Participant 13, female)*

### *Care-seeking represents loss of freedom, independence, and control over environment*

Decisions to seek professional care did not always translate into immediate action. For many, the notion of care-seeking implied immediate hospitalisation, and being in hospital signified a loss of freedom, independence, and control over their environment which led to feelings of frustration.

In some cases, participants described long periods of utilisation delay (time between decision and contact with health professional) when symptoms occurred in the evening, or over the weekend. For example, despite suffering a broken hip on Friday, this participant delayed seeking care until Monday to avoid the perceived chaos of a weekend admission.

> *They say 'why didn't you call us earlier?' when I broke my hip. I said 'Simply because it was a Saturday night, no, Friday night' I said 'do you think I'd call you then? No'. I didn't call them till the Monday! Well Friday night is disgusting in emergency. I was there Friday Saturday. I don't know what Sunday is like. I just give Sunday a miss too. But I've been in there Friday and Saturday nights and I never want to go back there again. And its too much pressure on the staff as well! When you got all these bloody stupid drunk people want to fight, and addicts and everything...nope its no fun in that emergency department on Friday and Saturday nights. (Participant 7, female)*

Although an example not directly related to HF symptoms, it is possible that such attitudes towards weekend admissions would not change in the case of HF-related symptoms.

In another example, despite positive experiences with providers, other disruptive patients on the ward cast negative light on the hospital experience, in general. Being forced to deal with rude and disruptive patients in nearby beds led to feelings of annoyance and frustration with the hospital environment.

> *'...But, overall its been incredibly positive however it is frustrating when you meet a certain patient that's ah...that thinks the hospital owes them something or that they are inconsiderate of other patients. That really gets on my nerves...and they're rude to the other patients, they're rude to the staff as you might have seen. (referring to troublesome patient in opposite bed) That's to me, that went on overnight. Its been*

> *going on for about a few days. I was saying 'just calm down, relax mate. That really, really gets on my nerve. I have no (inaudible) even though he's not rude to me, that patient, I said I don't want to see it. You know what I mean.' (Participant 9, male)*

The hospital environment was not one participants wanted to remain in, causing participants to question and negotiate with themselves whether it was worth remaining in hospital for treatment.

> Just because it...it makes me want to...occasionally I want to discharge myself. I truly want to go home but then again I can't because my condition is quite serious. (Participant 9, male)

This illustrates how deeply the hospital environment affects patients, which is something that may be overlooked as an important factor impacting decisions to return. This participant explained that the frequency of hospitalisation involving these unpleasant encounters made it more difficult to cope with. He negotiated the pros and cons of receiving treatment despite it being in an environment that frustrated him.

It was also noted that the experience of being in hospital meant a loss of independence. For one participant, the desire to maintain in control of her environment contributed to her preference to seek care with her GP and avoid hospitalisation. She described it as a way of maintaining freedom as opposed to being 'stuck' in hospital for an unknown length of time.

> *'Um...I feel like you still have your freedom (laughter) in terms of being able to continue with your day to day, and hopefully try and manage it that way. I think you feel... like the independence I guess. So you sort of feel happy, when you're in hospital I think a lot of that is taken away. You're reliant on a lot of other people organising things for you and you don't have any real control over the time or you know, it takes what it takes.' (Participant 13, female)*

This participant explained that she would recommend to others to seek care at the GP if they were ever experiencing any symptoms because it seemed like the ‘softer option’ as a sense of freedom is not lost in the process.

> *‘I'd tell them to go to the GP. I think unless its directly relating, you don't know. I'd just be going to the GP. It seems like the softer option to be honest…Well you can come and go (laughter). You know and you're not sort of locked away or you know. It’s all about the freedom (laughter)’* (Participant 13, female)

### *Perceived system delays lead to avoidance behaviours*

A number of participants also described system delays in relation to inefficient processes in hospital, as well as issues around accessing care, which was a particular problem for rural-dwelling participants. Perceived system delays, again, led to feelings of frustration which resulted in avoidance behaviour.

Involving more staff than necessary was perceived to contribute to inefficient service provision.

> *‘…Doctors would come down and say oh look I...and as soon as they say you know 'I'll get my registrar or get...' you know its going to take days, hours and they come down and they say look yeah I'm so and so's registrar and you know I'm sorry I should have been here yesterday. You know as I said to you there’s this great big delay process and then everyone accepts it. Why is there this delay? Why do they take a day just to get back to you? You know, what is the problem? You know, is it them getting the information from the doctor? Or is there too many people or....? Which you know, I don't know, but I wish someone would travel round with the doctors and the registrars and find out why is there such a delay. Everyone accepts it, you know. Everyone says oh well you know, we'll take you down for an X-ray today. Well, sometimes its the next day.’ (Participant 11, male)*

This participant expressed a sense of frustration, as he could not understand why multiple people needed to be involved for a particular task. He perceived large teams to be inefficient, and provided no utility except to 'palm tasks out' to others.

Frustration with experiences in hospital can become magnified when admissions were frequent and often lengthy. The following participant expressed a sense of exasperation about the quality of meals in hospital, incompetent staff, and inefficient care during his multiple stays in hospital.

> *Well, in the hospital you normally...like I've been in there for the long term. I've been in there for 2 weeks, 3 weeks and its a long time you know. The food is average, some of the nurses aren't very good… if you hit the button, they don't come there very quickly because at night there's only maybe one on the shift and they might be looking after someone else. And they don't exude any confidence you know, they'll tell you something and they'll...all they want to do is fix you and get out and go and sit down and wait for something else to happen. You know, they don't have time to tell you what's happening to you or anything like that.' (Participant 11, male)*

Timely delivery of care on the other hand made participants feel safe, calm and highly satisfied with care. For this participant, this occurred in the context the ambulance. He described how the immediate and efficient care provided by paramedics facilitated subsequent care seeking. Trust in their ability to immediately relieve symptoms motivated this participant to seek professional care to relieve symptoms, anxiety, and ensure security and a sense of calm.

> *'Ahh...pretty worried...of what was going to be the outcome (when I was getting symptoms) but the ambulance turned up really quickly and they were really nice blokes and they just gave me that assurance of being there and you know, you could stop sweating, you could stop worrying, just get in the ambulance.' (Participant 11, male)*

> *'he (the paramedic) was really fast and efficient and I was in that ambulance in like 5 minutes I was in hospital and he you know belted me with some stuff and I just felt so*

> *much better. Out of, I suppose that would be the best thing I've learnt is getting in an ambulance. You just don't believe how comfortable and once you get in there its so good.' (Participant 11, male)*

Despite being aware that nothing besides surgery would 'cure' his condition, the fast pace of paramedic care and immediate relief of symptoms motivated this participant to seek help. Having had multiple positive experiences in the past, he explained how he feels secure and in competent hands in the ambulance, which enables him to relax and avoid panic. Perceived system delays experienced in hospital provided a stark contrast to experiences in the ambulance. He made comparisons between receiving care in both contexts and described feeling somewhat overlooked by providers hospital, whilst in the ambulance, paramedics were able to give their full attention to the one patient without being distracted.

> *'Well sometimes you do (wait around idle in hospital) and you know because they've got so many people and then they can't get you a bed and da-di-da...and you know, it does happen. But in an ambulance they can give you morphine they can give you stuff under your tongue and you know that something...you know, he can't walk away and say I'll just go and see what the doctor wants because he is sitting in the back the ambulance and the other bloke is driving. He can't walk away. He can't delay it. I mean, he's Johnny on the spot. He's the one who's got to fix you.' (Participant 11, male)*

#### *Living rurally: limited access*

Participants who lived rurally described difficulty accessing appropriate health services, which played a role in their decisions to seek professional care. These participants often required transfers from their local hospital to better equipped specialist facilities. In the following example, this process was described as being a 'drag', lengthening the entire experience of being hospitalised, which led to avoidance behaviours.

> *'If I go into emergency at Wyong, anything to do with the heart they just transport you to North Sydney, so (chuckles) its a bit of a drag.' (Participant 13, female)*

Another participant who lived rurally described the limited access to appropriate health services, needing to travel an hour to see doctors.

> *'I say bugger it, I'm going to go down to Dubbo. Or even Bathurst or somewhere just to see a doctor. It's only about an hour drive or whatever. So, go and see a doctor...stay the night, back the next day…because Western Area Health is a bloody joke. It's an absolute bloody joke.... (Participant 15, male)*

### 6.7.3 Patient-provider interpersonal relationships

*Incongruence with providers affects trust and leads to avoidance*

Lack of congruence between patient and provider beliefs impacted symptom appraisal and led to delayed care-seeking. Moreover, in extreme 'crying wolf' situations, dismissal of participant's concerns led to complete collapse of trust in providers and avoidance behaviours.

It became clear that participants relied heavily on their providers for information about their condition. They used this information to help problem solve and discern what symptoms meant and what to do, and even adopted providers' views entirely without question. The power of the physician's words therefore had great consequences on some patients' health behaviours. If a doctor was concerned about a particular symptom, participants perceived they also had reason to be concerned. This also operated in reverse, where a doctor's dismissal of symptoms led to participants also ignoring symptoms.

For example, one participant described seeking professional advice after suffering an acute exacerbation of breathlessness whilst on a cruise only to be told nothing was wrong. Despite suffering symptoms thereafter, he ignored them, as he was told that there was no issue. It was not until he collapsed that he was treated in hospital.

> *‘He (GP) says "there's nothing wrong with ya". So alright, then I left to (inaudible?), and ahh when I went back to Papua New Guinea, I always had problems, I still had problems walking up an incline without running out of breath. And um, so I didn't think much about it.’* (Participant 5, male)

This highlights how symptom appraisal is affected by provider’s beliefs, and how symptoms can be ignored when sensations are incongruent with provider’s views.

In another example of incongruence with providers, rather than willfully adopting providers’ views about symptoms, a number of participants described ‘crying wolf’-type situations where providers dismissed participants’ personal health concerns as unjustified. These experiences were severely traumatic and damaging to patient-provider interpersonal relationships. These participants no longer trusted providers to listen and address their needs and feared they would not be taken seriously. This ultimately impacted patients’ decisions to interact with the health system in general, as they perceived that doctors lacked compassion.

For example, one participant described his previous experience of being told ‘you look fine’, which led to avoidance behaviours. Not being heard or believed impacted decisions to interact with the healthcare system, as he did not want to be rejected by providers for what he perceived were legitimate concerns.

> *'”’it appears there’s nothing wrong with you'. ‘I'm telling you! I've got this, I've got that.’ It depends on where you go (which hospital).”* (Participant 10, male)

In another example, a participant described a traumatic series of events involving suffering multiple heart attacks but being turned away from hospital and not believed each time. Her concerns were instead rejected and misattributed to unrelated causes.

> *‘…well April 2013 to August 2013 I had 5 heart attacks and the first 2 I went to hospital, taken by ambulance to hospital and um, and was turned away both times because they thought I was having a panic attack.’* (Participant 8, female)

She explained how not being ‘heard’ after the first two incidences led to delayed care-seeking in the third instance, deciding to ‘put up with it’ (heart attack symptoms) rather than seek professional care. Although these symptoms were nocturnal, which impacted her decision to avoid seeking care, she presumably also doubted her own judgment about the severity of symptoms, given her previous experiences.

> *‘The third time was in the middle of the night and I was (living out of home?/away from the phone?) so I just put up with it and suffered through it’ (Participant 8, female)*

Her fourth experience, once again, involved a situation where her symptoms of MI were misattributed to unrelated causes.

> *And then the 4th time, I went to see the GP, the day after and he was convinced I wasn't having a heart attack and he sent me for neck and shoulder ultrasounds instead, and then the results came back he showed me 'there it is, you've got spurs and all sorts of other thing on your neck and that’s why it’s sore'. (Participant 8, female)*

This participant had previous experience as a cardiac nurse, which helped her stay strong about her beliefs despite incongruence with what her providers perceived to be the issue.

> *And I knew there was something else going on because I had other symptoms of heart attack ...and the idiot, not knowing that I used to be a cardiac nurse 30 years before that...a lot of things change, but not in (inaudible) heart... (Participant 8, female)*

It was not until her fifth heart attack that her concerns were addressed and promptly treated with appropriate life-saving surgical intervention.

> *‘…by the 9th of August um, I had another one, and by that stage I was having pulmonary oedema so I could feel....well, now I know that’s what it was...I could feel my lungs were sort of vibrating kind of thing. So I called the ambulance and that’s when the paramedic worked out straight away that I was having a massive myocardial infarct. And then they switched on the (inaudible) things so they could get the instructions from the cardiologist*

> *at the cardiac cath lab at Liverpool so then they could just get me straight in there so within 15 minutes I was there. And that’s what saved my life. (Participant 8, female)*

Although this participant strongly suspected she was suffering heart attacks in the previous instances, it wasn’t confirmed until she underwent routine scans following the most recent event. Results from the scans not only provided her with proof of each event, but also triggered strong feelings of anger, underlining that her concerns were real and she was not listened to. She explained how her upbringing impacted her views about the importance of being heard, which made it all the more difficult to come to terms with the fact that in a life threatening situation, the people who were supposed to help you wouldn’t listen.

> *‘…my parents were teachers so they always allowed us to be heard, even though they couldn't do anything or whatever, but, to be heard and to be believed. So when my life is on the line and you know, if you can't be, um, listened to by your own Doctor, well what the hell are you doing here?’ (Participant 8, female)*

Her previous ‘crying wolf’ experiences abolished any sense of trust or belief in providers to help her in times of need, leading to avoidance behaviour. Needless to say, whilst she had the utmost confidence in being provided with high quality biomedical care, she perceived the human element is severely lacking in the medical profession. She expressed her belief that providers are not in touch with patient’s psychological wellbeing.

> *‘But you know what’s really funny, is there was one sentence, because they are aware that I have anxiety, in my discharge notes from Liverpool it says 'patient was teary and emotional, yet denies anxiety' and that was it... and I'm thinking you've got a pissy sentence like that for one...one sentence regarding my mental health?! My body is falling apart and you've got one sentence??! And I'm thinking yeah, and even the guys here as marvellous as they are...mental health euuu (makes face) that’s yucky. They...and you can see they don't know what to say, they don't know what to do 'we can get a social*

> *worker' and I'm thinking (says aggressively under breath) one more person tells me about a friggen social worker, I'm gonna smack em in the head! (laughter)' (Participant 8, female)*

For this reason she did not look to providers for support and compassion, but rather looks to pastoral care in hospital.

> *'…no, you can't ask for compassion from doctors though… they are too busy doing something else.' (Participant 8, female)*

### *Lack of benevolence, competence, and perceived discrimination leads to avoidance*

Negative patient-provider relationships were described in relation to perceived lack of benevolence, perceived discrimination, and incompetence, which led participants to believe self-management was more effective than professional care.

Perception of providers was not only influenced by most recent healthcare experience, but also early memories of interaction with providers and hospitals. For example, one participant suffered complications from minor surgery when he was a child, requiring subsequent operations for the next 5 years. This experience shaped his perceptions of health care and providers, adopting the belief that they lacked compassion looked out for their own best interests first, which were perceived to be financial. Another participant shared similar perceptions after his experience with the accountant of a specialist who attempted to settle an invoice at a time perceived to be inappropriate, and in a threatening manner.

> *'The anaesthetist didn't even come and see me! And he was, Serra, the worst anaesthetist of all time! His wife was the accountant and 2 days after the operation, she came up with an invoice and she said we'd like to settle before you leave the hospital. And she was just a horrible horrible piece of work. She would ring up and say look, you still owe me two hundred dollars, you know, if you don't pay me by tomorrow I'll take you to court and all that sort of stuff. (Participant 11, male)*

These previous unpleasant hospital experiences with doctors who lacked compassion led to avoidance behaviours.

In other cases, previous negative hospital experiences contributed to perceptions that doctors were incompetent and care received in hospital was completely unhelpful and detrimental to one's health.

> *'I went out of that place sicker than I went in.' (Participant 7, female)*

This led to the belief that self-management was more effective than professional intervention. For example, the following participant experienced perceived unhelpful treatment in hospital, became severely symptomatic post-discharge, and thus avoided calling for help at all costs. She maintained self-care management at home despite how difficult it became for her, as it seemed a more plausible option than being admitted to hospital where she perceived she wouldn't receive the care she needed anyway.

> *'I had the most vile eruption from my stomach, and that went on for 3 days. And the messes I had to clean up, and I was too weak to clean them up and, but I had to, and this went on and on you know, and I wouldn't contact them, I wouldn't go back into hospital, because I knew I had to do it myself to get anywhere. So I bought Sustagen from my chemist, he'll deliver anything to me. And I got myself going, after 2 weeks I finally got myself going on the right way up. I was too weak to do anything most of the time. Had my Sustagen, kept, had a nap 3 times a day, and I started to get better, I started to get stronger. And then it took me about another 3 weeks before I felt like I could do anything.' (Participant 7, female)*

She firmly believed that self-management was more effective than any treatment she could receive in hospital.

> *'I still can't eat much. I'll try food now and again. I'm still on Sustagen, it's the only thing that's keeping me alive. Not the doctors for sure. (Participant 7, female)*

It was therefore not surprising that this participant delayed seeking professional care when symptoms worsened, as she perceived it would cause more harm than good. The accumulation of negative health care experiences resulted in non-compliance behaviours. This participant no longer kept up with appointments, due to the sheer frustration and sense of despair resulting from her previous interactions with the health system.

> *'Well I stopped going to the diabetes clinic. I told them I was going to have a sabbatical. I just couldn't take it anymore. The same thing all the time, giving me the same x-rays, you name it, I had everything done.' (Participant 7, female)*

Another negative healthcare experience, impacting patient/provider interrelationships was perceived discrimination, namely due to smoking status. This participant felt as though she was not receiving the same treatment as the other patients on the ward because she was a smoker.

> *'And I thought, hmmmm there's something in this you know because I'm just being ignored, totally. And um then I thought ahh - it's the smoking. We shouldn't help you because you're smoking. They won't come out and say it, but it's just the feeling when you see other patients and you know what you're getting and your totally wiped. And I'm just jack of it quite frankly.' (Participant 7, female)*

This caused feelings of great frustration and annoyance, which led to avoidance behaviour.

### *Relational continuity, access, and effective communication impacts patient-provider interpersonal relationships and subsequent decisions to interact with health services*

It should be noted however, that amidst negative experiences, some participants did remain thankful and felt indebted to the medical profession. A focus on how treatment had ultimately been lifesaving facilitated this positivity.

> *'I've been coming here for about 4 years. So you develop an affinity for the place to see what's the positive and the negative… but predominantly now I feel...I owe my life to the medical profession.' (Participant 9, male)*

Positive provider experiences were not forgotten, as key individuals (providers) helped reshape, to an extent, a positive view of health professionals despite negative experiences. Participants described positive patient-provider interpersonal relationships in terms of care being accessible, involving effective communication, and providers ensuring relational continuity, which together made participants feel well supported and helped build a sense of trust. Furthermore, positive patient/provider relationships incorporating trust, compassion, and effective two-way communication made participants more comfortable to reach out to their trusted providers and this facilitated care-seeking behaviour.

Positive patient/provider interactions that influenced care-seeking were not only described in relation to the GP. Another participant described how her positive relationship with the cardiac rehabilitation nurse facilitated care-seeking. The nurse made herself available to this participant at all times, ensuring the participant felt comfortable to contact her at any time she needs. This abolished her fear of being perceived as a burden by calling for help.

> *'…she makes herself available to me at any time.' (Participant 8, female)*

Similarly, another participant described how established trusting relationships with his GP and nurse encouraged him to reach out in times of need. Both the nurse and GP made themselves accessible to him at all times, however, he preferred to call the nurse as a first line of action when symptoms worsened, as he perceived that nurses make more time for their patients.

> *'Because the doctor is always busy. The nurse, he drop everything. And that's it, he goes straight on you.'* (Participant 14, male)

For this participant, calling for help was the chosen method of coping time and time again due to its success in alleviating physical symptoms and reducing panic and anxiety, illustrating the constant feedback appraisal that plays a role in care-seeking decisions.

In contrast, some participants perceived doctors lacked the time to talk to patients, making them hesitant to seek care and voice their concerns. Lack of communication was linked with perceived incompetence and low patient satisfaction, and will be discussed in further detail in Chapter 7. One participant perceived that staff did not have time to communicate with patients as they and were occupied by other duties.

> *‘Yeah, they don't have time. They got, you know, at night I don't know what the staffing levels are, but I'm pretty sure they must be low. You know and they...all the night nurse does is make sure that everyone gets through…late at night into the morning and that’s their job. You know, they walk around with their torch and if anyone you know yells out they make sure they are alright, give them a sleeping a tablet, its alright, and that’s their job.’ (Participant 11, male)*

It should be noted that in some cases, this participant was highly satisfied with the care provided. Efficient nurses who were competent and genuinely caring provided the best care in his opinion. He explained both ends of the spectrum.

> *You can have, I've had really good nurses who are, you know, who are good and are in there fixing you up if you ask for something. They are in there and they know what they are doing, but other times you get a team of nurses and they are slow and they don't know what they are doing...and they don't seem to care. You know, you can go from very good to very bad. (Participant 11, male)*

Whilst easy access to care and effective two-way communication were noted as major facilitators of positive patient-provider relationships and a sense of security, relational continuity, as in being provided links to future care, was also highlighted as an important aspect of care. For example, the following participant explained that he had been highly satisfied with the quality of his care, as he perceived he was always referred to appropriate services whenever he needed.

> *'I feel that I've got a really good doctor here in Sydney that I've gone to for the last 7-8 years that cares about me enough to put me into the right direction meaning to a specialist, to have scans, to do whatever.' (Participant 12, male)*

Positive relationships with his doctors gave him a sense of confidence and feeling supported. Genuine caring relationships and continuity of care involving follow-ups and close monitoring were a large part of this feeling.

> *'So that makes you feel confident…that there are doctors and people there that do care… I'm going to the doctor this week (laughter) and I'm going to the bloody specialist next week…it's never-ending. If they didn't care, well oh yeah we'll see you in 6 months, if anything happens just give us a buzz kind of thing. But they are monitoring me closely.' (Participant 12, male)*

He stressed the importance of these patient-provider relationships in making him feel supported over time, particularly given his uncertainty regarding the future.

> *'…this is probably for you know, who know how long I've got. No one knows how long anyone's got really. But if I've got you know like a good doctors there and a good specialist and nurses and that, do you know like, and I have to deal with them and they have to deal with me so, I know that there's that support there. It makes you confident in the medical field' (Participant 12, male)*

## 6.8 Chapter summary and conclusion

This chapter has identified patient, provider and system-related factors that impacted participants' decisions to seek professional care, and described in what way they influence care-seeking decisions in an Australian HF population. The interview data revealed delayed care-seeking in all three stages, where participants struggled to link their symptoms with illness (illness delay), decide whether symptoms warranted professional intervention (appraisal delay), and had difficulty deliberating whether the care was worth the cost in term of the loss of freedom, independence, and perceived burden that was associated with care-seeking (utilisation delay). Part of the cost of seeking care was also interacting with health services and providers, which participants wanted to avoid due to previous negative healthcare experiences. Findings revealed that much of the patient-level factors identified fit within the SRM, whilst other provider and system-related factors are underrepresented in the model. Finding from this chapter are summarised below.

- Despite good levels HF knowledge and high levels of self-efficacy, as exemplified by 12/15 and 87.5/100 scores, respectively, participants described delayed care-seeking due to uncertainty about the cause and consequences of symptoms and preferences to avoid hospitalisation.
- Recognising symptoms was challenging for those who had grown accustomed to them over time. New and unfamiliar symptoms were more likely to initiate self-regulatory processes compared to old symptoms that became part of what participants perceived as normal.
- Painful symptoms were less easily tolerated than other symptoms, were perceived as more serious, more easily attributed to the heart (in the case of chest pain), and prompted timely care-seeking.
- HF symptoms posed a threat to the identity of participants whose representations of heart disease were not congruent with how they perceived themselves - led to emotion-focused coping strategies such as avoidance and denial.
- Comorbid conditions and previous experience with physical injury and capacity complicated symptom appraisal. Familiar symptoms led to rapid appraisals and greater confidence in appraisal. When symptoms were attributed to the heart, the seriousness of deterioration was recognised, and immediate care-seeking ensued.
- Persistent symptoms that interfered with daily activities (perceived physical consequences) negatively impacted quality of life and prompted care-seeking.

Perceived social consequences included the perception of being a burden to others and role loss and competing responsibilities, which often caused participants to feel reluctant to seek care.

- Despite perceived low level of personal control, some adopted an active approach to self-management and took ownership of their condition to cope.
- Hopefulness about the likely trajectory of symptoms (i.e. that they would get better) often led to coping with uncertainty in a passive manner (i.e. 'wait and see' response). In contrast, anxiousness about the unknown often led to approach coping strategies, where participants took an active approach to alleviate anxiety and fear.
- Reflection on previous experiences of delay led to positive attitudes towards seeking timely care in the future.
- Other people (friends and family) often facilitated symptom recognition and care-seeking.
- Having an a-priori action plan helped participants make decisions about seeking care with less uncertainty. Action plans were, in most cases, described in relation to symptoms of heart attack, rather than HF.
- Preferences for continuity with hospitals and providers impacted care-seeking decisions. Maintaining continuity with known providers and hospitals often took precedence over receiving timely care.
- Previous traumatic experiences in hospital involving physical and emotional turmoil led to avoidance behaviours.
- Hospitalisation represented a loss of freedom and control over the environment, which also contributed to avoidance behaviours.
- Perceived system delays led to feelings of frustration and also contributed to previous negative experiences in hospital. Rural-dwelling participants noted issues around access to appropriate health services that contributed to delayed care-seeking.

- Positive patient-provider interpersonal relationships involving trust, compassion, continuity and effective communication facilitated care-seeking, whereas, perceived paternalism, discrimination and lack of benevolence led to avoidance of services and providers.

# Chapter 7

# Preferences for heart failure information delivery and perceptions of patient-provider communication

## 7.1 Introduction

The previous chapter described in what way patient, provider and system-related factors influenced care-seeking in Australian patients with HF. This chapter presents interview findings relating to participants' perceived gaps in HF knowledge, patients preferences for HF information delivery, and perceived barriers and facilitators of effective patient-provider communication to answer the fourth research question: *What are Australian patients' perceptions of and preferences for HF information delivery and patient-provider communication?* These results are separate to, and also integral with those presented in the previous chapter. Whilst presented separately to the care-seeking findings, these results are inextricably linked with the decision making process and influence many of the aspects discussed in Chapter 6.

## 7.2 Perceived gaps in heart failure knowledge

Throughout interviews it became evident that certain aspects of HF and HF management were unclear to participants. Participants openly acknowledged that they did not understand enough about their condition, despite living with it daily as conveyed in the following excerpt:

> *'I don't know as much as I should.'* (Participant 9, male)

Specific aspects that were not well understood included: the use of appropriate labels (clinical terminology); pharmacotherapy; symptom recognition, appraisal and management; and the cause and chronicity of HF. Participants recognised these gaps in knowledge, and expressed an unmet need for more information on these topics. For example, the following participant explained how the appropriate term for her condition was learned only through attending cardiac rehabilitation, resulting in a sense of shock at her diagnosis.

> *'…she (cardiac rehab nurse) said 'you're here because you've got chronic cardiac failure'. 'Ahh no sorry, I'm probably in the wrong room'. No, sit yourself down, that's what you've got'. That just really, just REALLY blew me away. Totally.'* (Participant 8, female)

Others felt relatively well-informed about clinical terminology and pathophysiology pertaining to their condition, but expressed a need for more information about pharmacotherapy.

> *'I don't think I know enough about the drugs I'm taking, I must admit.'* (Participant 11, male)

Symptom recognition and appraisal was also noted as a weak area of HF knowledge. One participant explained the need for clear description to help identify the warning signs and symptoms of HF exacerbation, and most importantly, what to do when they occur.

> *'…I still don't know exactly what I should be looking out for so I'm hoping by the time I am discharged that someone will have sat me down and say, Dave, these are the symptoms of heart failure and you need to look out for these symptoms. When you do experience them, this is what you should do…apart from checking in (to hospital), prior to checking in… what do I do.'* (Participant 9, male)

The need for a specific action plan detailing the best action to take in case of symptom exacerbation (before the need for hospitalilsation) communicated by a credible source was emphasised as an important unmet need.

> *'Yeah I want to have a plan. Because I need to know, when I do get a symptom, what do I do? And not what do I do, what does the hospital recommend that I do.'* (Participant 9, male)

Participants wanted a clearer understanding of when symptoms warranted professional care and suggested the need for tailored information to help evaluate the seriousness of symptoms.

> *'… You've got swelling and you're thinking oh, can I be bothered going to the GP…it'll go down after a few days or, lets wait and see - is this a problem. You know in some cases they might say, for you, with this condition, its more of a problem than someone else. So it would be nice to be able to find...you're not asking it to do a prognosis on you but try and work out should you be concerned or not.'* (Participant 13, female)

Participants also expressed confusion about the cause of their condition and how long it would last. In the following example, the pathophysiology of HF was understood, although this participant expressed a sense of confusion about its cause, and did not comprehend its chronicity.

> *'…They've explained that it's the weakness of the heart and the fact that its working so hard and it's enlarged, it just puts more pressure on it. So there are still bits that you don't know. I don't know what the virus was that attacked it in the first place…and why it doesn't sort of go back to being normal...'* (Participant 13, female)

This participant perceived she was suffering from an acute illness rather than an underlying chronic condition and therefore questioned why she had not yet recovered. Her expectation is that she will recover, when the prognostic reality is that full recovery, as she perceives it, is not an option. This quote reveals that her expectations are out of line with her prognosis, but she did not know this.

Whilst most participants expressed the need for practical self-care information that would help them understand different aspects of their condition such as the cause, its treatment, and the meaning of symptoms, one participant expressed a need for more information about how to cope emotionally. This participant suffered fatigue daily and wanted more information to help accept the consequences and manage the feelings of frustration that ensued as a result of fatigue.

## 7.3 Preferences for heart failure information delivery

Whilst patients recognised a number of gaps in HF knowledge, they suggested a number of ideas to facilitate effective communication to support the development of a better understanding of their condition and management. In addition to describing their preferences for how HF information could be relayed most effectively, they also described their preferred sources of HF information. Participants described their preferences in relation to information retention, the need for tailored and personal information, and the ability to refer back to information post-discharge. Their preferences for how information was communicated revolved around these main themes.

Most participants expressed a preference for information to be delivered face-to-face to facilitate information retention.

> *'…I'd like it to be person to person. That's what I like actually. I know that face to face contact, I feel I can absorb more information…'* (Participant 9, male)

Dissemination of information over time in hospital rather than at one point in time only was also suggested as a way to facilitate information retention.

> *'Yeah (be told information on discharge) and even part way through the process because I was in there for 2 weeks so there is a length of time that you think you could be...that information could be disseminated over a period of time instead of one hit and you're going to take in only that much and the rest will just go *shunk* over your head. But if you were able to address bits in chunks, it would be easier.'* (Participant 13, female)

This participant described how information delivered all at once may challenge retention and hinder her ability to self-manage at home post-discharge.

> *'Usually when you first get told something its all new to you and you only retain such a little amount and then its like 'oh they were talking about that' but what implication does that have for me? What do I need to not do, or do? I just think there should be a*

> *better way of addressing that instead of letting you just go off on your merry way and you've sort of got no real idea of what you should be doing or what you should be looking out for'* (Participant 13, female)

A combination of verbal, visual, and written information was suggested as the most effective way of communicating HF information, with emphasis on the importance of having written information to refer back to post-discharge. Visual information was described as an effective way of conveying health messages clearly in a population that may not be well educated.

> *'Well, if its not clear they should have something in writing, right, with drawings. And explain on that, exactly what they are going to do, and what they plan to do…. A visual would be ideal. Not only for me. I'm a mediocre educated, but to get someone less (than) me that's not educated, then you got a problem.'* (Participant 5, male)
>
> *Umm, verbally and written. I prefer initially just to sit down with one of the doctors or the specialist or nurse to have a talk with me, but I prefer it to be in writing so that I can refer to it, take it with me…take it home with me. I know I can do it online but that's ...you know I don't want to...I want it directly. I prefer it directly from the doctors that are treating me. If they can sit me down and say this is your condition...'* (Participant 9, male)

Participants also stressed the need for HF information to be tailored, relating specifically to their medical history/comorbidities, and thus expressed the preference for this information to be delivered by their treating doctors. A number of participants did not identify as the 'typical' patient with HF and therefore felt that general information was not relevant or enough for them. For example, the following participant suffering multiple co-morbidities specifically wanted to know how HF was affecting him in the context of his pre-existing conditions.

> *'…To be related to me specifically, as in, to do with my cancer… how does it effect my cancer…I'm not your typical patient because of the cancer.'* (Participant 9, male)

This participant was already struggling to make the distinction between cancer symptoms and HF symptoms, and wanted a clear explanation to help dispel confusion and understand how his comorbidities may impact each other. His desire for tailored information specific to his case reflected his perceptions of being an atypical patient with HF. It should be noted however, that the ‘typical’ patient with HF does, in fact, suffer multiple comorbidities. This is something we need to consider in patient education.

Another participant expressed the desire for tailored information relating specifically to aetiology of HF.

> *‘…I see at the transplant thing that’s quite specific in terms of… I guess they know what they are addressing instead of being quite broad in the spectrum because when you fit into...what is it...some sort of… like they'll say ok I've got cardiomyopathy but I'm not ischaemic or...you know, you then know, OK, I fit into that bracket. So I would like to get information specifically for people like, you know, with my condition.’* (Participant 13, female)

Being younger than the average patient with HF, a woman, and not suffering ischaemic cardiomyopathy (which is the most common form), this participant struggled with finding where she ‘fit’ within the syndrome of HF. She felt the information available was too general, only catering for the ‘typical’ patient, and therefore wanted more tailored information.

Finally, the need for more self-care information and support upon discharge was also described, highlighting the value of relational continuity, or being provided links to future care, in this population.

> *‘…if you were discharged and they said look, if you've got any questions here’s our website or this is what we put out, would be useful.’* (Participant 13, female)

### 7.3.1 Sources of heart failure information

In terms of preferred sources of HF information, it became clear throughout interviews that credibility of information was of utmost importance to participants. Providers were perceived as the number one preferred source of HF information. Their credence as a trusted source combined with their ability to offer the most tailored HF information, as described in the previous section, further reinforced this preference. Familiarity with patient medical history was perceived as advantageous, enabling providers to impart the most appropriate healthcare information and advice. Additionally, positive interaction with providers imparted positive feelings of security that encouraged interaction with them. Positive interpersonal relationships involving mutual respect and compassion, effective communication, and ease of access to primary care made the GP the preferred choice for information for the following participant.

> *'Usually (I get information) from my GP. She sits, oh she never rushes you, never rushed me. If I rang up at a minute's notice she would take me straight in to see her and she is very good at explaining things too.'* (Participant 3, female)

Despite the preference for case-specific information from providers delivered face-to-face, participants did not exclusively rely on them for information at all times. Post-discharge from hospital, online and telephone services offered by disease-specific organisations were also noted as credible sources of information that were utilised by some participants. The following participant described how written information produced by a reliable source to avoid searching the Internet would help clarify uncertainty about symptoms.

> *'...having a booklet that maybe covers some basic points. I'm sure these aren't unique…if it was general information that you could get in booklet form or even through the website would be quite useful that you could go to and its not Dr. Googling it. If it was put out by an institution so you can rely on the information being accurate would probably be really useful because there isn't anywhere to go to when you're thinking I*

> *don't understand why this is happening but it doesn't feel right and you can't put your finger on it.* (Participant 13, female)

In most cases, the Internet was perceived as an untrustworthy source of information and to be avoided.

> *'Well, I don't want to go to the Internet because 2 or 3 clicks and you're clinically dead. So I don't want to go to the Internet.'* (Participant 6, male)

Others, however, were not completely averse to using the Internet, but interpreted this information with caution, recognising how it could easily be taken out of context.

> *'If I was concerned I could look it up on the Internet. But you know I tend not to because as they say there's you know, you hear about these Google doctors and everyone thinks that you know they've got this condition because they have read it on Google or something like that. I tend not to do that (chuckles) really.'* (Participant 12, male)

In other cases, participants felt the Internet was their only choice when questions and concerns about their condition arose outside of scheduled visits. Again, it was described that one should take heed with information sourced online.

> *'I either ask the GP or I ask the cardiologist when I see him but I only see him usually twice a year, sometimes more if there is any extra testing but usually its twice a year. So I would Google it (laughter) to you know.... you understand that the information you may get you can't take that as the gospel, you need to check that up...'* (Participant 13, female)

Only one participant perceived the Internet as the most useful source of information. He described that he would reserve specific questions relating to his condition for his cardiologist, but all other questions for the Internet.

Attendance at cardiac rehabilitation programs was noted as a major contributor to improved HF knowledge and understanding for some participants. These participants described that cardiac rehabilitation served as an invaluable resource for open communication and support.

> *‘We had about 30 people who had battery or open heart and they explained to you and you ask all the question. Any stupid question or good question. Yes, it change your life.’* (Participant 14, male)

## 7.4 Barriers and facilitators of effective patient-provider communication

Participants predominantly relied on providers as their main source of HF information, however, most participants pointed out that communication between providers and patients could be improved. A number of barriers and facilitators of effective patient-provider communication emerged from interviews, with certain factors acting as either a barrier or a facilitator depending on the individual patient. These findings are detailed below.

### 7.4.1 Facilitators of patient-provider communication

Participants described a number of factors that facilitated patient-provider communication including: patient note-taking during consultations; consistency of information from providers; and positive patient-provider interpersonal relationships involving trust and support.

#### *Patient note-taking facilitates information retention and management continuity*

For example, one participant explained that, together with her husband, she started to write things down during consultations with her health providers as a way of remembering vital information. She explained that this was also a great facilitator in communicating important facts to other health providers ensuring management continuity.

> *‘This time around we are writing things down so... then you can back track and you can go through. It’s a bit like when they said ok, you're defibrillator can go through the MRI scanner, but one of my leads can't. So, you know, its good to know in future that if you were in a situation, my husband and I both know that I can't have an MRI because of the lead.* (Participant 13, female)

### *Consistent information is the most powerful*

It was also noted that key content delivered consistently by all providers was most effective. For example, one participant described the coherence of a message delivered from multiple providers about not hesitating to call an ambulance when symptoms worsened. Not only did this make him feel supported, but also gave him reason not to delay seeking care when unsure. The patient did not have to weigh viewpoints, because they were all the same. They had a clear strategy.

> *'…its good that there's that support there and I now realise, coming from the doctor, the specialist and the nurse, that any problems - just ring an ambulance. They can decide whether its a problem or not.'* (Participant 12, male)

The effectiveness of the same health messages being relayed by multiple providers is highlighted, as the participant explained how this example of management continuity impacted his attitudes towards future care-seeking decisions.

> *'Straight onto the nurse then the ambulance, I wouldn't muck around.'* (Participant 12, male)

### *Positive patient-provider relationships facilitate open communication*

A number of participants described how established, trusting relationships with their providers facilitated open communication. Relationships incorporating trust, compassion, and effective two-way communication made participants more comfortable to reach out to their providers, namely those who made themselves easily accessible at any time of need.

> *'...I can just ring up and the girls (at reception) will just say come straight in, we'll fit you in, you know and she'll just fit me straight in she's very good like that. She's very very good. Very caring.'(Participant 3, female)*

## 7.4.2 Barriers of patient-provider communication

Barriers of effective patient-provider communication included: limited patient executive functioning; the use of complex language by providers; perceived lack of communication and concealment of information by providers; and patient-provider interpersonal relationships involving paternalism.

### *Limited executive functioning impedes effective two-way communication*

Limited executive function was a barrier to remembering health information, particularly clinical terminology. Difficulty recalling events and names including those to label symptoms, treatment, tests and diagnoses led to gaps in knowledge and impacted communication with providers. Difficulty labelling symptoms and instead using vague descriptions to explain events led to a perceived fragmented understanding of patients' concerns. In the following example, the participants' doctor was trying to ascertain what happened during symptom exacerbation, however, the participant struggled to remember labels and describe his symptoms, instead providing a vague picture of not feeling 'well'.

> *"I said "I don't feel well, I think you better take me down to the hospital" and that was it…Dr Moore come and see me and says you know "were you dizzy or were ya...?" I said, "I think I was", or woozy or what word he used or one of them. I said "No I think I was dizzy and you know, I didn't feel well".* (Participant 5, male)

### *Complex medical language as a barrier to patient understanding*

Participants also noted how complex medical language could impede patient-provider communication and affect understanding of the details of their condition. Contrarily, when participants spoke about effective provider communication where understanding was clear and shared, speaking in plain language was frequently noted as an important factor that influenced the quality of communication. For example, the following participant described how she appreciated the way her doctor relayed medical information.

> *'…because she just speaks....she doesn't speak in long words or anything, she just speaks so that anybody would understand what she was saying'* (Participant 3, female)

Whilst medical language was identified as a potential barrier to effective communication, asking for clarification was an effective way of mitigating this issue.

> *'He's usually pretty clear I think. If don't like the answering I tell him to dumb it down a bit so I can understand. Yeah. So it's always good to do. I mean they come up with these words like thoracic or all that sort of stuff and I say well what the hell is that? (laughs)'* (Participant 15, male)

### *Lack of communication: incoherent information leads to incoherent representations*

Heart failure information that was inconsistent, not detailed enough or incomplete led to gaps in patient understanding. Lack of communication and delivery of sufficiently detailed HF information left patients to connect pieces of information themselves, often from different providers, to construct the bigger picture. For example, one participant was simply told there was a black spot on his lung, which he later learned was a blood clot. He was left to determine how this information related to his symptoms. Using disjointed information from providers, he produced his own explanation of why he passed out, noting that nobody mentioned it could have been heart-related.

> *'...one of the things I didn't understand and I asked the Dr. I said "has that black spot gone?" and "what is it?" he said "oh that's a blood clot in your lung". Oh right. Then, that could have contributed to me passing out...if a blood clot blocks your air, your oxygen is down, and you'll be able to drop out. But, nobody told me, they would, said it was your heart. You got a problem with your heart.'* (Participant 5, male)

In another example, failure to explain diagnosis and management of HF in adequate detail led to a fragmented understanding of HF and general dissatisfaction with quality of care.

> *'...he said 'you've got a bad heart'. And I said 'well, can't the doctor come and tell me and explain it to me?' I said ' that's what I want, an explanation and to let me know what's happening!'. Nothing. And the next thing, one of the heart surgeons said to me 'I'll put in a couple of stents for you', I said 'that's nice of you'. (laughs) So I went down for another angiogram and they put a couple of, he put a couple of stents in my heart.*

> *And I even, to get to talk to him after the operation! It was just impossible! I wanted to book out.'* (Participant 7, female)

Due to perceived lack of communication, this participant's understanding of her condition did not extend beyond her knowing that her heart was *'very tired'* and that it was probably caused by plaque due to smoking. These examples illustrate how disjointed and perfunctory information from providers leaves patients to fill in the blanks about their condition, which may or may not be correct.

A number of participants perceived lack of clear and adequate information from providers in relation to pharmacotherapy and potential side-effects of medication.

> *'I don't think they do enough explanation of the drugs they are giving you. They come in and they say oh we'll give you this, this, and this. I've only really seen a pharmacist maybe once...no, twice or three times come in and actually explain to me what the drugs are. Its normally the nurses who come in and say "oh the doctor has prescribed this and this" and you ask the nurse and she says "oh its just for that". But they don't actually explain to you what 'that' is. And that's been another one of my ongoing sagas with the hospitals. They don't explain to you enough what tablets they are giving.'* (Participant 11, male)

After suffering severe side effects with medications in the past, one participant expressed a strong desire to play a more active role in making decisions about his care. He perceived that in the past he was not given a thorough explanation of the potential risks of pharmacotherapy, and was expected to oblige based on the little information provided.

> *'...like as I said, the Amiodarone, ok, they don't even bother you know like...'take that you've got bad rhythms' ok, but they don't say to you, as I said they don't say to you like 6-7 years time, it could kill your thyroid, you know, which they should fully explain it.'* (Participant 2, male)

Lack of patient-provider communication and effort to keep patients informed about the details of their management contributed to participants' overall negative healthcare experience, which was described as being a *'saga'*. Getting information was perceived as a *'long process'*, often leaving patients completely in the dark about their condition.

> *'But it's a long process to find out exactly you know...if I had a glass of red wine for the number of times other patients have said to me yeah I know what's going on but I don't, you know, like they have said that I'm going to do this but I really, you know, I don't know what's going to happen...most of the patients I talk to are in the dark… (Participant 11, male)*

As these examples illustrate, it was often noted that HF information delivered by providers was inadequate, not thoroughly explained, or simply not communicated at all. Some participants perceived that doctors lacked the time to talk to patients. Nurses were therefore often relied upon as a first point of call for advice rather than doctors.

### *Perceived deliberate concealment of information*

Furthermore, perceived deliberate concealment of information led to a fragmented understanding and fragmented patient-provider relationships. In some cases, this led to feelings of frustration that further compounded negative associations with hospitals and medical professionals. Lack of communication led some participants to question the credibility of what was being said, as it was perceived that doctors assured patients only in an attempt to keep them happy. The following participant expressed frustration in regards to perceived deliberate concealment of information, which led to her mistrust of providers.

> *''No, tell me everything! Be up-front! They're not going to upset me. No no no no no, they just say everything's good. And you're supposed to believe it? I can't believe anything.'* (Participant 7, female)

Perceived concealment or withholding of information often led to feelings of mistrust, however preference for provider transparency was not ubiquitous. One participant felt that health information was *'sugar-coated'*, but perceived this approach facilitated coping. *'Sugar-coated'* health information was described as deliberate omission of details that may upset or distress the participant. He perceived that details relating to disease progression were concealed by doctors in an effort to avoid alarm.

> *'My cardiologist seems to reassure me, he sugar-coats too sometimes I think... Yeah because I'm young, he doesn't want to put me down any more. He wants me to bit a little bit more strong and firm. So I think he sugar-coats a few things…like that I might be just a little bit worse than he makes out to be. That's my opinion anyway. Every time I'll ask him oh "How am I doing?" he goes "yeah yeah, you're the same, you're the same"'* (Participant 6, male)

He described that *'sugar-coated'* health information may have helped him cope with the ups and downs of his condition throughout the years.

> *'And maybe he has done good in a way by sugar-coating things. I was able to do 6 years without…I mean, I have had my ups and downs within those 6 years, it hasn't been an easy ride…consultations, doctors, check ups. Ok but, maybe it has done good.'* (Participant 6, male)

### *Patient-provider relationships: no realm for asking questions*

Patients described varying levels of comfort in openly communicating and asking questions during patient-provider consultations. This was, of course, largely dependent on the nature of the relationship between patient and provider either being positive and supportive, or paternalistic. In some cases, patients' embarrassment to ask questions due to lack of understanding was a barrier to effective communication. Patient-provider consultations were not perceived as an appropriate time for asking questions if one did not already possess a high level of understanding. As the following participant described, this attitude, however, dissipated with age and increased confidence. Over time, he grew more confident in asking questions as he saw the importance in filling in those knowledge gaps. The importance of understanding his condition outweighed the potential embarrassment of revealing lack of knowledge.

> *'….before I always took things as they come I didn't ask any questions, 'oh yeah it'll be right' um I think I was a bit embarrassed about asking….Because I didn't know it. Didn't know anything. So, but now, I don't care. I've gone past that stage of being embarrassed (chuckles).'* (Participant 5, male)

In other instances, participants described the relationship between patients and doctors as a paternalistic one that encumbered effective communication. It was perceived that doctors were not open to being asked questions and expected compliance without question, overlooking the patient's right to know and make decisions of their own volition.

> *'Doctors are a funny group. They don't like to be questioned, on decisions, but, you know, they should realise too, it's your life they are dealing with, not their own…'* (Participant 2, male)

> '*Well they think they're the ants pants! You can't question them or anything. Especially when they get into the specialty. Come on. You can't question them on anything. They don't like anybody outspoken **laughs** at all. Even when I say 'I don't understand it, why can't you explain to me…what it is'. That is...that's like swearing at them!'* (Participant 7, female)

Participant 7 perceived that asking questions, towards specialist providers in particular, was analogous to shouting profanity – both considered insulting and taboo. Participants described how people might feel forced to play the role of the passive patient. The perception that it was rude to ask doctors questions and perceived self-importance of the medical profession was identified as a major barrier to effective communication, and a reflection of the perceived social and cultural norms of being subordinate to those in the medical profession.

> *'…see this is the other thing 'I'll do as I'm told' because in our day... its rude to ask the Doctor something, you know, you just accept it.'* (Participant 8, female)

### 7.4.3 Patient orientation towards remaining informed

Participants' orientation towards remaining informed acted as either a barrier or facilitator of communication. This depended on whether they chose to engage in problem-focused coping (active) or emotion-focused coping (passive, avoidant), whether they recognised the seriousness of their condition, and whether they recognised the importance of being able to communicate important information to others.

#### *Emotion-focused coping: desire to remain uninformed*

The struggle to accept the sick identity, instead using denial to cope with the reality of living with chronic illness, corresponded with the wish to remain uninformed about the details of one's condition (emotion-focused coping).

> *I'm my own worst enemy sometimes, because, sometime I don't want to know the truth… because maybe I'm too scared of the truth. I still got so much to live for. I feel like I'm trying to persuade myself "It's going to be alright", "You're ok!" "There's nothing wrong with you". My heart is saying otherwise but you know…I don't want to know the whole story.'* (Participant 6, male)

These participants described a sense of ambivalence where practical self-care information was welcomed whilst information about prognosis and trajectory was avoided. Reluctance to hear about prognostic information was magnified when their condition progressed.

> *'But I don't look it up anymore, its too hard to read. Really hard to read. Especially when they say… Well, time limits on how long you are going to live. I'm just over it.'* (Participant 10, male)

Participants' experiences suggested that attitudes towards remaining informed changed over time and with disease progression. One participant explained that only in recent time had it become difficult for him to accept, as he had already beaten the odds of survival.

> *'I never used to ignore it, now I don't…well… now I won't. I used to all the time and think, oh well I've gone that far, I've gone that far. Yeah. I know I wont be an old man, but so be it.'* (Participant 10, male)

### *Problem-focused coping: knowledge is control*

Conversely, problem focused coping facilitated information searching which led to fewer gaps in knowledge and a more coherent understanding of HF. In these cases, a *'no excuse for ignorance'* attitude was adopted, and these participants felt it was their responsibility to remain informed about the details of their condition.

> *'There is no excuse for ignorance. In 2015, there is no excuse. If there is...you are ignorant of something you don't know, its because you don't want to know.'* (Participant 8, female)

Despite the noted barrier of doctor's paternalistic attitudes towards patients, this participant's orientation toward remaining in control and informed prevailed. She was not afraid to ask questions. She did not believe in the superiority of doctors, as she explained, after all, it was her life they were dealing with, not theirs.

In terms of HF knowledge and education, one participant described a shared responsibility between patients and providers. He believed it was his personal responsibility to actively seek information, and it was the provider's responsibility to provide appropriately tailored information.

> *'…Take an active role in your treatment. Doctors have a responsibility up to an extent. Above and beyond, we have a responsibility. Being aware of our organs, our conditions… we can contribute to our own well being.'* (Participant 9, male)

For a number of participants, choosing to be fully informed and taking an active role in treatment rather than a passive one helped restore a sense of control and facilitated coping. Whilst most participants did not feel a sense of control over the trajectory of their illness, they felt a sense of responsibility to take an active role in treatment.

> *'OWN the condition, and it's easier to live with the condition when you own it…* ' (Participant 8, female)

> *'Well (my role in controlling it is), to be...to take an active role in my treatment.'* (Participant 9, male)

Knowledge and control were often described in tandem. It was recognised that inadequate knowledge encumbered decision-making in terms of self-management. Not being able to take appropriate action when symptoms worsened restricted the capacity to remain in full control.

> *At the moment, I feel I only have average control.* Just at the moment I don't feel I have...I have average control, average knowledge. I don't believe that's enough.' (Participant 9, male)

Furthermore, knowledge facilitated coping in that it helped participants deal with feelings of anger and panic. In the following example, the participant described how getting to know the details of her condition helped her cope with her anger. Being angry about her condition was perceived as futile, whereas being informed and taking an active role in treatment was more likely to be beneficial to her health.

> *'that has also helped me to know my condition, and to get friendly with my condition because I think that before that when I was really really angry...so fucking angry... that all it did was just.. I was able to spit out my anger, but no body could do anything. Nobody...nothing happened, you know….well just because I was angry, it doesn't mean that my health got better. Just because I was angry doesn't mean that you know, all the hospitals say 'oops, sorry, we could have fixed that' you know.'*(Participant 8, female)

Knowledge also helped reduce panic. New symptoms caused by unidentifiable factors was anxiety inducing. As this participant explains, after attending cardiac rehabilitation classes, his understanding of his symptoms and condition improved dramatically which helped him cope with anxiety inducing symptoms.

> *'Because you know when you are sick and its new. Every time I used to feel palpitations I used to panic…I haven't panicked since I started going to these classes.' (Participant 14, male)*

This example highlights the invaluable role of cardiac rehabilitation for patients with HF, not only in helping them manage their physical symptoms, but also reducing panic and affective symptoms too.

### *Recognising the seriousness of a deteriorating heart*

Coming to terms with the seriousness of HF caused participants to realise that they could no longer assume the '*it'll be right'* attitude. Consequently these attitudes changed with disease progression when symptoms began to interfere with daily life more frequently, and thus impacted orientation towards remaining fully informed.

> *'I think I need to ask a lot more questions now. You know, like after I filled that thing in, the questionnaire in, then I went to see Professor Lewis that day. Well I did think, well I need to ask more things instead of saying oh yeah, it'll be right kind of thing...*(Participant 12, male)

The participant explained that he was no longer apathetic towards asking for medical information, as HF was affecting his life on a daily basis.

> *'Not now (there is no sort of communication breakdown with providers). Not when this is affecting my life and my lifestyle. I have to ask these questions.'* (Participant 12, male)

The notion of heart dysfunction was perceived as serious and not something to be overlooked. A major motivator of information or advice seeking was that the affected organ (the heart) was perceived to be of utmost significance.

> *'I'll tell you what, when its your heart (chuckles) its most important that you get as much information as you can now. Instead of just letting it go over your head. You know, like you just say you had a cold or something like that or you had oh we can say pneumonia but just say you had a small problem, you kind of let it go over your head but you know when they're talking about a heart condition, it makes you stop and think because that's what keeps you going, you know what I mean. You just…I've got a different light on things now.'* (Participant 12, male)

### *Communicating details to others*

And finally, a number of participants discussed the need to remain informed in order to communicate important health information to others. Others may be lay people (family and friends) and health professionals. Despite wanting to ignore prognostic information, the following participant realised the importance of staying informed about his health in order to explain details of his condition to others.

> *'It (information from the hospital) just helps me understand. Helps me understand so I can explain to people when things happen why it happens. Like, why have I got blue lips, why have I got...why am I always panting. Well, not always, but why am I panting.* (Participant 10, male)

The importance of being able to share information with others motivated him to remain informed of the details of his condition, despite how difficult it was for him to accept. He drew particular attention to the importance of being able to know the information well enough to be able to put it in layman's terms to effectively explain his situation to others, being well aware of the confusion medical terminology was likely to cause.

> *'It's the simple ways. You can't tell people you've got pulmonary hypertension, what's that? Or Eisenmenger syndrome, there's a good one.'* (Participant 10, male)

This participant also recognised that remaining informed about his condition was imperative to communicate effectively with providers who might not know anything about his medical history.

> *'You should know. Something happens you've got to tell the doctor or the ambulance people because then they start injecting you with all sorts of rubbish and no, I can't have that.* (Participant 10, male)

Another participant explained the same rationale for remaining informed. He did not perceive he had adequate knowledge about his pharmacotherapy and explained that he would struggle to inform doctors what he was on and why. He recognised how this could become problematic in terms of communicating effectively with providers, which facilitated his attitudes about wanting to be well informed about the details of his condition and management.

> *'They just tell you you're having this this and this and I don't know, you know, I've got a webster pack and I think I take about 20 drugs a day. Wouldn't have a clue (of what they do). And it annoys me when doctors ask me, you know, what are you on that for? And I'll say well the doctor gave it to me. It makes me feel a bit odd if I don't know enough about the drugs that I'm taking.* (Participant 11, male)

One example unerringly illustrates how communication can be compromised due to not knowing. The following participant explained that asking the right questions was key to effective communication.

> *'I usually don't have a problem asking any questions, but there's knowing what questions to ask, because in some cases, you don't know. Like fluid retention for me. I didn't know to ask about that, but the last 6 years I've put on a lot of weight, not because of my eating, changing eating habits, it just kept coming on and I'm thinking, is it the medication? Everyone is telling...my cardiologist is saying no, it wouldn't be that. And*

> *you're thinking, well its got to be something, and it was fluid retention so...'* (Participant 13, female)

She described that for the last six years, despite suffering fluid retention, she was not able to effectively communicate her concerns to her providers because she did not know to ask about it. She was unaware of what the problem was and therefore had difficulty trying to communicate her concerns. As a result, she suffered with symptoms for six years until she was prescribed diuretics.

## 7.5 Conclusion and chapter summary

This chapter has described participants' preferences for the type of HF information, reflected by self-identified gaps in knowledge, and also described preferences for how this information could be delivered most effectively. Despite an abundance of information available online, providers were clearly the preferred source of HF information. Findings revealed perceived barriers to and facilitators of patient-provider communication and highlighted the role of participants' orientation toward remaining informed in the effectiveness of communication. Findings from this chapter are summarised below.

- Participants perceived gaps in their knowledge relating to HF pharmacotherapy, symptom appraisal and management, and the cause and chronicity of HF. Participants expressed the unmet need for a specific action plan to help with symptom appraisal, and further explanation about the potential side-effects of HF pharmacotherapy.
- Providers were participants' preferred source of information, as they were perceived to be the most trustworthy (as opposed to information sourced from the Internet), and able to provide the most tailored and useful information.
- Face-to-face communication was preferred to facilitate information retention, and written information that could be referred back to was welcomed.
- Facilitators of patient-provider communication included: patient note-taking during consultations, which facilitated information retention and ensured management

continuity; consistent health information from providers so that health information was clear and not conflicting; and positive patient-provider interpersonal relationships involving trust and support, which facilitated open communication.

- Barriers to effective patient-provider communication included: participants' memory problems; the use of complex medical terminology by providers; lack of adequately detailed health communication or simply no communication at all; perceived deliberate concealment of information; and negative patient-provider interpersonal relationships involving lack of trust and paternalism, which did not allow for open communication.
- Findings revealed that participant's orientation towards remaining informed also impacted patient-provider communication. Some participants expressed the desire to not know the details of their condition in order to cope, whereas, others felt that knowledge about their condition restored a sense of control and helped them cope. Recognising the seriousness of a deteriorating heart often compelled participants to find out more about their condition, as did the need to relay important health information to others, including providers, friends and family.

# Chapter 8
# Discussion

The findings from this study describe care-seeking behaviour in patients with HF, an area of HF self-care often neglected, yet, with the potential to reduce avoidable HF admissions and deleterious outcomes associated with delay. The study has identified various patient, provider, and system-related factors that contribute to patients' decisions to seek or avoid professional care. These findings can be used to inform targeted interventions to promote timely care-seeking in HF. In this thesis, participants' voices have been prioritised and both qualitative and quantitative approaches were used to provide greater context and meaning to findings, generating a comprehensive account of care-seeking in HF. This chapter integrates the qualitative and quantitative findings of this study to answer the final two research questions of this thesis.

Quantitative findings reflected high levels of health literacy, HF knowledge, and self-efficacy in this population, signifying that participants had adequate skills and confidence to make well-informed decisions about their health. Despite these promising results, interviews revealed delayed care-seeking nonetheless. Previous healthcare experiences were key factors in care-seeking decisions and played a major role in decisions to interact with health services. The impact of these experiences on decision-making has received less attention in the HF literature to-date. These qualitative and quantitative findings are integrated in this chapter to answer the fifth research question of this thesis: *How do Australian patients with HF make decisions to seek or avoid professional care in the context of illness perceptions, self-efficacy, affective symptoms and health literacy?* These integrated findings are further related to the theoretical model examined in Chapter 2 to provide a more comprehensive understanding of care-seeking decisions for worsening symptoms in HF. These findings are discussed within the context of the current literature.

The qualitative meta-synthesis in Chapter 3 identified patient understanding of HF as a major area of weakness, impacting patients' capacity to self-manage, and pointing to patient-provider communication as a potential opportunity to intervene. Thus, this study has also described perceptions of HF knowledge, patient preferences for information delivery, and perceptions of patient-provider communication. In this chapter, quantitative and qualitative findings are integrated to highlight areas of HF knowledge participants struggled to comprehend, to better understand patients' educational needs and answer the final research question of this thesis: *What are Australian patients' perceptions and preferences of HF information delivery and patient-provider communication in the context of health literacy and HF knowledge?* Preferences for information delivery and perceived barriers and facilitators to patient-provider communication are also discussed in the context of currently used strategies, and the noted implications of improved patient-provider communication. This chapter also discusses the study limitations and implications for future research, policy, and practice.

## 8.1 Care-seeking in HF

It became clear throughout interviews that a number of patient-level factors impacted how participants responded to worsening HF symptoms. The principles of self-regulation helped shed light on how these factors contributed to delayed care-seeking, which, to-date, have not been applied in HF. Participants' capacity to recognise a change from normal, their representations of HF, emotional responses, and subsequent coping styles all contributed to the decision-making process. Whilst these findings fit within the SRM, interviews revealed other provider and system-related factors that led to delayed care-seeking. The impact of previous healthcare experience was important to participants given that it led to avoidance despite having the confidence to manage their condition (reflected by high self-efficacy), and possessing the skills to understand and use health information to make decisions (reflected by health literacy results). The impact of these system and provider-related factors were underrepresented within the model or simply did not fit. Although the SRM posits that coherence of the model, which includes coherence with providers, is an important aspect of self-regulation, this only addressed a small part of the provider-related barriers found to impact care-seeking. The model also notes 'social messages' as part of forming representations, however this is vaguely defined and described in seminal texts. The SRM therefore provides a useful framework to understand care-seeking in HF, however, lacks emphasis on the role of external factors which were found to be crucial in this HF population.

### 8.1.1 Patient-level factors

#### *Symptom perception*

Perceiving symptoms was a considerable problem for these participants, as they often grew accustomed to daily symptoms and became part of what they considered normal. The ESAS revealed that tiredness and breathlessness were the two physical symptoms participants perceived as most severe. Pain was perceived as the least burdensome, which is likely due to the fact that symptom perception was assessed in hospital at one point in time where participants were either likely to be receiving treatment for chronic pain, or were not suffering an acute exacerbation of pain at the time of assessment. It should also be noted that measurement of pain was limited to the general concept of pain, as assessment did not differentiate between different causes (i.e. musculoskeletal versus ischaemic). Growing accustomed to daily symptoms is not uncommon in chronic illness, and is often the case for many patients with HF around the world. In a multi-site study conducted in the US, delayed care-seeking was associated with reduced somatic awareness (i.e. the ability to detect bodily sensations).(1) The study also found that pattern of symptom onset independently predicted delayed care-seeking, where acute episodes were more likely to be acted upon in a timely manner in comparison to progressively worsening symptoms.(1) Acute worsening of symptoms was perceived as a change from normal, whereas 'old' ongoing background symptoms were more likely to be overlooked, as found in the current study.

A major facilitator of symptom recognition and subsequent action was the role of friends and family. Friends and family often pointed out worsening symptoms that were overlooked by participants themselves, particularly in the case of 'old' symptoms that participants grew accustomed to over time. The SRM describes this as coherence with cultural context, as explained in Chapter 2, where agreement or discordance between how people think about themselves and how others (friends and family) think can interrupt self-regulatory processes. In this case, discordance between how participants perceived symptoms and how loved ones perceived symptoms often prompted self-regulatory processes and led participants in the direction of active coping strategies involving care-seeking. Current HF management guidelines advocate for the involvement of families in HF management.(2) Findings from this thesis revealed that 72% of participants did not live alone, however, a study by Lee and colleagues revealed that living with another person was significantly associated with worse consulting behaviours (i.e. not contacting providers for guidance in response to symptoms).(3) Lee and colleagues posit that increased reliance on others to point out worsening symptoms and help with subsequent care-seeking decisions may act as a barrier to personally engaging in self-management.(3) Findings about the role of others are therefore mixed. Whilst most participants in this thesis did not live alone and described instances where others helped identify worsening symptoms, delayed care-seeking was still noted.

Findings also revealed that 'old' symptoms did not always mean delayed care-seeking, as familiar sensations led to rapid appraisals in some cases. This finding is supported by Jurgens' study, where patients with HF with previous experience of breathlessness hospitalisation had shorter delay times,(1) indicating that they learned from experience. Following on from this study and another examining delay in elders with HF,(4) Jurgens and colleagues developed a symptom monitoring and response training intervention to improve patients' ability to recognise and respond to changes in HF symptoms.(5) Their pilot study revealed that the intervention had positive short-term effects on outcomes, but resulted in no significant difference in event-free survival at 90 days (i.e. no significant impact on hospitalisation or death at 90 days).(5) This lack of sustained impact on outcomes further reinforces the complexity of care-seeking in HF. Recognising symptoms and forming sound cognitive representations about what they mean is just one part of what effects the decision-making process. It is therefore not surprising that addressing this aspect alone did not yield sustained results. Emotional responses, coping styles and appraisal of coping are other factors that impact response to symptoms and should also be woven into interventions promoting timely care-seeking.

### *Cognitive and emotional representations of HF*

Both interviews and questionnaire results revealed confusion and misconceptions about HF, which is in keeping with the HF literature.(6) Perceived identity, cause, consequences, controllability/curability, and timeline conceptualisations varied amongst participants, reflecting the general uncertainty about aspects of HF pathophysiology and management.

Despite being only one symptom that can be associated with HF, pain was commonly noted as a facilitator of care-seeking, as participants perceived pain to be indicative of danger, and thus warranted care. It should also be noted that the identity of pain, namely chest pain, was easily attributed to heart attack. Despite Australian HF guidelines recommending education topics that 'clarify the difference between heart failure and heart attack',(7) the perception that only pain equates to a serious problems alludes to known confusion in this area. Furthermore, the identity of heart disease did not fit with participants' perception of themselves, creating a sense of cognitive dissonance that led to emotion-focused coping and avoidance behaviours. Participants often linked heart disease with being overweight and unfit, as someone who hadn't 'taken care' of themselves and thus, could not accept the reality of their condition. This may be due to the high proportion of participants suffering non-ischaemic HF (52%), where ischaemic HF usually represents approximately two thirds of cases.(2) Despite this comparatively higher proportion of non-ischaemic HF cases, participants only had the general image of heart disease as a point of reference for their condition. It was not uncommon for participants to describe their condition as having ‘heart problems’, with very few able to delineate their condition from other cardiac illnesses. This highlights the need for public health initiatives to raise the profile of HF, enabling patients with HF to understand how their condition is different, and giving them another image to identify with other than the one assumed for general heart conditions.

In terms of perceived cause, the BIPQ revealed that diet, lack of activity, and genetic factors were most commonly thought to have contributed to participants’ conditions. When responses from this item of the BIPQ were grouped, it was clear that lifestyle factors mainly were perceived to be the most important contributor to HF. In contrast to these findings, a study conducted in the UK found that lifestyle factors were not commonly noted as a perceived cause of illness in patients with HF, but rather, participants identified stress as a key factor in their condition.(8) Interview findings from this thesis likewise revealed symptoms were not linked with illness in many cases, however the third most common response to the perceived causality item on the BIPQ was indeed a cardiac event/comorbidity, suggesting that participants were able to link their condition and symptoms with underlying illness in other cases. Interviews also revealed that comorbid conditions often interfered with symptom appraisal, with many unsure about which symptoms to attribute to which condition. A similar study conducted in Uganda exploring patients’ perceptions of their condition also revealed that it was common for patients to not link their symptoms with illness, and/or attribute them to comorbid conditions.(9) Symptom appraisal is inherently challenging in HF, as characteristic symptoms are not unique to this life-threatening condition. HF symptoms can be easily misattributed to other conditions with overlapping symptoms. In addition to the complications caused by comorbidities in symptom attribution, Dickson and colleagues also found that HF self-care in general became increasingly compromised as the number of co-morbidities increased.(10) Dickson and colleagues demonstrated that the impact of co-morbid conditions stretched beyond complicating symptom appraisal, but also interfered with patients’ self-efficacy, and impacted how patients prioritised and integrated multiple and often conflicting self-management instructions.(10) For example, patients with COPD might be encouraged to self-manage and avoid healthcare utilisation, whereas, patients with HF are encouraged to seek care. As the SRM suggests, cognitive representations of the health threat, of which perceived cause is a feature, shapes coping responses. Not being able to link HF symptoms with illness, or misattributing them to comorbid conditions interferes with the patients' ability to generate an appropriate response to these bodily sensations that are in reality a sign of decompensated HF. Interviews revealed that confusion around the perceived cause of symptoms led to delayed care-seeking in many cases.

Participants perceived physical and social consequences of HF, as well as perceived role loss that impacted decisions to seek or avoid professional care. These Australian patients with HF offer a different perspective to those involved in the UK study,(8) who predominantly reported physical consequences of their condition, rather than social implications. Care-seeking was described when symptoms interfered with daily life (physical consequence), and was avoided when perception of being a burden (social consequence) was considerable. Throughout interviews it became clear that fear of being perceived as a burden was linked with a sense of pride and desire to remain independent. As noted in the SRM, coping strategies must be coherent with personality, and in cases where asking for help was perceived as a sign of weakness, those who took pride in their independence would not seek professional care. A recent study by Zhang and colleagues examined the role of non-health-related goals with adherence to HF self-care maintenance.(11) Maintaining autonomy was the most valued non-health-related goal in this cohort of patients with HF, who valued *'maintaining my physical independence'*, '*having the energy to do things that I want to do'*, and *'having control of how I live my life'* above all else.(11) Maintaining physical wellbeing was also important for these patients, but not as much as maintaining autonomy, which was consistent with findings from interviews in this thesis. Maintaining social relationships was also noted as an important goal domain, with a third of these patients selecting *'to avoid being a burden on my family*' and *'to take care of my family and loved ones'* as a priority.(11) Whilst these non-health-related goals did not predict self-care behaviour, the sample was relatively small (n=40) and the study focused on self-maintenance behaviours such as daily weighing, diet and exercise.(11) The role of these non-health-related goals on more complex self-management behaviours such as care-seeking is unknown. Findings from this thesis suggest a strong sense of cognitive dissonance, which can also be conceptualised as goal incompatibility. Goal incompatibility relates to life goals and compatibility and incompatibility with self-care maintenance and self-management behaviours. Participants' values associated with maintaining independence and autonomy, as well as avoiding the social consequences of being a burden, conflicted with seeking professional care. The act of asking for help and seeking-care represented a loss of freedom and independence for many. Fear of being a burden and the desire to maintain independence and control over their environment (i.e. not being in hospital) were repeatedly noted as factors that led to avoidance and contributed to delay. Both this thesis and the Zhang study highlight the importance of maintaining autonomy to patients with HF. Measuring the impact of these goals on HF self-care management in a larger sample would enable us to quantify their effects on more complex self-management behaviours, and may allow further insight into care-seeking decisions. Additionally, the priority of health in the context of competing family and employment roles was not eminent. As Dickson and colleagues explain in their typology of self-care management in HF, patients who were classified as *inconsistent* self-managers differed from self-management *experts* in that competing responsibilities such as work, family roles, and comorbid conditions often took precedence over HF management leading to inconsistent HF self-care management.(12)

In terms of perceived timeline, one participant expressed confusion around the chronicity of her condition, however, results from the BIPQ suggest that most participants knew their condition would last forever. The study conducted in Uganda exploring illness representations in HF also showed mixed results in terms of perceived timeline, with most patients hoping for a cure, and others recognising they would live with HF for the rest of their lives and only hoped for improvement.(9)

Perceptions of controllability varied according to the BIPQ, with personal control perceived as low, and treatment control comparatively high. Whilst participants recognised they could not control the fate of their illness and they would spend the rest of their lives with HF, controllability in terms of HF management varied, with some taking an active role in management, controlling what they could and taking ownership of self-management decisions, whilst others adopted a more passive role in the management of their condition. This thesis revealed that some participants relinquished control to their trusted health providers, and perceived themselves as having insufficient expertise and were unqualified to make decisions about the management of their condition. Other studies have demonstrated similar attitudes from patients with HF from different cultural backgrounds, (13, 14) suggesting there may be links with cultural beliefs and perceived control in this respect. Whilst the findings from this thesis showed that some participants did adopt a 'doctor knows best' attitude, more active self-managers expressed a sense of frustration with regards to perceived paternalism, which will be discussed in the patient-provider relationships section of this chapter. Almost a third of participants in this study did not identify as Caucasian, which is reflective of the general multicultural Australian population, and if perceptions of control are indeed strongly culturally linked, this may explain the variation.

A combination of these cognitive representations and emotional responses shaped coping strategies, leading patients to seek or avoid professional care. The emotional responses described above illustrate the psychological burden of living with chronic HF. Results from the DASS-21 also reveal that 74% of participants experienced symptoms of anxiety, and over half (62%) experienced at least moderate depressive symptoms, as reflected by the PHQ-9. A recent review illustrated that along with cognitive impairment, anxiety and depression can decrease one's ability and interest in performing self-care.(15) With the vast majority of participants in this thesis screening positive for depressive and anxious symptoms, which not means unique in HF, it is not surprising that many revealed emotion-focused coping strategies involving denial and avoidance which ultimately led to delayed care-seeking in the interviews. Navidian and colleagues stress the importance of tailoring HF education according to patients' psychological status, suggesting the incorporation of motivational interviewing techniques in HF education as a useful way of improving HF self-care maintenance and self-care management.(16) In their recent study, motivational interviewing was more effective than conventional HF education in improving self-care maintenance, management, and confidence in depressed patients with HF.(16) This highlights the importance of tailoring education strategies to account for the psychological effect of HF, in order to see meaningful improvements in HF self-management. This is one step towards the solution to help shift coping styles from emotion-focused to problem-focused, steering patients with HF towards timely care-seeking rather than avoidance behaviours. Furthermore, higher levels of anxiety have been associated with worse consulting behaviours (contacting providers for guidance) as well as self-care management.(3) According to the study by Lee and colleagues, patients with a higher level of anxiety were less likely to engage in expert-level consulting behaviours (OR 0.50, 95% CI 0.26-0.95). This highlights the importance of also addressing anxiety in HF, which, to-date, receives less attention than depression, yet evidence suggests that both are key in self-management failures, and care-seeking specifically.

### *Coping and appraisals*

Interviews revealed delayed care-seeking despite high levels of HF knowledge, health literacy and self-efficacy. These are factors known to impact self-management, yet, participants described instances that led to delayed care-seeking nonetheless. A recent study by Lee and colleagues, however, suggest that care-seeking, or consulting behaviour, as the authors label it, overlaps with self-care management, but one only minimally informs the other.(3) Authors found that there was a weak, yet statistically significant linear relationship between consulting behaviours and self-management, inferring that patients who have a good understanding of when to seek professional care may not have expertise in self-management.(3) This inference can also operate in reverse whereby expert self-managers may not engage in expert-level consulting behaviours.(3) In other words, factors contributing to HF self-management behaviour may not be closely related to care-seeking behaviour. Furthermore, Lee and colleagues found that those who were considered novices in consulting behaviour performed worse in all domains of self-management compared to consulting experts, however, there was no difference in self-care confidence between groups.(3) This finding may explain the pervasiveness of delayed care-seeking behaviours in this thesis despite high levels of self-efficacy. Whilst self-efficacy, or self-care confidence, has been shown to impact engagement in HF self-care management, it may be unrelated to care-seeking behaviour specifically. Lee's findings show divergences between consulting behaviour and self-management suggest that interventions targeted to improving self-care management would likely be tailored differently to interventions aiming to improve professional care-seeking in HF.(3) They posit that it is therefore important to differentiate the steps patients take to self-manage their condition with the steps they take when making decisions about calling for help when there is a change in symptoms.(3) This highlights the importance of considering care-seeking as related, but separate to self care-management and thus underscores the importance of this thesis.

Furthermore, findings also revealed that participants often recognised the detrimental impact of delay in hindsight, illustrating how self-regulatory processes occur in a constant feedback loop. When participants reflected upon previous symptoms exacerbations that led to delayed care-seeking, they were better able to identify the cause of symptoms and recognise what they should have done to manage them. Reflecting on past experiences, thus, had great impact on re-shaping representations of illness, yet it became clear that participants hadn't done so until they were asked about their previous experiences during the interview. A recent study conducted by Sethares and colleagues tested the effect of guided reflection on self-care maintenance and management.(17) Questions involved in the guided reflection intervention, informed by Gibb's reflective cycle (18), were similar to that involved in the interviews of this thesis and included: *'What happened?'; 'What were you feeling and thinking?; 'What was good* *and bad about the situation?'*; *'What sense can you make of the situation?'*; *'What else could you have done?'*; *'If the situation arose again?'* and; *'What would you do?'*.*(17)* This intervention was effective in improving self-care maintenance and management, as patients were able to develop insight into their HF symptoms and their response/actions.(17) Sethares' findings revealed that reflections on actions taken during symptom exacerbation did lead to changes in HF self-management,(17) suggesting that encouraging reflection through a simple guided reflection intervention may be a useful strategy to encourage timely care-seeking in HF, capitalising on the feedback appraisal aspect of self-regulatory processes.

### *Symptoms prevent care-seeking*

The recent update on factors related to self-care in patients with HF highlights the role of cognitive and physical function in the capacity to self-manage.(19) Participants in this thesis described how limiting symptoms, such as fatigue, interfered with their capacity to physically seek professional care. These findings are in keeping with the recent literature, wherein general and exertional fatigue have been independently and significantly linked with poor consulting behaviour and self-management, controlling for sleep, mood problems, and other clinical factors.(15) This also corresponds with results from the Lee study, which showed that worse functional class was significantly associated with worse consulting behaviours.(3) The impact of symptoms themselves on the capacity to seek professional care is not something represented in the SRM, yet both this thesis and evidence suggests that functional capacity plays a role in care-seeking decisions.

### *A-priori action plan*

Having an a-priori action plan was key in making prompt decisions about how to manage worsening HF symptoms. This is not exclusively a patient-related factor, as these plans are generally developed in conjunction with providers. Having an a-priori action plan is therefore situated somewhere in the middle of being a patient-level factor and a provider-related factor. Developing a plan of action for worsening symptoms is recommended in national guidelines,(2) however, interview findings revealed that few had pre-determined plans specific for HF symptoms and were more likely to have an action plan for chest pain only. In their typology of HF self-care, Dickson and colleagues note that a key difference between self-care *experts* and *inconsistent* managers was having a pre-determined action plan for symptoms.(12) According to this typology, participants from this thesis were seldom self-care *experts,* explaining the propensity towards delay. A recent update on the theory of self-care in chronic illness highlights that a key skill involved in effective self-care management is the ability to transfer learned information into a specific context.(19) Learning how to make self-care maintenance and self-care management practices fit into daily life is a skill requiring experience in successful symptom management.(20) Having an a-priori action plan, developed in collaboration with providers helps patients apply learned information to the specific context of worsening symptoms even without previous experience. Relating this back to the SRM, an a-priori action plan ensures that IF-THEN rules are established with the guidance of health professionals rather than solely relying on previous experience of the patient. The SRM posits that patients choose how to cope based on IF-THEN rules learned from experience, but if these rules can be provided by health professionals, there is little room for deliberation and delay. The effectiveness of having an a-priori action plan for heart attack symptoms was well represented in interviews, yet few, if any, participants described having an a-priori action plan for HF symptoms. A focus on building action plans specific to HF symptoms is key in helping patients progress from *inconsistent* self-managers to *expert* self-managers.

### 8.1.2 The healthcare experience (provider and system-related factors)

The above-mentioned factors were crucial in decisions to seek or avoid professional care and must be addressed to promote a timely response to worsening symptoms. Patient-level factors alone, however, do not illustrate the full picture. Whilst perceptions of illness and wellness, the ability to detect symptoms, and emotional responses to HF largely contribute to decisions regarding the appropriateness of professional intervention, the behaviour in question, care-seeking, fundamentally requires a decision to interact with the healthcare system. Previous experiences within it are therefore equally important considerations in making decisions to once again interact with health services. Like the meta-synthesis in Chapter 3, findings from this thesis identified a range of provider- and system-related factors that are generally underrepresented in the SRM, yet played a major role in care-seeking decisions. Other HF self-care theories conceptualising self-care as a naturalistic decision making process such as the situation specific theory of HF self-care,(21) assign more weight on environmental factors that may impact self-management. Concepts thought to impact self-care are generally largely patient-related. Whilst experiences with symptoms are acknowledged as key in the development of skills to adequately manage HF, experiences in healthcare receive considerably less attention in the HF self-care literature. Moser's model of self-care does note previous experiences with the healthcare system as a factor influencing self-care, yet this section is relatively terse, reflecting the paucity of research in this area. The recent update of factors relating to HF self-care, according to the Middle-Range Theory of Self-Care in chronic illness, also comments on the impact of providers in self-care with regards to access.(19) However, healthcare experiences are generally not the focus of studies exploring factors influencing self-care behaviours in HF. As noted by Lee and colleagues, there are divergences between processes involved in HF self-management behaviour and care-seeking behaviour.(3) Whilst healthcare experience may not be a large focus of HF self-care theory, it could play a much larger role in care-seeking behaviour specifically, as was demonstrated in this thesis. Ultimately, this self-management behaviour requires a decision to interact with health providers and the system. These types of factors may be equally as important as patient-level factors in delayed care-seeking.

Findings from this thesis revealed that preference for continuity, previous hospital experiences, and patient-provider interpersonal relationships led patients to seek or avoid interaction with healthcare services. The majority of participants described delayed care-seeking in relation to the desire to avoid hospitalisation. For most, hospitalisation evoked painful memories, served as a reminder of being ill and meant renouncing independence and control, which led to avoidance behaviour. A study of patients with HF and chronic obstructive pulmonary disease (COPD) also revealed delayed care-seeking in these patients due to fear of being hospitalised, as hospitals were perceived as *'a place to get worse'*.(22) The study found that hospitalisation represented a loss of control, similar to that described by participants in this thesis, and fear associated with worsening health.(22) These findings corresponded almost entirely with participants from this thesis who did not want to accept the reality of their condition. An ethnographic study conducted in the UK has also revealed that organisational fragmentation, poor continuity of care (management continuity) and access to specialist HF services were major barriers to services utilisation, leading to unplanned hospitalisation in patients with HF.(23) Another study has shown that perceiving an 'advocate' within the health system improved patient experiences, whereas negative patient-provider relationships and the lack of a perceived advocate impacted patients' capacity to self-manage and their motivation to do so.(24) In conjunction with findings from this thesis, results from these studies strengthen the evidence for the impact of patient healthcare experience (including patient-provider relationships) on HF self-management and care-seeking decisions. These findings support further research into the impact of patient healthcare experiences on HF and self-management, and suggest the need for healthcare experience to be integrated into current theories guiding HF self-management interventions, and certainly to be considered in the development of intervention to promote timely care-seeking in HF.

### 8.1.3 Conclusion and recommendations

Findings from this study revealed delay in all three stages of care-seeking decisions: appraisal delay, illness delay, and utilisation delay. The discordance between promising quantitative results showing high levels of knowledge, health literacy and self-efficacy and delayed care-seeking as described in interviews suggests factors contributing to effective self-care management may not necessarily lead to prompt care-seeking behaviour. As Lee and colleagues suggest, whilst self-care management and consulting behaviours are related, the mechanisms underlying the two may not be the same. This inference may explain why participants in this study described delay despite promising questionnaire data indicating they had the skills, knowledge and confidence to make sound health-related decisions. This could also, however, be due to the fact that the S-TOFHLA is a measure of functional health literacy (basic health literacy), which may not accurately reflect this cohort's ability to use health information in a more critical and sophisticated way. Participants' capacity to use health information, particularly for the complex decision-making involved in care-seeking, may be overestimated. Nevertheless, these findings highlight the need for further research examining delayed care-seeking as a related, but distinct concept to HF self-management, requiring the use of a standardised measure of delay reflecting all three stages, which has not yet been developed. Furthermore, theory-driven research is essential to better understand factors that impact on care-seeking to develop tailored interventions to improve HF self-management. There is a pressing need to consider patient-level factors, as identified by this thesis and supported by the SRM and previous HF literature, but there is also a pressing need to acknowledge the role of perceived system and provider-related factors in patients' decisions to interact with health services. The role of healthcare experiences needs to be integrated in current HF self-care theory and considered in interventions aimed to improve how patients respond to their HF symptoms.

This chapter has discussed care-seeking in HF, integrated quantitative and qualitative data, and contextualised findings from this thesis within the current literature. Interactions with health providers and the healthcare system clearly play a major role in decisions to seek or avoid professional care. Patient-provider interactions have the capacity to help re-shape misrepresentations of HF, and attitudes towards timely care-seeking. The remainder of this chapter will discuss findings pertaining to the final research question of this thesis: *What are Australian patients' perceptions of and preferences for HF information delivery and patient-provider communication in the context of health literacy and HF knowledge?*

## 8.2 HF knowledge and information needs

Results from questionnaires revealed good overall understanding of HF. Despite high average total score on the DHFKS, interviews revealed that participants still felt they did not know enough about their condition. They expressed the need for more information and indicated a lack of understanding about the following topics: labels (appropriate terms for symptoms, treatment and diagnosis); pharmacotherapy; symptom recognition, appraisal and management; and the cause and chronicity of HF. Whilst knowledge of terminology was not assessed in the DHFKS, the areas of weakness identified by participants in the interviews corresponded with DHFKS items that participants performed worst on, with the exception of pharmacotherapy.

The two items of the DHFKS participants performed the best on related to the importance of adherence and the purpose of diuretics, yet in interviews, participants highlighted the need for more information relating to pharmacotherapy. It should be noted that in these instances, participants perceived they did not know about the side effects of specific drugs they were taking and what they were for, which was not assessed in the DHFKS. Whilst participants did recognise the purpose of diuretics, this is only one drug class patients with HF are commonly prescribed. The national guidelines for the prevention, detection and management of HF in Australia clearly state that patient education should cover the function of medications, and the possible side effects of therapy.(2) Despite being a guideline-recommended topic, patients expressed uncertainty about the purpose of medications other than diuretics, their potential side effects, and the need for more information in this area.

Multidisciplinary care programs are recommended by HF guidelines globally to provide biomedical care, self-care education and support, psychosocial care, and palliative care for patients with HF post-discharge.(2, 25, 26) These programs have been shown to decrease hospitalisation, improve quality of life, and survival, (27-29) therefore, access to best-practice multidisciplinary HF care is a Grade A recommendation for all who have been hospitalised for HF.(2) Programs ideally involve pre-discharge and home review by a community care nurse, pharmacist, and allied health personnel with education regarding prognosis, compliance, exercise and rehabilitation, lifestyle modification, vaccinations and self-monitoring.(2) Evidence suggests issues around availability and access to multidisciplinary HF management programs, which may explain the unmet educational needs expressed by participants in this thesis. In a study examining all HF management programs across Australia from 2005-2006, results showed that only 6.3% of hospitals nationwide provided a HF multidisciplinary management program, which does not equate to the burden of disease in Australia.(30) Driscoll and colleagues found that during this time, 8000 patients in total were managed by multidisciplinary HF programs, which represented only 20% of those who needed it.(30)

Furthermore, efficacy of multidisciplinary care relies on adherence to guideline recommendations in real-world population and settings.(31) Heart failure guidelines only state that a multidisciplinary approach is recommended, with no mention of a specific model of care that should be adopted, or specifications about whom the multidisciplinary team should include. Evidence suggests large heterogeneity and diversity amongst disease management programs and populations.(29) Provider preferences, available resources, reimbursement models, and policy recommendations largely determine models of care adopted, contributing to the heterogeneity of disease management programs in real-world settings.(32-34) In the nationwide study of HF multidisciplinary programs, models of care included: home visits (nurse visiting patient's home); extended cardiac rehabilitation (combination of education and exercise sessions and home visits); hybrid model (combination of home visit and group sessions); and telemonitoring.(30) Findings from the national study also revealed heterogeneity in terms of staffing, where the multidisciplinary 'team' ranged from one nurse to at least four members.(30) Only 39% of programs included a pharmacist as part of the multidisciplinary team, and level of training and education of HF nurses that acted as sole practitioners varied.(30) The experience of multidisciplinary care will therefore vary from one participant to the next, where HF pharmacotherapy education is likely to also vary depending on the intensity of the program, and the involvement of a pharmacist. Multidisciplinary teams without pharmacists may impact these participants understanding of the details of HF pharmacotherapy.

Participants also stressed the need for more information regarding symptom recognition, appraisal, and management. In accordance with these findings, participants performed the worst on the DHFKS item related to symptom appraisal. Results showed that participants most commonly attributed symptom exacerbation to lifestyle factors rather than correctly linking rapid symptom onset to a cold or flu. Difficulty attributing symptoms to HF is common amongst people living with the condition, as highlighted earlier in this chapter and in the metasynthesis of the qualitative HF literature in Chapter 3.(6) Attributing symptoms to age or overwork rather than an underlying chronic condition impacts the perceived severity of symptoms, and underpins decisions about what to do in response to them. Throughout this thesis, the role of symptom appraisal in delayed care-seeking has been emphasised through the use of the SRM, and exemplified in the findings of this study and the existing HF literature. Once again, national guidelines from around the world stress the importance of educating patients with HF about signs indicating deterioration of their condition,(2, 25, 26) yet correctly attributing symptoms to HF remains a challenge in this population. The challenge of correctly attributing non-specific and seemingly innocuous symptoms of breathlessness, fatigue, and peripheral oedema (reflected by weight gain) to a life threatening condition is further emphasised when considering the average patient with HF has multiple conditions. Participants in the current study had an average of 6±2 comorbidities, many with overlapping symptoms, which contributed to the complex nature of attributing symptoms to the correct underlying condition. Whilst current multidisciplinary guidelines advocate for a holistic approach in HF management involving assessment of comorbidities and subsequent tailoring of biomedical care, self-care education and action plans, confusion in determining the cause of symptoms suggest there may be issues around implementation of these approaches.

In interviews, participants also described the need for a specific action plan to help determine what to do in case of symptom exacerbation. Participants wanted to know when to be alarmed about symptoms, and when professional intervention was necessary. Two items on the DHFKS pertained to care-seeking directly. These quantitative findings, too, revealed confusion around how to appropriately respond to symptoms. Results showed that deciding how to respond to symptoms was particularly challenging when participants were required to appraise signs indicating deterioration. When participants were required to discern the meaning of weight gain and subsequently determine how best to proceed, they were more likely to select the delayed care-seeking option. In contrast, when they were asked about how they would respond to increased shortness of breath or swelling, only a couple of participants said they would wait until their next check up. The difference between these two responses indicates that there was more confusion about the urgency of professional care when participants were required to interpret the meaning of weight changes. According to Dickson and colleagues, correctly making judgments about the cause of symptom exacerbation, linking them with mechanisms of HF and, subsequently knowing what action to take falls under the *expert* typology of self-care management.(12) In comparison to *novice* or *inconsistent* self-managers*,* only self-care *experts* had skills (developed over time and with experience) which enabled them to evaluate symptoms and take appropriate action.(12) *Experts* also had positive attitudes and self-efficacy that enabled sustained self-care management, and developed action plans to manage symptoms during difficult times(12) Whilst the study population of this thesis demonstrated high self-efficacy as reflected by the KCCQ, interviews revealed varying attitudes towards self-management, and few described having a-priori action plans for HF symptom exacerbation. This may explain why participants were unable to make consistent well-informed decisions about care-seeking. Furthermore, the study by Dickson and colleagues posits that *inconsistent* self-managers had experience but lacked the skills necessary to respond to symptoms appropriately or were inconsistent in their appraisals and management.(12) Dickson explains that in these instances, HF self-care management is often not a top priority. Competing responsibilities such as employment, other comorbid conditions, and family roles are perceived as more important, resulting in inconsistent HF self-care management.(12) Other *inconsistent* self-care managers also described becoming less vigilant with symptoms over time, taking a more lackadaisical approach to self-management.(12) As evident in the study population of this thesis, many participants described competing responsibilities such as employment and family roles that interfered with seeking professional care – a vital part of self-care management. Participants also described becoming more relaxed about symptom management over time and growing accustomed to symptoms they once deemed as severe. According to the typology proposed by Dickson and colleagues, most participants in this study, therefore, fell into the *inconsistent* or *novice* self-care management category, which explains why they had such difficulty interpreting signs of deterioration, linking them with mechanisms of HF, and taking appropriate and timely action.

The authors also posit that self-care *novices* can become self-care *experts* as skills are developed with time and experience. Again, HF management programs are responsible for ensuring education and support for patients with HF post-discharge, and the challenge of symptoms appraisal and response have not gone unnoticed by HF organisations around the world. The European HF guidelines stress the importance of educating patients in symptom monitoring and self-care management to support the development of skills to monitor and recognise changes in signs and symptoms. These guidelines also specifically mention the importance of educating patients about HOW and WHEN to contact a healthcare professional.(25) The Australian guidelines specify that seeking healthcare when signs and symptoms worsen is an important component of self-care management.(2) Again, despite these recommendations, the inadequate number of HF management programs available to support and educate patients with HF, and the heterogeneity amongst programs makes achieving this goal difficult.(30, 31) Providing an action plan for symptoms would help support the advancement of self-care *novices* and *inconsistent* managers to self-care *experts*. Whilst there are resources available to help patients with HF make decisions about when symptoms should cause alarm, it is unclear how many patients and clinicians are accessing these resources. A simple mnemonic such as FAST used to help people with stroke appraise and respond to symptoms (Face: has their face drooped? Arms: can they lift both arms? Speech: is their speech slurred and can they understand you? Time: is critical. Call 000 if you see any of these signs)(35) would be of great value in this population.

### 8.2.1 Conclusion and recommendations for practice

Whilst many of the topics from the DHFKS aligned with topics patients perceived as problematic, total DHFKS score did not reflect the level of perceived uncertainty described by participants in interviews. Development of the DHFKS involved content and face validity assessment by a team of 12 HF experts (10 experienced HF nurses and 2 cardiologists) and 6 patients with HF.(36) The tool should be reviewed for content with larger consumer involvement to better represent patients' knowledge needs.

Participants identified a number of areas where understanding could be improved. Whilst there were few discrepancies between patients' educational needs and guideline recommended topics for HF education, evidence suggests that the heterogeneity and lack of HF management programs available to deliver this education may contribute to patients' poor understanding. Furthermore, to support the development of self-care *novices* and *inconsistent* managers to self-care *experts*, providing an easy-to-remember specific action plan for worsening HF symptoms is vital. Adherence to guideline recommended education and focus on how information can be best delivered to this specific population with specific needs can help better support patient understanding. Communication strategies and barriers and facilitators to effective patient-provider communication will be discussed in the next section.

## 8.3 Preferences for information delivery and patient-provider communication

Participants suggested a number of ideas to facilitate effective communication to support the development of a better understanding of their condition and management. Participants described their preferences for information delivery in relation to information retention, the need for tailored and personal information, and the ability to refer back to information post-discharge. Preferences for how information was communicated revolved around these main themes. Interview findings also revealed that credibility of information was of utmost importance, and thus most participants relied on providers as their main source of information, with most avoiding the Internet where possible. The qualitative data also captured perceived barriers and facilitators of effective patient-provider communication. These findings revealed interpersonal relationships largely impacted quality of communication, where effective communication was an integral part of positive patient-provider relationships. Other factors contributing to the effectiveness of patient-provider communication included: consistency of health information; patient's own limited executive function; and patients' orientation towards remaining informed.

### 8.3.1 Preferences for information delivery

#### *Sources of HF information*

Despite the abundance of information available online, providers were the number one source of HF information for these participants. These results are consistent with findings from a national survey exploring preferences for cancer information sources, which revealed physicians were the most highly trusted sources of information.(37) This study also suggested age-related differences in actual (rather than preferred) sources of information, with those aged over 65 years being ten times more likely to see a provider first before going to the Internet (75.6% vs. 7.7%), whereas younger people went to the Internet first (38.9% vs 46.6%).(37) This may be because younger people are more likely to use the Internet and have greater confidence in using technology for information. The age of participants in this study (61±15 years) most likely explains the preference for providers over the Internet. With the majority of HF cases occurring in the elderly, it can be assumed that this preference is not unique to this population, and that the majority of 'typical' patients with HF would prefer face-to-face patient-provider communication rather than via the Internet.

Whilst providers were clearly the preferred source of HF information, online and telephone services offered by disease-specific organisations were also noted as credible sources of information used by some participants post-discharge from hospital. These peak professional bodies were preferred to indiscriminate searching via search engine, highlighting the importance of providing reliable information that can be easily accessed by patients at any time.

Currently, the National Heart Foundation of Australia website(38) offers information for people with a range of heart conditions, including information specific to patients with HF. This information is written in plain language and covers topics such as diagnosis and symptoms of HF, monitoring fluid and symptoms, and lifestyle changes. It also includes links to the Heart Foundation Helpline, which is a free telephone service that patients can ring during business hours for more personalised information and support, offered by a health professional. The American Heart Association also offers online resources for people living with HF,(39) including a HF support network, which encourages patients to 'connect with people like me'. The support network is a forum where people can post questions and get answers from health professionals, share experiences with others online and comment on others' stories, and learn about coping with HF and regaining independence. In the interview findings from this thesis, one participant described his struggle in coping with chronic fatigue, wanting more information about how he could better manage the emotional consequences of limiting symptoms. An online forum encouraging people to share their experiences and learn about how others manage the physical and psychological effects of symptoms may be valuable for this population. Heartfailurematters.org(40) is another online resource, developed by the European Society of Cardiology and available in 10 different languages, tailored specifically for people living with HF and their caregivers. Content includes video interviews with patients and caregivers, educational animations, and a virtual guide for the website to enhance usability. This website also includes a section on myths and facts about HF and printable self-management resources to stimulate self-maintenance and taking appropriate action in response to deterioration. Finally, another online resource developed by the National Heart Foundation of Australia(41) offers information for both health professionals and patients, to educate and support self-care management in heart disease including a weight and symptoms diary, and videos that aim to help people understand their condition and how best to manage it. This resource also provides links to the aforementioned heartfailurematters.org website(40) for further information for patients. There is, however, little evidence to suggest if/how people are using these online resources and tools, and how it impacts self-care management and coping.

As noted in the previous section, multidisciplinary HF programs are key post-discharge management and education portals that are recommended by HF guidelines.(2) The scarcity of programs available, with respect to the number of hospitalised patients with HF, has already been noted as a major barrier to optimal post-discharge management. Limited access to multidisciplinary HF programs due to geographic or funding barriers has seen the rise in the use of telehealth. Telehealth is a term used to describe delivery of health care and/or support via telecommunications. There has been limited uptake of the more technologically advanced forms (telemonitoring) with some services using structured telephone support. Results from the WHICH? II trial, however, revealed that a combination of home visits plus structured telephone support with intensity tailored to level of risk was no better than standard care (which would be considered high level of care).(42)

Interview findings revealed that in some cases, participants felt the Internet was their only choice when questions and concerns about their condition arose outside of scheduled visits. The ability to reach providers easily through a secure online portal would help patients avoid needing to scrutinise the reliability of information sourced from the Internet. Online tools associated with electronic health records generally include a function that allows secure communication between a patient and health provider electronically. In 2013 in the US, approximately 40% of physicians in outpatient settings had some type of patient portal to assist in the management of chronic disease.(43) These have been shown to improve general adherence to medical advice and satisfaction with patient-provider communication in patients with HF.(44) Satisfaction with patient-provider communication improved in terms of how well these patients with HF felt their problems were understood, and how well doctors explained information.(44) There is mixed evidence regarding the impact of patient-physican messaging on healthcare utilisation.(45, 46) A recent systematic review suggests there is insufficient evidence to show that patient portals improve health outcomes, cost, or healthcare utilisation, and demonstrate mixed results about patient satisfaction.(47) Whilst this systematic review demonstrates mixed outcomes for patients across all chronic disease, its use in a HF population yielded positive results.(44) Providing a realm for patients to effectively and rapidly communicate with their providers outside of scheduled visits in situations of rapid deterioration, as in HF symptom exacerbation,(48) is an invaluable way of potentially reducing avoidable HF hospitalisation. Attitudes towards the use of patient portals however vary, with major concerns around the safety of secure messaging online. (49) Whilst the use of electronic health records with patient portals has been gaining traction in the US for the last decade, electronic health records have only launched in Australia since 2016. In the 2017 national budget, the Australian government announced plans to create a My Health Record for every Australian beginning mid-2018 on an opt-out basis.(50) This scheme is intended to help improve the continuity of care between facilities (i.e. one record for all providers). The My Health Record insofar, however, does not offer a secure messaging portal for patients to communicate with their providers.

### *Information retention*

Participants voiced preferences for information delivery and communication style, which centred around strategies that would facilitate information retention. For example participants suggested the use of multiple methods of delivery (i.e. written, visual and verbal), pacing of information, and expressed a preference for-to-face communication.

In a long-term randomised controlled study, investigators explored the effects of a repetitive-cyclic re-education program where people with HF received repetitive information every 6 months as part of the HF disease management program.(51) Results from this randomised controlled study support this strategy, showing a decrease in unplanned admissions, total days in hospital, ED visits and improved quality of life for those in the intervention group where the mean follow up was 2.47±1.75 years.(51)

Heart failure management programs prioritise face-to-face delivery of information and care for high-risk patients with HF i.e. those who have experienced HF-related hospitalisation and are symptomatic (NYHA II-IV).(2) According to these guideline recommendations and the inclusion criteria of this study, all participants should have had access to a multidisciplinary HF program. Although quantitative data was not collected in relation to participation in a post-discharge multidisciplinary program, interview findings revealed some participants had experienced cardiac rehabilitations and other models of care, whereas it was clear others had not. There are various potential reasons for this that could be provider or patient-related. All suggestions noted by participants to facilitate information retention to help effectively manage HF in their day-to-day lives are strategies reflected by the guideline recommendations for post-discharge multidisciplinary care.(52) The 2013 consensus statement '*A systematic approach to chronic heart failure care'*(53) stresses the need for care to be delivered systematically to ensure access to appropriate and coordinated care for all patients with HF. The statement also recommends care to be documented, allowing activities to be audited for quality improvement to ensure care is evidence-based.(53) Using the multidisciplinary guidelines to assess whether the delivery of care is evidence-based will ensure patients with HF receive the best-practice face-to-face education that is recommended.

Note-taking during medical consultations were described as a simple and effective way of retaining information and ensuring management continuity, which could easily be adopted by most patients with HF. The literature suggests audio recording medical encounters could also be a way to enhance understanding and information recall. A recent review provides evidence of greater engagement in treatment decisions, enhanced understanding and information recall and the ability to easily share information with friends and family as a result of providing recordings of clinical consultations to patients.(54) Authors explain the potential value of recording medical encounters, particularly in specialties such as HF where emotional reactions might interfere strongly with cognitive processing of information.(54) Findings from the review revealed that patients heard ‘new’ and forgotten information in recordings, and reported better emotional and psychological adjustment to their illness.(54) The review also suggests that patients with lower socio-economic status, older age, impaired abilities and overwhelmed with stress may benefit more,(54) almost aligning entirely with the characteristics of a typical patient with HF. Providers had mixed feelings about recording consultations, dependent on clinical area. Specialists, mostly oncologists, generally supported this method, whereas surgeons and GPs had contrasting views. The review also found that physicians (specialists and GPs) with fewer years of experience were more likely to be open to recording consultations. In terms of the medico-legal aspects of recording clinical consultations, in Australia, laws vary by state. All-party consent is required in NSW, the ACT, Tasmania, and WA unless the patient does not share or publish the conversation with anyone not involved.(55) In the Northern Territory, Queensland and Victoria, there is no law against using recording devices in a private conversation that a party is involved in.(55) In all states however, it is illegal to share a recording of a consultation without the consent of their health professional.(55) Recording of consultations could be a strategy to combat issues relating to information retention in HF, however this could potentially come at the cost of damaging patient-provider relationships, which may, paradoxically, hinder communication. Patients may be wary of being caught recording medical encounters or be concerned about asking permission to record for fear of upsetting their health providers.(56) On the other hand, providers could potentially be concerned about the being covertly recorded.(56) Both of these situations impacts on trust between providers and patients, which may thwart open and effective communication.(56) Elwyn and colleagues suggest the development of guidelines and regulations on patient recording in collaborative effort between clinicians, patient advocacy groups and policy makers.(56)

### *Tailored information*

Participants stressed the importance of getting tailored information specific to their aetiology, and that accounted for their comorbid conditions. It was noted on countless occasions that participants did not perceive themselves as the 'typical' patient with HF, expressing the need for more case-specific information that took into consideration the nuances of their health status. It was largely for this reason that participants preferred to get information from their treating doctors who knew the details of their case. Despite being slightly younger than the average HF population and with a greater diversity of aetiolgies, this cohort was still representative of the 'typical' HF population in that multiple comorbid conditions and frailty were common. This is something that needs to be considered in patient education and HF management as it is fruitless to educate patients on one body system when multiple are failing. The interaction and relationship between multiple comorbid conditions makes treatment and patient education challenging, however, efforts must be made to take a more holistic approach, viewing patients as an entire being rather than focusing on one condition in isolation. Information needs to be patient-focused, not disease-focused. Whilst this embodies the idea of multidisciplinary care, noted issues around access and availability of programs and fidelity to guideline recommendations is problematic. Furthermore, known patient-level barriers such as cognitive impairment, memory loss and difficulty retaining information also impacts outcomes of HF education. These barriers to patient-provider communication will be further discussed below.

## 8.3.2 Barriers and facilitators to effective patient-provider communication

### *Depth and consistency of information*

Consistent information delivered by providers was perceived as the most effective in terms of successfully conveying health messages. When participants heard the same message coming from more than one provider such as the health message of 'any symptoms, call an ambulance' relayed by the nurse, doctor and specialist, they were more likely to retain this information and bear the intent to act accordingly. Conversely, fragmented health messages that may or may not be conflicting are likely to add to the confusion around self-management. The potential for mixed messages and ambiguous coordination are a consequence of the very aspect of healthcare that offers strength – a multidisciplinary approach.(57, 58) A multidisciplinary approach to HF management means that patients with HF are cared for by an array of providers. It is imperative that care is coordinated where goals of care are coherent between specialties and clinical areas to ensure management continuity. Haggerty and colleagues define the concept of management continuity as *"a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs".*(59) They stress the importance of management continuity in the context of chronic disease that require management from several providers, as in HF.(59) Delivery of services in a complementary and timely manner and shared management are all strategies that facilitate management continuity.(59) Best-practice multidisciplinary care needs to be flexible, however expectations and roles of each team member need to be clarified from the start.(60) Furthermore, strategies to improve patient-provider communication (detailed in section titled *'Patient-provider relationships'*) can be used to enhance provider-provider communication to facilitate open and transparent communication styles.(60) These strategies could be used to ensure coordinated care in HF disease management programs, to ensure patients with HF receive care and education that is consistent and coherent.

Consistency of information was an important part of effective patient-provider communication, as was depth of communication. Many participants perceived they were not provided with sufficient information about their condition due to perceived lack of time. Lack of patient-provider communication and general effort to keep patients informed about their condition contributed to participants' overall negative perceptions of healthcare experiences. Despite wanting to take an active role in their care, some participants felt they were unable to so because these conversations were either inadequate, or simply not happening at all. Perception that there is too little time to effectively communicate is not an uncommon perceived barrier reported by patients suffering chronic conditions.(61) It should also be noted, however, that participants' perceptions of insufficiently detailed information might be impacted by their ability to remember information. Whilst cognitive functioning was not assessed in this study, participants alluded to memory problems that impacted their capacity to self-manage in the interviews, and struggled to recount details of their condition and management. Findings from a double blind RCT revealed that patients who received an audio-recording of their medical consultation perceived that they received more information about their condition than those that did not have an audio-recording to jog their memory.(54) Potential patient-level barriers in relation to cognitive capacity may therefore contribute to participants' perceptions of insufficient/fragmented delivery information. These barriers will be discussed in greater detail in the next section.

Participants also described perceived concealment of information that impacted patient-provider communication. This differed from perceived lack of communication in that concealment was perceived as deliberate. Participants described their providers 'sugar-coating' health information, particularly in relation to prognosis, which in some cases facilitated coping, but in other led to lack of trust. Participants perceived that providers sometimes did not deliver important information, whether deliberate or not, or that they minimised severity. Reasons for not comprehensively discussing prognosis may include the inherent challenge of determining prognosis in HF, the idea that not every patient wants to know, and the potential effect of therapies that can dramatically change trajectories. Also, providers may be uncomfortable discussing end-of-life issues, or perceive it can cause patients to lose hope.

### *Complex medical language and limited patient executive function*

Participants noted how complex medical language impedes effective patient-provider communication, yet noted the simple solution of asking providers to present information in plain language if it was too complex. Effective patient-provider communication was described in relation to clear and thorough explanations with no unnecessary use of technical jargon. Doctors and nurses sometimes speak in clinical terms, which may not be understood by patients. It is crucial for all clinicians to develop plain language skills to enhance communication with patients.

The importance of using plain language to communicate information is vital to ensure patients receive usable information to effectively self-manage in their daily lives. This is particularly important to implement in a HF population, as approximately 39% of people with HF have low health literacy (inadequate and marginal).(62) This thesis reflected a slightly lower prevalence of low health literacy than the studies in HF, but represented a quarter of participants nonetheless (25% marginal or inadequate). Interviews also revealed memory problems that encumbered participants' ability to recall health information and thus impacted understanding of HF and symptoms. In a relatively small scale study conducted in the US involving 95 hospitalised patients with HF, adequate health literacy was associated with higher HF knowledge and self-care confidence, but not self-care management or self-care maintenance.(63) However, in a recent study examining the three domains of health literacy (functional, communicative, and critical) with self-care behaviours, authors found that critical health literacy was an independent predictor of fewer self-care behaviours and consulting behaviour.(64) Critical health literacy is defined as the ability to critically analyse and use information to gain greater control over life events and situations.(65) Critical health literacy would therefore enable patients with HF to recognise worsening symptoms and make appropriate decisions about seeking timely care,(64) so its association with self-care and consulting behaviours is not surprising. In a slightly larger study (n=192) which used the STOFHLA to assess health literacy in patients with HF, findings showed that patients with adequate health literacy had 64% fewer HF hospitalisations (incidence rate ratio, 0.34; 95% CI, 0.15–0.76).(66) In an even larger study involving 1494 outpatients with HF, low health literacy was significantly associated with higher all-cause mortality.(67) In addition to its role as a major barrier to effective patient-provider communication, the association of low health literacy with poor outcomes and self-care in patients with HF warrants attention.

Whilst improvements can be made in terms of delivery of HF information, patient-related barriers such as low health literacy and memory problems impact the ability for people with HF to understand health information and adhere to recommendations. Despite all efforts to effectively educate and support patients with HF, they are often older, have low health literacy, and memory problems. Furthermore, even patients who are well-educated and have adequate literacy skills can experience stress-induced limited health literacy, where emotional response and physical symptoms interfere with the ability to pay attention and listen effectively.(68) This has been found to be the case in the context of serious illness,(68) which relates to this cohort, and patients with HF globally. People with HF are, therefore, limited by their own executive function. Management and education strategies should be tailored to cater for the needs of those who might have difficulty understanding, using, and remembering vital health information to enable effective self-management. The ways in which these health messages are conveyed are of utmost importance. Whilst the tailoring of written health information has been shown to improve health literacy, enhancing the 'listenability' of oral health messages is equally as important. Rubin suggests a shift from the readability paradigm to the listenability paradigm, where focus is on improving the quality of the spoken health message.(69) In this thesis, it has been shown that despite the abundance of information available to patients with chronic illness online and through other sources, such as via telehealth, face-to-face communication with providers is the preferred way of receiving health information.(37) Patients generally obtain much of their health information from listening, rather than reading. Rubin suggests to enhance the 'listenablity' of health messages, use oral-based language rather than written and also ensure considerateness of the health message.(69) Rubin describes considerate health messages as those that allow listeners to predict what is coming in the conversation, recommending narrative style discourse to help guide patients through the information.(69) He posits that story-like formats are familiar and are thus a valuable strategy to enhance 'listenability' of health messages and improve health literacy.(69)

### *Patient-provider relationships*

Patient-provider interpersonal relationships played a major role in perceived quality of communication. Lack of communication, respect, not being heard, and paternalism were described in relation to negative relationships with providers, which were deleterious to effective two-way communication. On the other hand, trusting relationships involving providers that effectively took time to listen and who offered compassion facilitated open communication. These positive patient-provider relationships made participants feel more comfortable to reach out to their trusted providers, overcoming any barriers related to the fear of being perceived as a burden.

Providing empathy, information, and reassuring patients are important strategies to improve the quality of patient-provider communication, however this has been labeled as a somewhat reductionist way of improving medical communication.(70) Van Dulmen draws attention to the multidimensional concept of listening, which involves more than simply hearing what the other person is saying.(70) Listening also requires eyes (patient directed gaze), a heart (compassion), and undivided attention. A good listener not only hears the content of what is being said, but also understand the underlying emotions. Examples from participants in this thesis demonstrate that effective provider listening is not ubiquitous. Participants described countless instances where concerns were deemed as unjustified, and felt they did not have the undivided attention of their providers. For one participant, this led his preference for being treated in the ambulance rather than the hospital, as he felt the paramedics had nowhere to go and simply could not be distracted by other patients or responsibilities. Listening is an act of acquiring the perspectives of another person and is thus integral in person-centred care.(71) As evident in participants' accounts, this can be neglected in patient-provider communication due to perceived lack of time, and long term patient-provider relationships where patients' perspectives, attitudes and preferences are assumed.(72) A pilot study involving medical students who were trained in listening techniques or listening attitudes found that those who were taught listening attitude responded better to patients' feelings.(73) A listening provider is highly valued by patients as it can be therapeutic and stress-reducing, and is an act of respect which facilitates positive patient-provider relationships.(74) Results from this thesis have illustrated the damaging effects of not being heard, highlighting the importance of listening to improve patient-provider relationships and thus communication. When providers do not listen, quality of care is threatened.

The concept of listening is not limited to the busy health provider, but also the patient. Of course, a listening health provider implies that a patient's voice counts, but a listening patient shows appreciation for expert opinion.(70) As explained in the previous section, the capacity for a patient with HF to be attentive and actively participate during patient-provider consultations is limited by executive function. Furthermore, in the context of serious illness such as HF, emotional and physical symptoms may impede patients' ability to pay attention and listen effectively.(68) Older patients with lower health literacy, which reflects a large proportion of HF patients, are likely to experience greater difficulty in maintaining focus and attention during consultations. (68) Van Dulmen suggests listening attitude and skills of patients and health professionals need to be enhanced through interventions at policy, practice, and research levels. For example, on the policy level, training courses to enhance communication skills can be used to enhance patient listening.(70) On the practice level web-based tools can be used to enhance communication during medical consultations(70) such as the Question Builder developed by the Australian Commission on Safety and Quality in Health Care in partnership with Healthdirect Australia.(75) This newly launched online tool aims to help patients get more out of the limited time they have during patient-provider consultations by helping patients prepare questions to help remember key concerns requiring discussion. Another previously noted strategy is the use of audio-recordings of medical consultations.(70) On a research level, van Dulmen suggests a shift from research *on* patients, to research *for* patients, to research *with* patients, advocating for larger consumer involvement in research design, and inclusion of the patient's voice.(70)

Consideration of patient perceptions, preferences for transparency, delivering information clearly and simply and being sensitive to emotional responses have been flagged as important concepts to implement in a recent review of patient-provider communication in HF.(60) The review suggests several strategies to enhance patient-provider communication, often used in a palliative care context, but equally as appropriate and transferable to a HF population. A simple mnemonic, "SPIKES", which is widely used in palliative care provides a guide for effective patient-provider interactions.(76) The 'S' stands for setting, 'P' for perception, 'I' for invitation, 'K' for knowledge, 'E' for emotion, and 'S' for subsequent/summary. The first step, 'setting' involves reviewing what is to be discussed, which required co-ordination of care particularly if multiple providers are involved. 'Perception' involves understanding what the patient knows and how they perceive their condition. 'Invitation' relates to asking the patient how much they would like to know, taking into consideration that every patient has the right to decline to receive any information and may prefer this information to be communicated to someone else on their behalf. 'Knowledge' involves sharing of the information using simple language with room for silence so patients can absorb the information. 'Emotion' involves giving patients and family members time to react to the information without being rushed and being prepared to respond in a supportive manner whatever their response. Providers may need to moderate their own emotions at this stage and can acknowledge the patient's emotions and ask them to describe how they feel (e.g. " You appear to be angry. What are you thinking right now?"). In the final step, 'Subsequent/summary', the provider should plan the next steps and ensure relational continuity should the patient require referrals for emotional/practical support.

Hauser also suggests that throughout any patient-provider encounter, the 'Ask-Tell-Ask' approach can be used to ensure patient comprehension by getting feedback about what they understood. Another mnemonic, NURSE (Name, Understand, Respect, Support, Explore),(77) is a helpful guide to facilitate expressions of empathy and can be used in consultations with patients with HF. Motivational interviewing (MI) uses empathetic understanding to increase motivation for behaviour change whilst reducing ambivalence about changing behaviour(78) and has been shown to improve HF self-care.(79) A recent study by Riegel and colleagues has identified the key aspects of MI that effectively impact self-care in patients with HF.(80) Results from this study revealed that: reflection and reframing; genuine empathy, affirmation and humour; and individualised problem solving were the three MI techniques that were related to improved self-care. These techniques facilitated openness to goal setting, positive self-talk, change talk and improved patients' perceived capacity to conquer barriers.(80) The way in which the MI techniques facilitated self-care was through improving self-efficacy and promoting the development of discrepancy, as in recognising how current behaviours were different to ideal behaviours and goals.(80) Results from this study suggest that MI techniques can be used to better engage patients with HF in self-care and promote behaviour change.(80)

#### *Patients' orientation toward remaining informed*

Finally, participants' orientation towards remaining informed impacted patient-provider communication either facilitating open and effective communication in the case of problem-focused coping, or avoiding information in cases of emotion-focused coping. Recognising the seriousness of a deteriorating heart and the importance of being able to communicate details to others impacted participants' attitudes about remaining informed.

As noted in the previous section, the 'I' of the SPIKES mnemonic (representing 'invitation') highlights the importance of ascertaining how much a patient wants to know in order to facilitate effective patient-provider interactions. Findings from this study revealed that orientation towards remaining informed varied, further confirming the importance of this step.

### 8.3.3 Conclusion and recommendations

Despite the widespread availability of information, face-to-face communication with providers was the preferred source and method of receiving HF information. Enhancing patient-provider communication is, therefore, key to provide the basic knowledge required for effective self-management. Consistency and depth of information, the use of complex medical language, and patient-provider interpersonal relationships were found to impact quality of communication. To assuage some of these barriers identified, a listening approach rather than listening techniques could be adopted to improve both patient-provider communication and interpersonal relationships. The use of complex medical language, and lack of in-depth information were other factors that impacted the quality of communication and patient understanding. Since face-to-face interactions were the medium in which patients got most of their information, a focus on the quality of oral health information is important. Furthermore, consistent information was found to be the most powerful, highlighting the importance of also enhancing provider-provider communication, to ensure management continuity. Whilst provision of information that is readable, listenable, consistent and detailed enough is crucial, evidence and findings from this thesis suggests patient's own limited executive functioning can impact complex decision-making processes such as deciding what symptoms mean and what to do. Memory problems and health literacy interfere with decision-making and patient-provider communication. Tailoring educational intervention to facilitate information retention and account for those with lower health literacy is key in providing best-practice care. It should be noted that effective communication is proportional to a patient's willingness to learn and/or ability to absorb and remember. Efforts to educate may be futile if not supported by patients and/or tailored to address these patient-level barriers. For example, enhancing listenability of health messages to improve health literacy, and using patient prompt lists or medical recordings to help patients remember forgotten health information.

## 8.4 Study conclusions

### 8.4.1 Strengths and limitations

The major strength of this study is that it draws attention to an aspect of HF self-care management that is not well understood, yet could help to considerably reduce avoidable emergency admissions, reduce lengths of stay in hospital, and improve quality of life. Exploring patients' experiences of care-seeking and interactions with the healthcare system through in-depth semi-structured interviews provides a voice for this vulnerable population and an opportunity to express unmet needs. A focus on patient representations of illness through the use of IPA enables us to get as close as possible to the world as they see it, allowing for greater insight into the decision-making process and illuminating the complexities of how unique contextual factors may impact care-seeking. Using a mix of methods, where one dataset compliments the other, provided a clearer understanding of care-seeking in HF, and greater insight into perceived quality of patient-provider communication. The pragmatic 'what works' approach adopted in this thesis meant that the research problem of delayed care-seeking was central and a mix of methods were used to provide the best chance of answering them. Using both qualitative and quantitative approaches revealed that factors typically associated with HF self-management such as self-efficacy may not impact decisions to seek professional care to the same degree. Findings from one dataset helped illuminate the other, in this case illustrating the importance of previous healthcare experience, which included interactions with providers, in decisions to seek or avoid professional care. Finally, this study involved theory-driven research, where the SRM was used to help understand how patient-level factors can impact care-seeking in a HF population. The principles of self-regulation have previously been used to understand delayed care-seeking in other illness populations, such as stroke and symptoms of heart attack. This thesis demonstrates its use in HF, and offers a framework to understand how patient representations can inform behaviour in illness.

The main limitations of this study were centred around measurement of variables and limited capacity to undertake further statistical analysis due to the relatively small sample size of the study population. Firstly, the primary outcome of delayed care-seeking was not measured quantitatively, as there is no standard measure of delay that incorporates all three stages of care-seeking (i.e. illness delay, appraisal delay and utilisation delay). Previous studies have used patient report to assess delayed care seeking as a single measure, or have relied on notes from admission to hospital which are often inconsistent. For this reason, it was decided that delay would not be measured and the processes underlying care-seeking would instead be explored qualitatively. Secondly, this study was part of a larger pre-existing study being conducted at St. Vincent's Hospital Sydney, therefore bringing about limitations in terms of what variables could be added to the already comprehensive battery of questionnaires. Cognitive function was not added to the list of assessments to minimise responder burden and uphold ethical principles of patient wellbeing. Cognitive function and other variables such as level of education were omitted from the CRF/questionnaires due to these limitations around study design and responder burden. It should also be noted that there were a number of other HF studies occurring at the same time so it was not possible to design a separate study specifically for this thesis. Furthermore, this study assessed functional health literacy using the S-TOFHLA, as it is one of the most commonly used assessments in HF and the most appropriate tool to use in a chronically ill patient population due to its brevity. As noted in the introduction, there are different types of health literacy, and functional health literacy, the most basic form, although important, may not be the type of health literacy most likely to impact decisions to seek or avoid professional care. Critical health literacy may be a more appropriate measure for exploring this health behaviour due to the higher level of skills required to make decisions complex in nature such as professional care-seeking. The measurement of functional health literacy using the S-TOFHLA, whilst appropriate in this population and allowed for benchmarking with patients with HF globally, does not reflect health literacy as a multidimensional concept. Finally, the relatively small sample size of this study did not enable the researcher to perform meaningful analysis to assess correlations between variables, and the impact of measured variables on outcomes (i.e. rehospitalisation and death) despite these outcomes being collected at 30 days and 6 months as part of the larger study. Due to these limitations, analysis was limited to descriptive statistics. It should also be noted that participants recruited into this study might not be representative of the general Australian HF population, as participants were recruited from a single site, which also happens to be the Centre of Excellence for HF management, caring for the most ill and atypical cases. A methodological limitation of the interviews was that member checking did not occur (i.e. responses were not validated by participants following transcription of interviews). However, interpretations were checked during the interview process, where the researcher summarised what participants said and confirmed whether her interpretations of their experiences were correct.

### 8.4.2 Concluding comments and summary of recommendations

This study provided a comprehensive account of care-seeking in HF, bringing to light patient, provider and system-related factors that contributed to patient decision-making. Integration of the qualitative and quantitative data suggests the importance of previous healthcare experiences in care-seeking decisions. Discussion of these findings, including strategies to improve patient-provider communication, has generated recommendations for research, policy and practice that can promote timely care-seeking in HF. Summaries of these recommendations are detailed below.

Future research

- Development of a measure of delay reflecting all three stages (appraisal delay, illness delay and utilisation delay) to enable further research to assess the impact of influential factors on outcomes.
- Use of a brief measure of critical health literacy to assess patients’ capacity to use health information for more complex problem solving.
- Addressing the limitations of the study including the assessment of cognitive function, and the use of a larger sample size to enable more sophisticated quantitative analysis. In addition to the use of a valid measure of delay, further quantitative analysis with a larger sample can help determine which factors are significantly linked with each stage of delay.

- Improved integration of previous healthcare experiences into current HF self-care theory, and consideration of these factors in the development of interventions to improve response to symptoms in HF.
- Although care-seeking is a part of HF self-management, the notion that the two may be conceptually independent must be considered in future research and theory development.
- The DHFKS tool should be reviewed for content with larger consumer involvement to better represent patients' knowledge needs.

Policy and practice

- Public health initiatives to raise the profile of HF to help patients with HF (and the general public) understand how HF is different from other types of cardiovascular disease. This will help provide another image and symptom profile for patients with HF to identify with, other than the one assumed for general heart conditions.
- Motivational interviewing to help depressed patients with HF manage their loss of independence and increased reliance on others by fostering active coping, rather than avoidance or passive coping styles.
- A guided reflection intervention may be a useful strategy to encourage timely care-seeking in HF, capitalising on the feedback appraisal aspect of self-regulatory processes.
- Consideration of anxious symptoms as well as depressive symptoms in interventions to improve care-seeking in HF. The impact of anxiety receives less attention than depression in HF self-management, yet is highly prevalent in this population and contributes to care-seeking decisions.
- A focus on building a clear and specific action plan for HF symptoms, which is made available to all patients with HF.
- Providing tailored HF education that accounts for patients' co-morbid conditions.

- Assessment of multidisciplinary HF management programs to ensure fidelity to guideline recommendations.
- Enhancing patient-provider communication and provider-provider communication to ensure management continuity and improve health literacy. Strategies to enhance communication must focus on the quality of oral health information and advocate for the use of a listening approach rather than listening techniques.
- Providing a pathway for patients with HF to communicate meaningfully with providers outside scheduled visits (e.g. through a secure online portal).
- Tailoring communication strategies to facilitate information retention and account for those with lower health literacy is key in providing best-practice care.

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## Appendix 1 Search Strategies

**Table 1**

MEDLINE search strategy and results (1956-present)

| Searches | Results | Search Type |
|---|---|---|
| 1 | heart failure.mp. or Heart Failure/ | 140193 |
| 2 | chronic heart failure.mp. | 11390 |
| 3 | cardiac failure.mp. | 10227 |
| 4 | congestive heart failure.mp. | 33777 |
| 5 | ventricular dysfunction.mp. or Ventricular Dysfunction/ | 33022 |
| 6 | ventricular dysfunction, left.mp. or Ventricular Dysfunction, Left/ | 20839 |
| 7 | ventricular dysfunction, right.mp. or Ventricular Dysfunction, Right/ | 3635 |
| 8 | 1 or 2 or 3 or 4 or 5 or 6 or 7 | 167766 |
| 9 | qualitative research.mp. or Qualitative Research/ | 25189 |
| 10 | interview$.mp. or Interview/ | 251621 |
| 11 | focus group$.mp. or Focus Groups/ | 26625 |
| 12 | ethnograph$.mp. | 6070 |
| 13 | phenomenol$.mp. | 16015 |
| 14 | grounded theory.mp. | 6028 |
| 15 | thematic.mp. | 10444 |
| 16 | content analysis.mp. | 11862 |
| 17 | 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 | 299471 |
| 18 | 8 and 17 | 1130 |
| 19 | symptom$.mp. or Symptom Assessment/ | 778219 |
| **20** | **18 and 19** | **313** |

**Table 2**

CINAHL search strategy and results

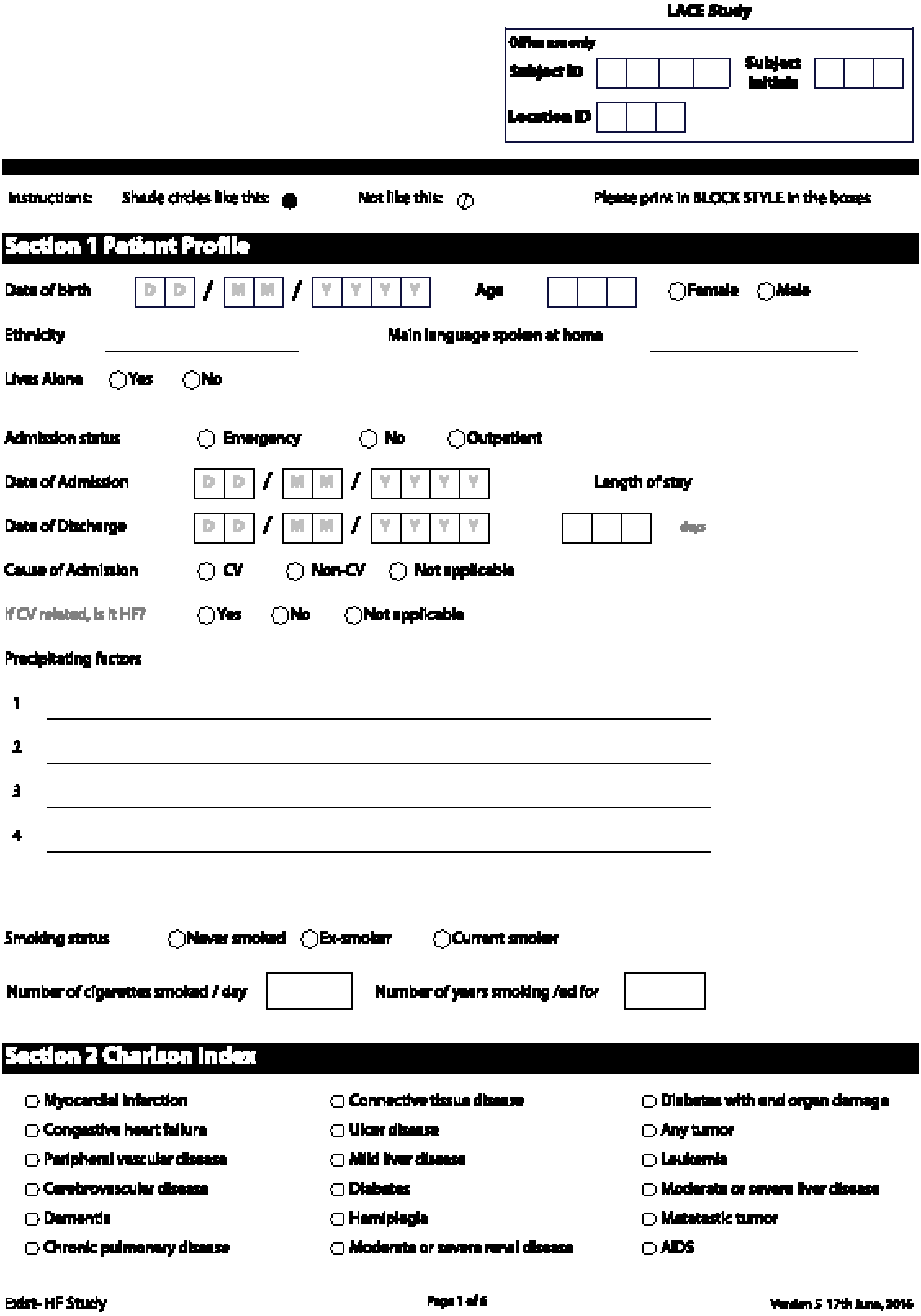
| Search Terms | Search Options | |
|---|---|---|
| S19 | S6 AND S15 AND S18 | (82) |
| S18 | **S16** OR S17 | (26,03) |
| S17 | "symptom assessment" | (550) |
| S16 | (MH "Symptoms") OR "symptom$" | (26,034) |
| S15 | S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 | (172,631) |
| S14 | (MH "Content Analysis") OR "content analysis" | (19,639) |
| S13 | (MH "Thematic Analysis") OR "thematic" | (29,888) |
| S12 | (MH "Grounded Theory") OR "grounded theory" | (9,947) |
| S11 | (MH "Phenomenological Research") OR (MH "Phenomenology") OR "phenomenol$" | (10,853) |
| S10 | (MH "Ethnographic Research") OR "ethnograph$" | (4,639) |
| S9 | (MH "Focus Groups") OR "focus group$" | (21,842) |
| S8 | (MH "Interviews") OR "interview$" | (135,190) |
| S7 | (MH "Qualitative Studies") OR "qualitative research" | (51,700) |
| S6 | S1 OR S2 OR S3 OR S4 OR S5 | (21,790) |
| S5 | "ventricular dysfunction, right" | (708) |
| S4 | "ventricular dysfunction, left" | (3,772) |
| S3 | (MH "Ventricular Dysfunction") OR "ventricular dysfunction" OR (MH "Ventricular Dysfunction, Right") OR (MH "Ventricular Dysfunction, Left") | (5,236) |
| S2 | "cardiac failure" | (418) |
| S1 | (MH "Heart Failure") | (17,673) |

**Table 3**

Embase search strategy and results (1974- 2014 July 09)

| Searches | Results | Search Type |
|---|---|---|
| 1 | heart failure.mp. or heart failure/ | 243379 |
| 2 | chronic heart failure.mp. | 17429 |
| 3 | congestive heart failure.mp. or congestive heart failure/ | 79254 |
| 4 | cardiac failure.mp. | 13562 |
| 5 | ventricular dysfunction.mp. | 18103 |
| 6 | ventricular dysfunction, left.mp. | 220 |
| 7 | ventricular dysfunction, right.mp. | 61 |
| 8 | 1 or 2 or 3 or 4 or 5 or 6 or 7 | 258505 |
| 9 | qualitative research.mp. or qualitative research/ | 31879 |
| 10 | interview$.mp. or interview/ | 296074 |
| 11 | focus group$.mp. | 26732 |
| 12 | ethnograph$.mp. | 7276 |
| 13 | phenomenol$.mp. | 20621 |
| 14 | grounded theory.mp. or grounded theory/ | 7223 |
| 15 | thematic analysis/ or thematic.mp. | 11948 |
| 16 | content analysis.mp. or content analysis/ | 14936 |
| 17 | 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 | 352743 |
| 18 | symptom/ or symptom assessment/ or symptom$.mp. | 1145631 |
| **19** | **8 and 17 and 18** | **521** |

## Appendix 2 LACE Case report forms



**LACE Study**

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Instructions: Shade circles like this: ● Not like this: ⊘ Please print in BLOCK STYLE in the boxes

### Section 1 Patient Profile

Date of birth D D / M M / Y Y Y Y Age ☐☐☐ ○Female ○Male

Ethnicity ____________ Main language spoken at home ____________

Lives Alone ○Yes ○No

Admission status ○ Emergency ○ No ○Outpatient

Date of Admission D D / M M / Y Y Y Y Length of stay

Date of Discharge D D / M M / Y Y Y Y ☐☐☐ days

Cause of Admission ○ CV ○ Non-CV ○ Not applicable

If CV related, is it HF? ○Yes ○No ○Not applicable

Precipitating factors

1 ____________________

2 ____________________

3 ____________________

4 ____________________

Smoking status ○Never smoked ○Ex-smoker ○Current smoker

Number of cigarettes smoked / day ☐ Number of years smoking /ed for ☐

### Section 2 Charlson Index

- ○ Myocardial infarction
- ○ Congestive heart failure
- ○ Peripheral vascular disease
- ○ Cerebrovascular disease
- ○ Dementia
- ○ Chronic pulmonary disease
- ○ Connective tissue disease
- ○ Ulcer disease
- ○ Mild liver disease
- ○ Diabetes
- ○ Hemiplegia
- ○ Moderate or severe renal disease
- ○ Diabetes with end organ damage
- ○ Any tumor
- ○ Leukemia
- ○ Moderate or severe liver disease
- ○ Metastatic tumor
- ○ AIDS

Exist- HF Study Page 1 of 6 Version 5 17th June, 2016

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## Section 3 Previous Medical History

Has the patient had any of the following conditions?

| | | No | Yes |
|---|---|---|---|
| Myocardial Infarction | | ○ | ○ |
| Hypertension | | ○ | ○ |
| High blood cholesterol | | ○ | ○ |
| Type I Diabetes | | ○ | ○ |
| Type II Diabetes | | ○ | ○ |
| Heart Failure | | ○ | ○ |
| Stroke/Mini Stroke | | ○ | ○ |
| Mental Illness | ○ Depression | ○ | ○ |
| | ○ Other (eg Bi-polar, schizophrenia | ○ | ○ |
| Irregular Heart Beat / Atrial Fibrillation / Palpitations | | ○ | ○ |
| Angina | | ○ | ○ |
| Coronary Artery Disease | | ○ | ○ |
| Vascular disease | ○ Peripheral arterial disease | ○ | ○ |
| | ○ Other – Please specify ____________ | ○ | ○ |
| Aneurysm *(Abdominal, thoracic)* | | ○ | ○ |
| Heart Valve Condition | | ○ | ○ |
| Pacemaker | | ○ | ○ |
| Implanted Defibrillator | | ○ | ○ |
| Renal Disease | | ○ | ○ |
| Sleep Apnoea | | ○ | ○ |
| Asthma / Lung Disease *(eg. Emphysema, COPD)* | | ○ | ○ |
| Arthritis | ○ Rheumatoid | ○ | ○ |
| | ○ Osteoarthritis | ○ | ○ |
| Eye disease / retinopathy | | ○ | ○ |
| Migraine | | ○ | ○ |
| Stomach ulcer | | ○ | ○ |
| Cancer | | ○ | ○ |
| Other serious condition<br>Please specify ______________________ | | ○ | ○ |

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## Section 4 Blood test results

### Blood chemistries

**Date of test** D D / M M / Y Y Y Y

| | | | | | |
|---|---|---|---|---|---|
| Sodium | ☐☐☐ | mmol/L | ALT | ☐☐☐ | mmol/L |
| Potassium | ☐ . ☐ | mmol/L | AST | ☐☐☐ | mmol/L |
| Urea | ☐☐ . ☐ | mmol/L | GGT | ☐☐☐ | mmol/L |
| Creatinine | ☐☐☐ | umol/L | Alkaline Phosphate Level | ☐☐☐ | mmol/L |
| eGFR | ☐☐☐ | | Calcium Level | ☐ . ☐☐ | mmol/L |
| Total Bilirubin | ☐☐☐ | umol/L | Corrected Calcium Level | ☐ . ☐☐ | mmol/L |
| Albumin | ☐☐☐ | g/L | Magnesium | ☐ . ☐☐ | mmol/L |
| Total Protein | ☐☐☐ | g/L | Phosphate | ☐ . ☐☐ | mmol/L |
| HbA1c | ☐ . ☐☐ | % | C-Reactive protein | ☐☐ . ☐☐ | mg/L |
| Homocysteine | ☐☐☐ | umol/L | | | |

### Haematology results

| | | | | | |
|---|---|---|---|---|---|
| Red blood cells | ☐ . ☐ | x $10^{12}$/L | Haemoglobin | ☐☐☐ | g/L |
| Haematocrit | ☐ . ☐☐ | | White blood cells | ☐ . ☐☐ | x $10^{9}$/L |
| Platelets | ☐☐☐ | x $10^{9}$/L | Fibrinogen | ☐ . ☐ | g/L |

### Coagulation studies

| | | | | | |
|---|---|---|---|---|---|
| PT | ☐☐ | sec | INR | ☐ . ☐ | |
| APTT | ☐☐☐ | sec | | | |

### Endocrinology

| | | | | | |
|---|---|---|---|---|---|
| TSH | ☐ . ☐ | mIU/L | ft 3 | ☐☐ . ☐ | pmol/L |

### Lipids

Fasting ○ Yes ○ No

| | | | | | |
|---|---|---|---|---|---|
| Total cholesterol | ☐ . ☐ | mmol/L | HDL | ☐ . ☐ | mmol/L |
| LDL | ☐ . ☐ | mmol/L | Triglycerides | ☐ . ☐ | mmol/L |

**Were these bloods taken at time of admission?** ○ Yes ○ No ○ Outpatient bloods

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## Section 6 Current medications

| | Generic name | Route | Dose | Unit | Frequency |
|---|---|---|---|---|---|
| 1. | | | | | |
| 2. | | | | | |
| 3. | | | | | |
| 4. | | | | | |
| 5. | | | | | |
| 6. | | | | | |
| 7. | | | | | |
| 8. | | | | | |
| 9. | | | | | |
| 10. | | | | | |
| 11. | | | | | |
| 12. | | | | | |
| 13. | | | | | |
| 14. | | | | | |
| 15. | | | | | |
| 16. | | | | | |
| 17. | | | | | |

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## Section 11 Physical examination

Date of assessment D D / M M / Y Y Y Y

NYHA Class ○ I ○ II ○ III ○ IV  Rhythm ○Sinus Rhythm ○Atrial Fibrillation ○Paced Rhythm

AKPS ○ 0 ○ 10 ○ 20 ○ 30 ○ 40 ○ 50 ○ 60 ○ 70 ○ 80 ○ 90 ○ 100

Canadian Class ○ I ○ II ○ III ○ IV

Fontaine stage ○ I ○ IIa ○ IIb ○ III ○ IV

Dizziness ○ Yes ○ No ○ No data

Palpitations ○ Yes ○ No ○ No data

Ascites ○ Yes ○ No ○ No data

JVP ○ No ○ Raised ○ No data

Crepitations ○ No ○ Basal ○ Widespread ○ No data

Oedema ○ No ○ Ankle ○ Calf ○ Knee ○ Higher than knee ○ No data

Heart rate ☐☐☐ beats/min

Respiratory rate ☐☐☐ breaths/min

SaO2 (Room air) ☐☐☐ %

Height ☐☐☐ cm

Weight ☐☐☐ . ☐ Kg

Hip ☐☐☐ cm

Waist ☐☐☐ cm

### Heart sounds

| | | | |
|---|---|---|---|
| S1/S2 | ○Yes | ○No | ○No data |
| S3 | ○Yes | ○No | ○No data |
| S4 | ○Yes | ○No | ○No data |
| Systolic murmur | ○Yes | ○No | ○No data |
| Diastolic murmur | ○Yes | ○No | ○No data |

### Blood pressure

Lying$_1$ ☐☐☐ / ☐☐☐ mm/Hg

Sitting$_1$ ☐☐☐ / ☐☐☐ mm/Hg

Lying$_2$ ☐☐☐ / ☐☐☐ mm/Hg

Sitting$_2$ ☐☐☐ / ☐☐☐ mm/Hg

**Rutherford stage**

| | |
|---|---|
| ○ Grade 0 Category 0 | ○ Grade 2 Category 4 |
| ○ Grade 1 Category 1 | ○ Grade 3 Category 5 |
| ○ Grade 1 Category 2 | ○ Grade 4 Category 6 |
| ○ Grade 1 Category 3 | |

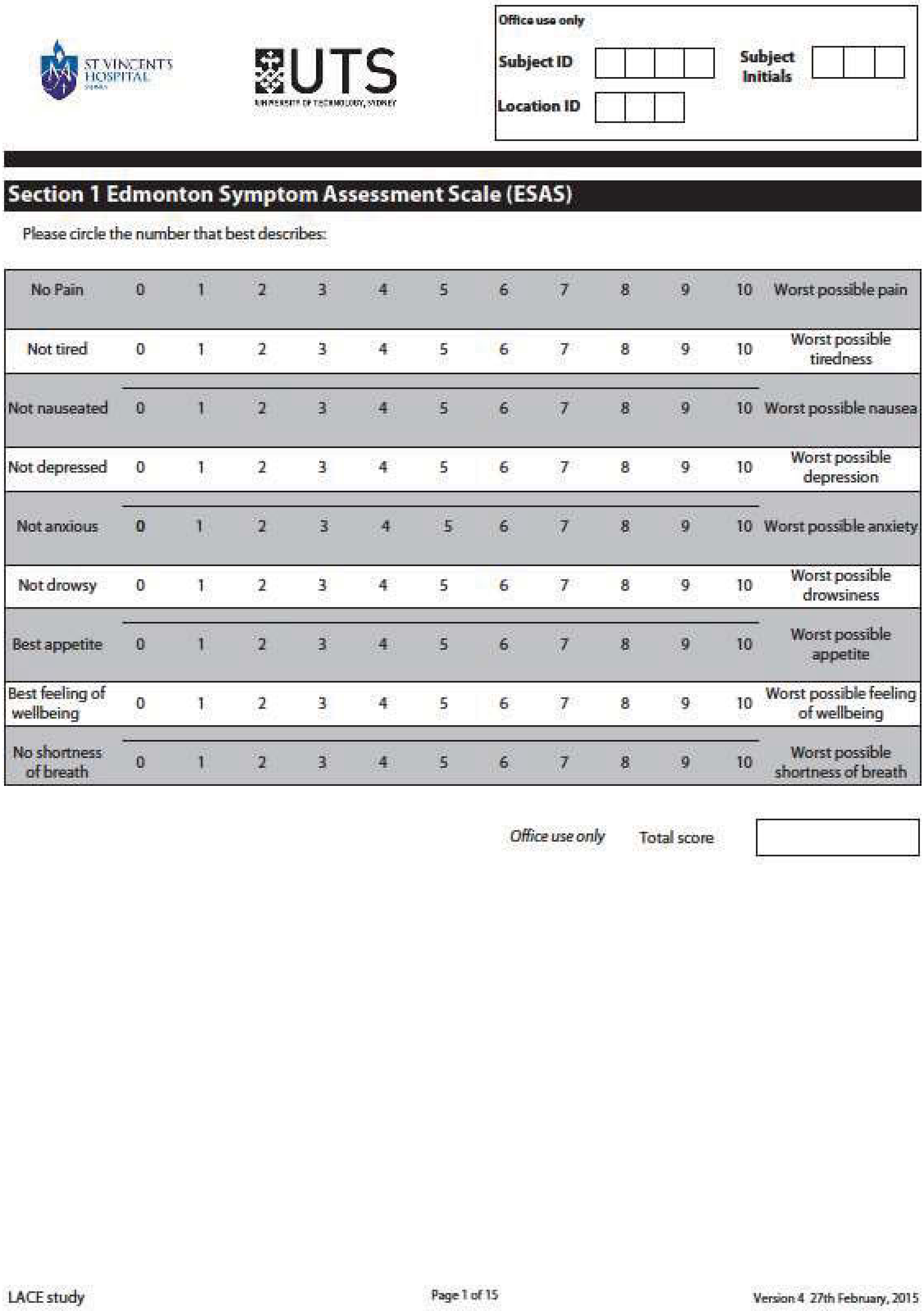
**Six minute walk test**

Distance walked ☐ metres

○Declined ○Unable Reason ____________

Ejection fraction ☐☐ %

## Appendix 3 LACE Study questionnaires



ST VINCENT'S HOSPITAL SYDNEY

UTS UNIVERSITY OF TECHNOLOGY, SYDNEY

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### Section 1 Edmonton Symptom Assessment Scale (ESAS)

Please circle the number that best describes:

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| No Pain | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible pain |
| Not tired | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible tiredness |
| Not nauseated | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible nausea |
| Not depressed | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible depression |
| Not anxious | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible anxiety |
| Not drowsy | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible drowsiness |
| Best appetite | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible appetite |
| Best feeling of wellbeing | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible feeling of wellbeing |
| No shortness of breath | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible shortness of breath |

*Office use only* Total score ☐

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## Section 2 Kansas City Cardiomyopathy Questionnaire

The following questions refer to your **heart failure** and how it may affect your life. Please read and complete the following questions. There are no right or wrong answers. Please mark the answer that best applies to you.

1. **Heart failure** affects different people in different ways. Some may mainly feel shortness of breath while others mainly feel fatigue. Please indicate how much you have been limited by **heart failure** (for example, shortness of breath or fatigue) in your ability to do the following activities over the past 2 weeks.

| | **Extremely** limited | **Quite a bit** limited | **Moderately** limited | **Slightly** limited | **Not at all** limited | **Limited for other reasons or did not do the activity** |
|---|---|---|---|---|---|---|
| Dressing yourself | ○ | ○ | ○ | ○ | ○ | ○ |
| Showering / Bathing | ○ | ○ | ○ | ○ | ○ | ○ |
| Walking 1 block on level ground | ○ | ○ | ○ | ○ | ○ | ○ |
| Doing gardening, housework or carrying groceries | ○ | ○ | ○ | ○ | ○ | ○ |
| Climbing a flight of stairs without stopping | ○ | ○ | ○ | ○ | ○ | ○ |
| Jogging or hurrying (as if to catch a bus) | ○ | ○ | ○ | ○ | ○ | ○ |

2. Compared with 2 weeks ago, have your symptoms of **heart failure** (for example, shortness of breath, fatigue, or ankle swelling) changed?

My symptoms of **heart failure** are now ...

| Much worse | Slightly worse | Not changed | Slightly better | Much better | I've had no symptoms over the last 2 weeks |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |

3. Over the past 2 weeks, how many times did you have **swelling** in your feet, ankles or legs when you woke up in the morning?

| Every morning | 3 or more times a week, but not every day | 1-2 times a week | Less than once a week | Never over the past 2 weeks |
|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ |

4. Over the <u>past 2 weeks</u>, how much has **swelling** in your feet, ankles or legs troubled you?
It has been ...

| **Extremely** troublesome | **Quite a bit** troublesome | **Moderately** troublesome | **Slightly** troublesome | **Not at all** troublesome | I've had **no swelling** |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |

5. Over the <u>past 2 weeks</u>, on average, how many times has **fatigue** limited your ability to do what you wanted?

| All of the time | Several times a day | At least once a day | 3 or more times a week but not every day | 1-2 times a week | Less than once a week | Never over the past 2 weeks |
|---|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ | ○ |

6. Over the <u>past 2 weeks</u>, how much has your **fatigue** troubled you?
It has been ...

| **Extremely** troublesome | **Quite a bit** troublesome | **Moderately** troublesome | **Slightly** troublesome | **Not at all** troublesome | I've had **no fatigue** |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |

7. Over the <u>past 2 weeks</u>, on average, how many times has **shortness of breath** limited your ability to do what you wanted?

| All of the time | Several times a day | At least once a day | 3 or more times a week but not every day | 1-2 times a week | Less than once a week | Never over the past 2 weeks |
|---|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ | ○ |

8. Over the <u>past 2 weeks</u>, how much has your **shortness of breath** troubled you?
It has been ...

| **Extremely** troublesome | **Quite a bit** troublesome | **Moderately** troublesome | **Slightly** troublesome | **Not at all** troublesome | I've had **no shortness of breath** |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |

9. Over the <u>past 2 weeks</u>, on average, how many times have you been forced to sleep sitting up in a chair or with at least 3 pillows to prop you up becuase of **shortness of breath**?

| Every night | 3 or more times a week, but not every night | 1-2 times a week | Less than once a week | Never over the past 2 weeks |
|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ |

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**Subject ID** ☐☐☐☐ **Subject Initials** ☐☐☐

**Location ID** ☐☐☐

15. How much does your **heart failure** afffect your lifestyle? Please indicate how your **heart failure** may have limited your participation in the following activities over the past 2 weeks.

Please fill in one circle on each line

| **Activity** | **Extremely** limited | **Quite a bit** limited | **Moderately** limited | **Slightly** limited | **Not at all** limited | **Limited for other reasons or did not do the activity** |
|---|---|---|---|---|---|---|
| Hobbies, recreational activities | ○ | ○ | ○ | ○ | ○ | ○ |
| Working or doing household chores | ○ | ○ | ○ | ○ | ○ | ○ |
| Visiting family or friends out of your home | ○ | ○ | ○ | ○ | ○ | ○ |
| Intimate or sexual relationships | ○ | ○ | ○ | ○ | ○ | ○ |

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**Subject Initials** ☐☐☐
**Location ID** ☐☐☐

## Section 3 Patient Health Questionnaire 9

Over the last 2 weeks, how often have been bothered by any of the following problems?
(Please tick the box to indicate your answer)

| | Not at all | Several days | More than half the days | Nearly every day |
|---|---|---|---|---|
| 1. Little interest or pleasure in doing things | 0 | 1 | 2 | 3 |
| 2. Feeling down, depressed or hopeless | 0 | 1 | 2 | 3 |
| 3. Trouble falling or staying asleep, or sleeping too much | 0 | 1 | 2 | 3 |
| 4. Feeling tired or having little energy | 0 | 1 | 2 | 3 |
| 5. Poor appetite or overeating | 0 | 1 | 2 | 3 |
| 6. Feeling bad about yourself - or that you are are a failure or have let yourself or your family down | 0 | 1 | 2 | 3 |
| 7. Trouble concentrating on things, such as reading the newspaper or watching television | 0 | 1 | 2 | 3 |
| 8. Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual | 0 | 1 | 2 | 3 |
| 9. Thoughts that you would be better off dead, or of hurting yourself in some way | 0 | 1 | 2 | 3 |

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Add up the total for each column ☐ + ☐ + ☐

Total score ☐

## Section 4 DASS

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

*The rating scale is as follows:*

0 Did not apply to me
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

| | | | | | |
|---|---|---|---|---|---|
| 1 | I was aware of dryness of my mouth | 0 | 1 | 2 | 3 |
| 2 | I experienced breathing difficulty (eg excessively rapid breathing, breathlessness in the absence of physical exertion) | 0 | 1 | 2 | 3 |
| 3 | I experienced trembling (eg, in the hands) | 0 | 1 | 2 | 3 |
| 4 | I was worried about situations in which I might panic and make a fool of myself | 0 | 1 | 2 | 3 |
| 5 | I felt I was close to panic | 0 | 1 | 2 | 3 |
| 6 | I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat) | 0 | 1 | 2 | 3 |
| 7 | I felt scared without any good reason | 0 | 1 | 2 | 3 |

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**Subject ID** ☐☐☐☐

**Subject Initials** ☐☐☐

**Location ID** ☐☐☐

## Section 5 Dutch Heart Failure Knowledge Questionnaire

**1. How often should patients with severe heart failure weigh themselves?**

○ every week
○ now and then
○ every day

**2. Why is it important that patients with heart failure should weigh themselves regularly?**

○ because many patients with heart failure have a poor appetite
○ to check whether the body is retaining fluid
○ to assess the right dose of medicines

**3. How much fluid are you allowed to take at home each day?**

○ 1.5 to 2.5 litres at the most
○ as little as possible
○ as much fluid as possible

**4. Which of these statements is true?**

○ when I cough a lot, it is better not to take my heart failure medication
○ when I am feeling better, I can stop taking my medication for heart failure
○ it is important that I take my heart failure medication regularly

**5. What is the best thing to do in case of increased shortness of breath or swollen legs?**

○ call the doctor or the nurse
○ wait until the next check-up
○ take less medication

**6. What can cause rapid worsening heart failure symptoms?**

○ a high-fat diet
○ a cold or the flu
○ lack of exercise

**7. What does heart failure mean?**

○ that the heart is unable to pump enough blood around the body
○ that someone is not getting enough exercise and is in poor condition
○ that there is a blood clot in the blood vessels of the heart

**8. Why can legs swell up when you have heart failure?**

○ because the valves in the blood vessels in the legs do not function properly
○ because the muscles in the legs are not getting enough oxygen
○ because of accumulation of fluid in the legs

| | | | |
|---|---|---|---|
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| **Subject ID** | ☐☐☐☐ | **Subject Initials** | ☐☐☐ |
| **Location ID** | ☐☐☐ | | |

**9. What is the function of the heart?**

○ to absorb nutrients from the blood

○ to pump blood round the body

○ to provide the blood with oxygen

**10. Why should someone with heart failure follow a low salt diet?**

○ salt promotes fluid retention

○ salt causes constriction of the blood vessels

○ salt increases the heart rate

**11. What are the main causes of heart failure?**

○ a myocardial infarction and high blood pressure

○ lung problems and allergy

○ obesity and diabetes

**12. Which statement about exercise for people with heart failure is true?**

○ it is important to exercise as little as possible at home in order to relieve the heart

○ it is important to exercise at home and to rest regularly in between

○ it is important to exercise as much as possible at home

**13. Why are water pills prescribed to someone with heart failue?**

○ to lower the blood pressure

○ to prevent fluid retention in the body

○ because then they can drink more

**14. Which statement about weight increase and heart failure is true?**

○ an increase of over 2 kilograms in 2 or 3 days should be reported to the doctor at the next check-up

○ in case of an increase of over 2 kilograms in 2 or 3 days, you should contact your doctor or nurse

○ in case of an increase of over 2 kilograms in 2 or 3 days, you should eat less

**15. What is the best thing to do when you are thirsty?**

○ suck an ice cube

○ suck a lozenge

○ drink a lot

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**Subject ID** ☐☐☐☐

**Subject Initials** ☐☐☐

**Location ID** ☐☐☐

## Section 6 The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views

**1. How much does your illness affect your life?**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| no affect at all | | | | | | | | | | severely affects my life |

**2. How long do you think your illness will continue?**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| a very short time | | | | | | | | | | forever |

**3. How much control do you feel you have over your illness?**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| absolutely no control | | | | | | | | | | extreme amount of control |

**4. How much do you think your treatment can help your illness?**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| not at all | | | | | | | | | | extremely helpful |

**5. How much do you experience symptoms from your illness?**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| no symptoms at all | | | | | | | | | | many severe symptoms |

**6. How concerned are you about your illness?**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| not at all concerned | | | | | | | | | | extremeley concerned |

**7. How well do you feel you understand your illness?**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| don't understand at all | | | | | | | | | | understand very clearly |

**8. How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| not at all affected emotionally | | | | | | | | | | extremely affected emotionally |

**9. Please list in rank-order the three most common factors that you believe caused <u>your illness</u>. *The most important causes for me:***

1. ______________________
2. ______________________
3. ______________________

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**Subject ID** ☐☐☐☐
**Subject Initials** ☐☐☐
**Location ID** ☐☐☐

## Section 12 Short Test of Functional Health Literacy in Adults

Read the following passages and fill in the missing word in each statement from the 4 possible words provided. Choose the word that makes the most sense. Circle the letter in front of the word you choose.

### Passage A

Your doctor has sent you to have a ________________ X-ray.

a. stomach
b. diabetes
c. stitches
d. germs

You must have an ________________ stomach when you come for ________.

a. asthma
b. empty
c. incest
d. anaemia

a. is
b. am
c. if
d. it

The X-ray will ________________ from 1 to 3 ________________ to do.

a. take
b. view
c. talk
d. look

a. beds
b. brains
c. hours
d. diets

THE DAY BEFORE THE X-RAY

For dinner have only a_________snack of fruit, ________and jam, with cofee or tea.

a. little
b. broth
c. attack
d. nausea

a. toes
b. throat
c. toast
d. thigh

After ________________ , you must not ________________ or drink anything

- a. minute
- b. midnight
- c. during
- d. before

- a. easy
- b. ate
- c. drank
- d. eat

at ________________ until after you have ________________ the X-ray .

- a. ill
- b. all
- c. each
- d. any

- a. are
- b. has
- c. had
- d. was

THE DAY OF THE X-RAY

Do not eat ________________ .

- a. appointment
- b. walk-in
- c. breakfast
- d. clinic

Do not ____________ , even ______________ .

- a. drive
- b. drink
- c. dress
- d. dose

- a. heart
- b. breath
- c. water
- d. cancer

If you have any ________________ , call the X-ray ________________ at 616-4500.

- a. answers
- b. exercises
- c. tracts
- d. questions

- a. Department
- b. Sprain
- c. Pharmacy
- d. Toothache

## Passage B

I agree to give correct information to__________if I can receive a Sickness Allowance

a. hair
b. salt
c. see
d. ache

I ____________to provide Centrelink information to _________________ any

a. agree
b. probe
c. send
d. gain

a. hide
b. risk
c. discharge
d. prove

statements given in this _________________ and hereby give permission

a. emphysema
b. application
c. gallbladder
d. relationship

to ______________________to get such proof.

a. inflammation
b. religion
c. iron
d. Centrelink

I __________ that for a Sickness Allowance I must report any __________ in my

a. investigate
b. entertain
c. understand
d. establish

a. changes
b. hormones
c. antacids
d. charges

circumstances within __________(14) days of becoming ________ of the change.

a. three
b. one
c. five
d. fourteen

a. award
b. aware
c. away
d. await

I understand __________if I DO NOT like the ______________made on my

a. thus
b. this
c. that
d. than

a. marital
b. occupation
c. adult
d. decision

case, I have the ___________ to a fair hearing. I can ____________ a

a. bright
b. left
c. wrong
d. right

a. request
b. refuse
c. fail
d. mend

hearing by writing or ______________ the office where I applied.

a. counting
b. reading
c. calling
d. smelling

If you __________ additional benefits for any family __________ , you will

a. wash
b. want
c. cover
d. tape

a. member
b. history
c. weight
d. seatbelt

have to __________ a different application form. __________ , we will use

a. relax
b. break
c. inhale
d. sign

a. Since
b. Whether
c. However
d. Because

the __________ on this form to determine your __________ .

a. lung
b. date
c. meal
d. pelvic

a. hypoglycaemia
b. eligibility
c. osteoperosis
d. schizophrenia

## Appendix 4 Interview guide

1. **Can you tell me a bit about your heart condition, and how it all started?**

   *Prompts*

   - What has it been like living with…(use the label participant assigns to condition)
   - What is your understanding of your heart condition and symptoms?
     - Can you tell me a bit more about what you think causes it?
     - Can you tell me a bit more about what the effects of it are?
     - Can you tell me a bit more about what you think it means for the future?
     - Can you tell me a bit more about what you think your role is in controlling it?
   - Is there anything you don't understand about your condition and symptoms, or would like to know more about?

2. **If you want more information about your condition, where/how do you get it?**

   *Prompts*

   - Do you find this information helpful?
   - Is it easy to understand?
   - If not, can you suggest how information about your condition could be communicated more effectively?

3. **Can you tell me about what happened before you came to hospital?**

   *Prompts*

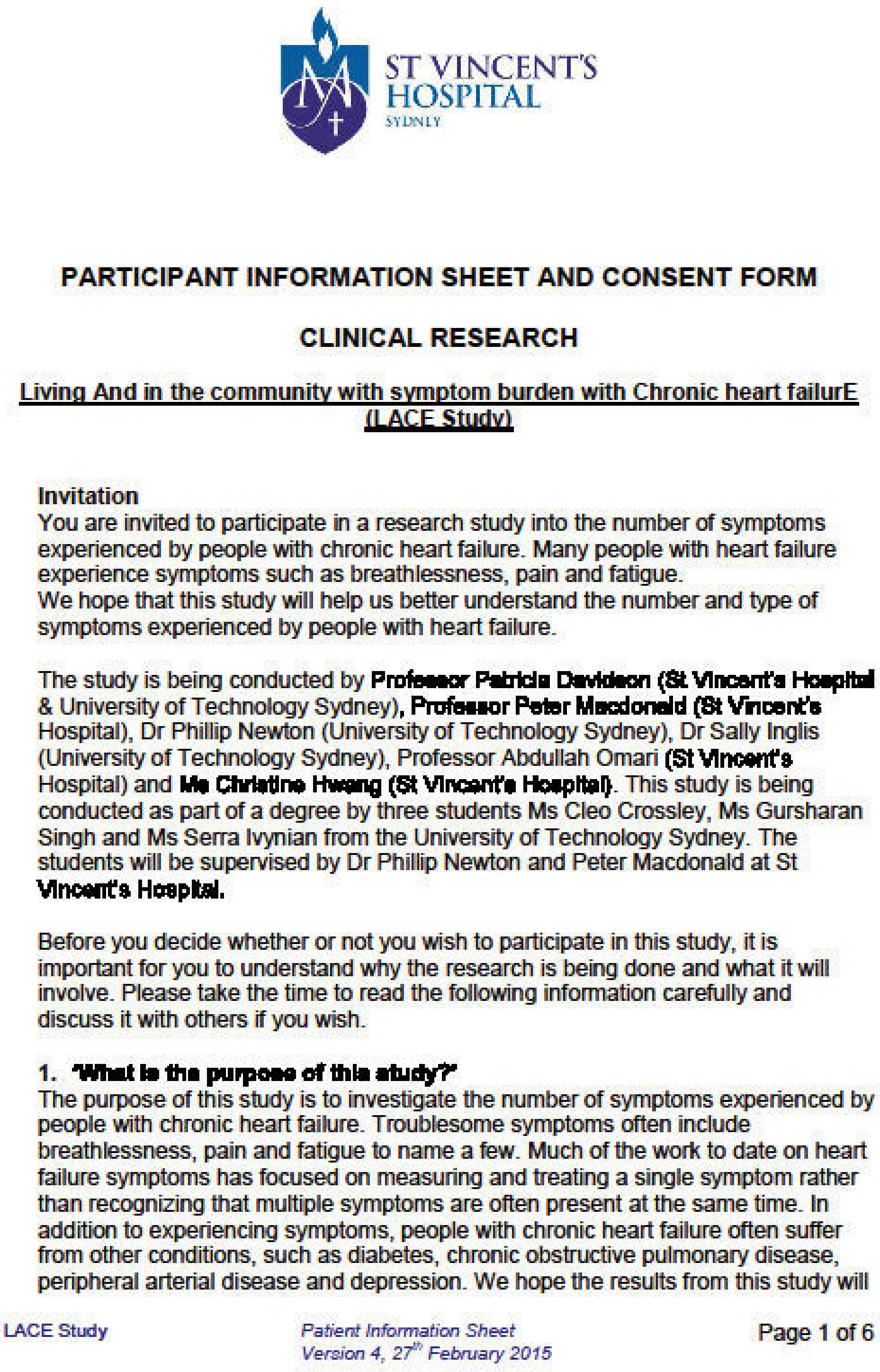
   - Did you notice your symptoms were getting worse?
   - What did you do when you felt like your symptoms were getting worse?
   - What were you thinking about at the time?
   - How did you feel?
   - What caused you to seek help for your symptoms?
     - What (if any) information helped?
     - What (if any) training helped?
     - What (if any) support from a health professional helped?
     - What (if any) support from family and friends helped?
   - Is there any reason you may have waited before you called for help?
   - Can you think about anything that has made it difficult to get help when you wanted it?

4. **In light of what you have just told me, and your experiences, what would you do next time your symptoms get worse?**

   *Prompts*

   - Is there anything you would do differently?
   - What advice would you give others who are experiencing worsening symptoms of your condition?

## Appendix 5 Participant information and consent form



# PARTICIPANT INFORMATION SHEET AND CONSENT FORM

## CLINICAL RESEARCH

## Living And in the community with symptom burden with Chronic heart failurE (LACE Study)

**Invitation**
You are invited to participate in a research study into the number of symptoms experienced by people with chronic heart failure. Many people with heart failure experience symptoms such as breathlessness, pain and fatigue.
We hope that this study will help us better understand the number and type of symptoms experienced by people with heart failure.

The study is being conducted by **Professor Patricia Davidson (St Vincent's Hospital** & University of Technology Sydney)**, Professor Peter Macdonald (St Vincent's** Hospital), Dr Phillip Newton (University of Technology Sydney), Dr Sally Inglis (University of Technology Sydney), Professor Abdullah Omari **(St Vincent's** Hospital) and **Ms Christine Hwang (St Vincent's Hospital)**. This study is being conducted as part of a degree by three students Ms Cleo Crossley, Ms Gursharan Singh and Ms Serra Ivynian from the University of Technology Sydney. The students will be supervised by Dr Phillip Newton and Peter Macdonald at St **Vincent's Hospital.**

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

**1. 'What is the purpose of this study?'**
The purpose of this study is to investigate the number of symptoms experienced by people with chronic heart failure. Troublesome symptoms often include breathlessness, pain and fatigue to name a few. Much of the work to date on heart failure symptoms has focused on measuring and treating a single symptom rather than recognizing that multiple symptoms are often present at the same time. In addition to experiencing symptoms, people with chronic heart failure often suffer from other conditions, such as diabetes, chronic obstructive pulmonary disease, peripheral arterial disease and depression. We hope the results from this study will

help us better understand the difficulties that can arise because of these multiple symptoms and conditions.

**2. 'Why have I been invited to participate in this study?'**

You are eligible to participate in this study because you are a patient at St **Vincent's Hospital with chronic heart failure.**

**3. 'What if I don't want to take part in this study, or if I want to withdraw later?'**

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

New information about the treatment being studied may become available during the course of the study. You will be kept informed of any significant new findings that may affect your willingness to continue in the study.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. If you do decide to withdraw, your data will be removed from the database.

**4. 'What does this study involve?'**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form.

This study will be conducted over a 6 month period although most of questions and procedures will occur on the first day of the study with only two brief phone calls in the following six months.

If you agree to participate in this trial, you will be asked to undergo the following procedures which will take approximately 45-75 minutes in total to complete: This data will be collected at the bedside if you are currently in hospital or in the outpatient clinic. If required, a more private location will be found.

- Complete an interview to collect information such as your age, gender, and information about any recent hospitalisations you may have had.
- Complete a maximum of ten questionnaires which will ask you things about your condition, any symptoms you have experienced and questions about your health in general.
- We will ask you to squeeze a machine with your hands to measure the strength of your hand grip
- We will measure how far you can walk in six minutes
- Undergo a test called an ankle-brachial index where we measure the blood pressure in both arms and the blood pressure in both legs. The purpose of this test is to assess if you might have any narrowing in the arteries in your legs which might be caused by a condition known as peripheral arterial disease.

The researchers would like to have access to your medical record to obtain information about your heart condition and any other medical condition you might have relevant to the study. We will also collect the results of your latest blood tests, your latest echocardiography and any vascular diagnostic results.

At 30 days after you have been discharged or 30 days after we saw you in the clinic, we will phone you to find out if you have been admitted to hospital or the Emergency Department during this period. This phone call will take approximately 5-10 minutes.

At six months after you have been discharged or six months after we saw you in the clinic, we will phone you to find out if you have been admitted to hospital or the Emergency Department during this period. This phone call will take approximately 5-10 minutes.

Both phone calls will take place at a time which is convenient for you.

### 5. How is this study being paid for?'

This study has been funded by the University of Technology Sydney. All of the money being paid by the sponsor to run the study will be deposited into an account managed by the University of Technology Sydney. Funds will then be transferred to St Vincent's Hospital, Sydney for administration of the study. No money is paid directly to individual researchers

### 6. 'Are there risks to me in taking part in this study?'

All medical procedures involve some risk of injury. In addition, there may be risks associated with this study that are presently unknown or unforeseeable. These risks might include: experiencing shortness of breath during the walking test or experiencing some minor discomfort when your blood pressure is being taken. In spite of all reasonable precautions, you might develop medical complications from participating in this study.

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the study, the study coordinator is able to arrange for counselling or other appropriate support. Any counselling or support will be provided by staff who are not member s of the study team.

### 7. 'What happens if I suffer injury or complications as a result of the study?'

If you suffer any injuries or complications as a result of this study, you should contact the study doctor as soon as possible, who will assist you in arranging appropriate medical treatment.

You may have a right to take legal action to obtain compensation for any injuries or complications resulting from the study. Compensation may be available if your injury or complication is caused by the study procedures, or by the negligence of any of the parties involved in the study. If you receive compensation that includes an amount for medical expenses, you will be required to pay for your medical treatment from those compensation monies.

If you are not eligible for compensation for your injury or complication under the law, but are eligible for Medicare, then you can receive any medical treatment required for your injury or complication free of charge as a public patient in any Australian public hospital.

**8. 'Will I benefit from the study?'**
This study aims to further medical knowledge and may improve future treatment of chronic heart failure however it may not directly benefit you.

**9. 'Will taking part in this study cost me anything, and will I be paid?**
Participation in this study will not cost you anything and you will not be paid.

**10. 'How will my confidentiality be protected?'**
Only the researchers involved in the study, the nursing staff involved in your care and your treating doctors will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above and the Human Research Ethics Committee (HREC) for monitoring purposes will have access to your identifiable details and results which will be held securely at **St Vincent's** Hospital.

**11. 'What happens with the results?'**
If you give us your permission by signing the consent document, we plan to discuss/publish the results in peer-reviewed journals, presentation at conferences or other professional forums and as part of university course work. In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish. Data will be kept for five years following completion of the study.

**12. 'What should I do if I want to discuss this study further before I decide?'**
When you have read this information, the researcher Professor Peter Macdonald will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact him on 8382 1111.

**13. 'Who should I contact if I have concerns about the conduct of this study?'**
This study has been approved by **St Vincent's** Hospital HREC. Any person with concerns or complaints about the conduct of this study should contact the Research Office who is nominated to receive complaints from research participants. You should contact them on 02 8382 2075 and quote LNR/12/SVH/79.

**Thank you for taking the time to consider this study.**
**If you wish to take part in it, please sign the attached consent form.**
**This information sheet is for you to keep.**

ST VINCENT'S
HOSPITAL
SYDNEY

# CONSENT FORM

## Living And in the community with symptom burden with Chronic heart failurE (LACE Study)

1. I,.............................................................................................................
of..............................................................................................................
agree to participate as a participant in the study described in the Participant Information Sheet set out above *(or: attached to this form).*

2. I acknowledge that I have read the Participant Information Sheet, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the information sheet has been explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my relationship to the **St Vincent's Hospital** and the University of Technology Sydney.

5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

6. I understand that if I have any questions relating to my participation in this research, I may contact Professor Peter Macdonald on telephone 8382 2641 who will be happy to answer them.

7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Sheet.

Complaints may be directed to the, Research Office, Phone: 02 83822075

| | | |
|---|---|---|
| **Signature of participant** | **Please PRINT name** | **Date** |
| **Signature of witness** | **Please PRINT name** | **Date** |
| **Signature of investigator** | **Please PRINT name** | **Date** |

ST VINCENT'S
HOSPITAL
SYDNEY

## Living And in the community with symptom burden with Chronic heart failurE (LACE Study)

### REVOCATION OF CONSENT

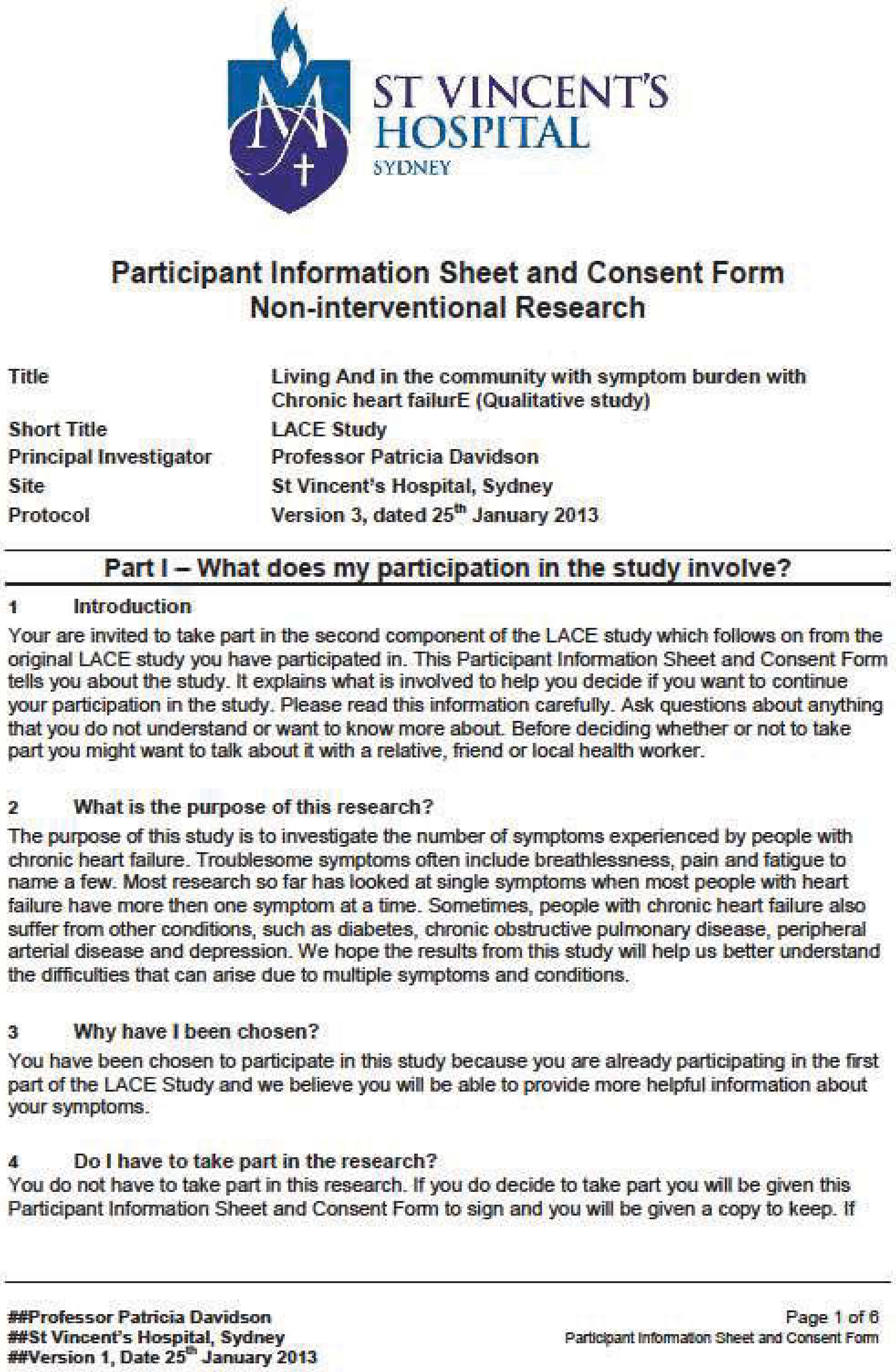
I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my **relationship with St Vincent's Hospital or the University of Technology Sydney** or my medical attendants.

Signature Date

Please PRINT Name

The section for Revocation of Consent should be forwarded to **Professor Peter Macdonald, St Vincent's Hospital, 390 Victoria Street, Darlinghurst, NSW 2010.**

# Appendix 6 Participant information and consent form



ST VINCENT'S HOSPITAL
SYDNEY

## Participant Information Sheet and Consent Form
## Non-interventional Research

| | |
|---|---|
| Title | Living And in the community with symptom burden with Chronic heart failurE (Qualitative study) |
| Short Title | LACE Study |
| Principal Investigator | Professor Patricia Davidson |
| Site | St Vincent's Hospital, Sydney |
| Protocol | Version 3, dated 25th January 2013 |

### Part I – What does my participation in the study involve?

**1 Introduction**

Your are invited to take part in the second component of the LACE study which follows on from the original LACE study you have participated in. This Participant Information Sheet and Consent Form tells you about the study. It explains what is involved to help you decide if you want to continue your participation in the study. Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether or not to take part you might want to talk about it with a relative, friend or local health worker.

**2 What is the purpose of this research?**

The purpose of this study is to investigate the number of symptoms experienced by people with chronic heart failure. Troublesome symptoms often include breathlessness, pain and fatigue to name a few. Most research so far has looked at single symptoms when most people with heart failure have more then one symptom at a time. Sometimes, people with chronic heart failure also suffer from other conditions, such as diabetes, chronic obstructive pulmonary disease, peripheral arterial disease and depression. We hope the results from this study will help us better understand the difficulties that can arise due to multiple symptoms and conditions.

**3 Why have I been chosen?**

You have been chosen to participate in this study because you are already participating in the first part of the LACE Study and we believe you will be able to provide more helpful information about your symptoms.

**4 Do I have to take part in the research?**

You do not have to take part in this research. If you do decide to take part you will be given this Participant Information Sheet and Consent Form to sign and you will be given a copy to keep. If you decide to take part you can change your mind later and leave the study at any stage, for any reason.

### 5 What will happen to me if I take part?

If you decide to take part in this study, you will be asked to take part in an interview with a researcher. The interview will occur after you have completed the LACE Study baseline questionnaire when convenient for you and the researcher.

With your permission, we will audio record the face-to-face interviews.

### 6 What do I have to do?

If you take part in an interview the researcher will be asking questions about your experience of symptoms, what they mean and what may have contributed to them. The information you provide in the interview will be used with your answers you have already given us for our research. It is expected that the interview will last between 15-30 minutes.

### 7 What are the possible benefits of taking part?

There will be no clear benefit to you from your participation in this research.

### 8 What are the risks of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question you may skip it and go to the next question, or you may stop the interview. If you become upset or distressed due to the study, we are able to arrange for counselling or other appropriate support. Any counselling or support will be provided by staff who are not members of the study team.

### 9 What do I do if I wish to withdraw from the research?

Participation in any research project is voluntary. If you do not wish to take part you do not have to. If you decide to take part and later change your mind, you are free to leave the study at any time. If you wish to leave this study please advise the study team. The study coordinator will inform you if there are any special requirements linked to leaving, for example, signing a form.

If you decide to leave the project, the researchers would like to keep the personal and/or health information about you that has been collected. This is to help them make sure that the results of the research can be measured properly. If you do not want them to do this, you must tell them before you leave the research project.

### 10 What happens when the study ends?

Your participation in this part of the LACE Study ends after you finish the interview. You will still receive a phone call at 30 days, then again at six months as part of the main LACE Study.

## Part II – How is the study being conducted?

### 11 What will happen to information about me?

By signing the consent form you consent to relevant research staff collecting and using personal information about you for the study project. Any information obtained in connection with this study project that can identify you will remain confidential. The audio recordings will be transcribed and then stored in a locked filing cabinet at St Vincent's Hospital, Sydney. Only the researchers have access to the filing cabinet. Your information will only be used for the purpose of this study project and it will only be disclosed with your permission, except as required by law.

The interview transcripts will remain at St Vincent's Hospital for 5 years after the study is finished. It is anticipated that the results of this study will be published and or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission.

In accordance with relevant Australian and/or NSW privacy and other relevant laws, you have the right to request access to the information collected and stored by the study team about you. You also have the right to request that any information with which you disagree be corrected. Please contact the study team member named at the end of this document if you would like to access your information.

### 12 Who is organising and funding the research?

This study is being conducted by Serra Ivynian as part of a Bachelors of Medical Science (Honours) degree.

### 13 Who has reviewed the study?

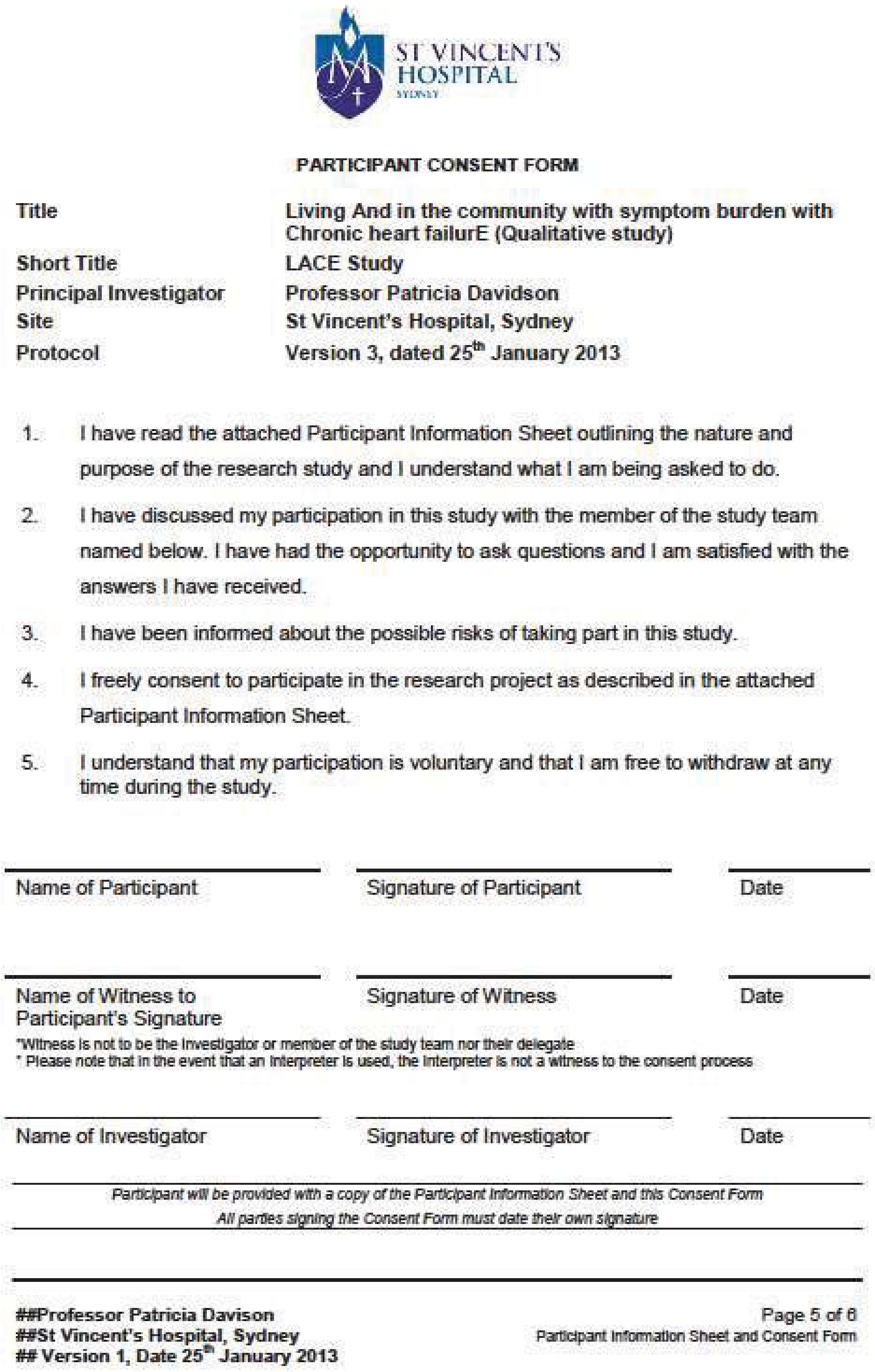
All research in Australia involving humans is reviewed by an independent group of people, called a Human Research Ethics Committee (HREC). This study has been reviewed and given approval by St Vincent's Hospital (Sydney) Human Research Ethics Committee.

### 14 Further information and who to contact

If you would like any further information on this study you may contact Professor Patricia Davidson.

If you would like to talk to someone not directly involved with the study for any further information regarding your rights as a study participant or should you wish to make a complaint to people independent of the study team, you may contact the St Vincent's Hospital (Sydney) Research Office on (02) 8382 2075 and quote the HREC reference number:

| Question | Who to contact | Phone / Facsimile |
|---|---|---|
| General questions or concerns during the study | Study Coordinator<br>Serra Ivynian<br>Principal Investigator<br>Professor Peter Macdonald | Phone<br>Facsimile<br>Phone |
| Questions about the way the research is being conducted | Dr Phillip Newton<br>Institutional Research Governance Officer | Phone 9514 2858<br>Facsimile 9514 4474<br>Phone<br>Facsimile |



ST VINCENT'S HOSPITAL
SYDNEY

### PARTICIPANT CONSENT FORM

| | |
|---|---|
| **Title** | **Living And in the community with symptom burden with Chronic heart failurE (Qualitative study)** |
| **Short Title** | **LACE Study** |
| **Principal Investigator** | **Professor Patricia Davidson** |
| **Site** | **St Vincent's Hospital, Sydney** |
| **Protocol** | **Version 3, dated 25th January 2013** |

1. I have read the attached Participant Information Sheet outlining the nature and purpose of the research study and I understand what I am being asked to do.
2. I have discussed my participation in this study with the member of the study team named below. I have had the opportunity to ask questions and I am satisfied with the answers I have received.
3. I have been informed about the possible risks of taking part in this study.
4. I freely consent to participate in the research project as described in the attached Participant Information Sheet.
5. I understand that my participation is voluntary and that I am free to withdraw at any time during the study.

| | | |
|---|---|---|
| Name of Participant | Signature of Participant | Date |
| Name of Witness to Participant's Signature | Signature of Witness | Date |

*Witness is not to be the investigator or member of the study team nor their delegate
* Please note that in the event that an interpreter is used, the interpreter is not a witness to the consent process

| | | |
|---|---|---|
| Name of Investigator | Signature of Investigator | Date |

*Participant will be provided with a copy of the Participant Information Sheet and this Consent Form*
*All parties signing the Consent Form must date their own signature*

ST VINCENT'S
HOSPITAL
SYDNEY

### *WITHDRAWAL OF PARTICIPATION*

| | |
|---|---|
| **Title** | **Living And in the community with symptom burden with Chronic heart failurE (Qualitative study)** |
| **Short Title** | **LACE Study** |
| **Principal Investigator** | **Professor Patricia Davidson** |
| **Site** | **St Vincent's Hospital, Sydney** |
| **Protocol** | **Version 3, dated 25th January 2013** |

I hereby wish to WITHDRAW my intent to participate further in the above research project and understand that such withdrawal will not jeopardise my future health care.

Participant's Name (printed) ……………………………………………………

Signature ……………………………………………………

Date ……………………………………………………

In the event the participant decided to withdraw verbally, please give a description of the circumstances. Coordinating Investigator to provide further information here:

| |
|---|
| |

Coordinating Investigator to sign the withdrawal of consent form on behalf of a participant if verbal withdrawal has been given:

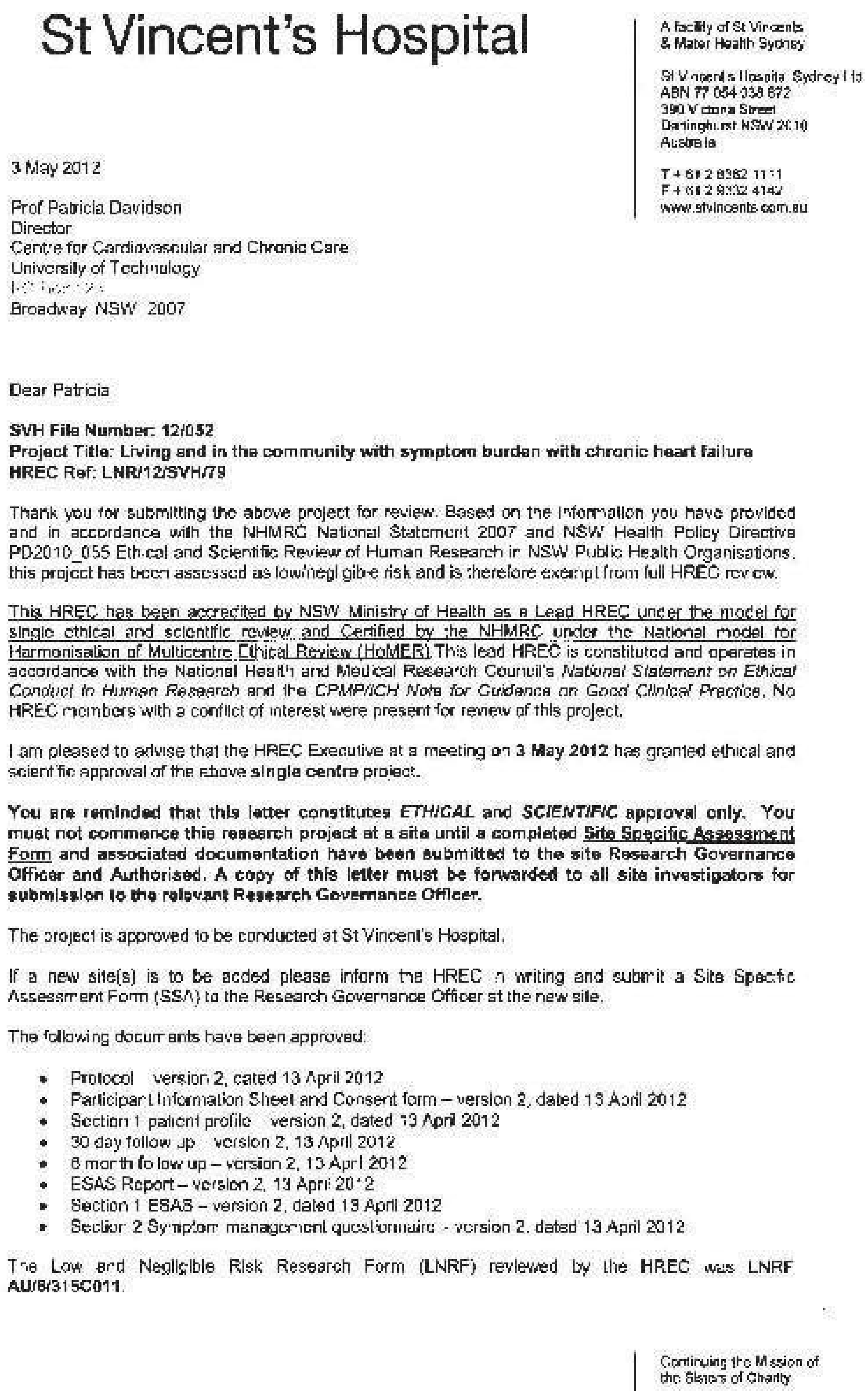
Participant's Name (printed) ……………………………………………………

Signature of Investigator ……………………………………………………

Date ……………………………………………………

*Participant will be provided with a copy of this Withdrawal of Consent Form*

## Appendix 7 Ethics approval



St Vincent's Hospital

A facility of St Vincents
& Mater Health Sydney

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Darlinghurst NSW 2010
Australia

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www.stvincents.com.au

3 May 2012

Prof Patricia Davidson
Director
Centre for Cardiovascular and Chronic Care
University of Technology
PO Box 123
Broadway NSW 2007

Dear Patricia

**SVH File Number: 12/052**
**Project Title: Living and in the community with symptom burden with chronic heart failure**
**HREC Ref: LNR/12/SVH/79**

Thank you for submitting the above project for review. Based on the information you have provided and in accordance with the NHMRC National Statement 2007 and NSW Health Policy Directive PD2010_055 Ethical and Scientific Review of Human Research in NSW Public Health Organisations, this project has been assessed as low/negligible risk and is therefore exempt from full HREC review.

This HREC has been accredited by NSW Ministry of Health as a Lead HREC under the model for single ethical and scientific review and Certified by the NHMRC under the National model for Harmonisation of Multicentre Ethical Review (HoMER). This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. No HREC members with a conflict of interest were present for review of this project.

I am pleased to advise that the HREC Executive at a meeting on **3 May 2012** has granted ethical and scientific approval of the above **single centre** project.

**You are reminded that this letter constitutes *ETHICAL* and *SCIENTIFIC* approval only. You must not commence this research project at a site until a completed Site Specific Assessment Form and associated documentation have been submitted to the site Research Governance Officer and Authorised. A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.**

The project is approved to be conducted at St Vincent's Hospital.

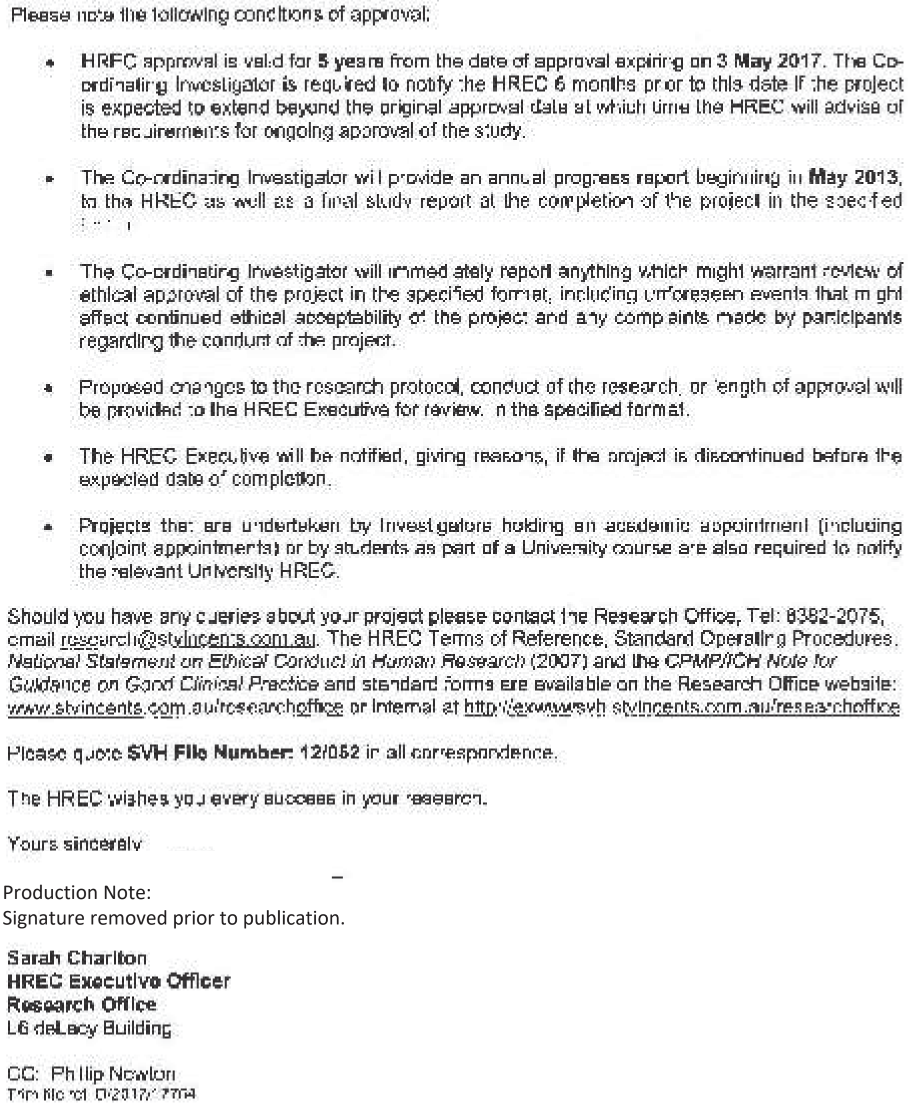
If a new site(s) is to be added please inform the HREC in writing and submit a Site Specific Assessment Form (SSA) to the Research Governance Officer at the new site.

The following documents have been approved:

- Protocol – version 2, dated 13 April 2012
- Participant Information Sheet and Consent form – version 2, dated 13 April 2012
- Section 1 patient profile – version 2, dated 13 April 2012
- 30 day follow up – version 2, 13 April 2012
- 6 month follow up – version 2, 13 April 2012
- ESAS Report – version 2, 13 April 2012
- Section 1 ESAS – version 2, dated 13 April 2012
- Section 2 Symptom management questionnaire - version 2, dated 13 April 2012

The Low and Negligible Risk Research Form (LNRF) reviewed by the HREC was LNRF **AU/6/315C011**.

Continuing the Mission of
the Sisters of Charity



Please note the following conditions of approval:

- HREC approval is valid for **5 years** from the date of approval expiring on **3 May 2017**. The Co-ordinating Investigator is required to notify the HREC 6 months prior to this date if the project is expected to extend beyond the original approval date at which time the HREC will advise of the requirements for ongoing approval of the study.
- The Co-ordinating Investigator will provide an annual progress report beginning in **May 2013**, to the HREC as well as a final study report at the completion of the project in the specified [illegible]
- The Co-ordinating Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project and any complaints made by participants regarding the conduct of the project.
- Proposed changes to the research protocol, conduct of the research, or length of approval will be provided to the HREC Executive for review, in the specified format.
- The HREC Executive will be notified, giving reasons, if the project is discontinued before the expected date of completion.
- Projects that are undertaken by Investigators holding an academic appointment (including conjoint appointments) or by students as part of a University course are also required to notify the relevant University HREC.

Should you have any queries about your project please contact the Research Office, Tel: 8382-2075, email research@svhm.org.au. The HREC Terms of Reference, Standard Operating Procedures, *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice* and standard forms are available on the Research Office website: www.stvincents.com.au/researchoffice or Internal at http://exwwwsvh.stvincents.com.au/researchoffice

Please quote **SVH File Number: 12/052** in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely

Production Note:
Signature removed prior to publication.

**Sarah Charlton**
**HREC Executive Officer**
**Research Office**
L6 deLacy Building

CC: Phillip Newton
Trim file ref: D/2012/[illegible]7704

St Vincent's Hospital

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& Mater Health Sydney

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12 May 2015

Prof. Patricia Davidson
Centre for Cardiovascular & Chronic Care
University of Technology Sydney
PO BOX 123
Broadway NSW 2007

Dear Patricia,

**SVH File Number: 12/052**
**Project Title: Living and in the community with symptom burden with chronic heart failure**
**HREC Reference Number: LNR/12/SVH/79**

Thank you for submitting a request for an amendment dated **27 February 2015, received by the Research Office 15 April 2015,** to the above project. This was considered by the St Vincent's Hospital HREC at its Executive meeting held on **20 April 2015.** This HREC has been accredited by NSW Ministry of Health as a Lead HREC under the model for single ethical and scientific review and Certified by the NHMRC under the National model for Harmonisation of Multicentre Ethical Review (HoMER). This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. No HREC members with a conflict of interest were present for review of this project.

I am pleased to advise that, upon reception of outstanding documentation on **11 May 2015**, the following documents were reviewed and approved:

- Protocol, version 4 dated 27 February 2015
- I ACT Case Report Forms, version 4 dated 27 February 2015
- Participant Information Sheet and Consent Form, version 4 dated 27 February 2015
- Third day Follow up Questionnaire, version 4 dated 27 February 2015
- Six month Follow up Questionnaire, version 4 dated 27 February 2015

**This amendment has also been reviewed by the Research Governance Officer at St Vincent's Hospital. Further authorisation of the above approved documents is not required for any site that has the Research Governance conducted by St Vincent's Hospital Research Office. Implementation of this amendment can now proceed.**

Please note that only an electronic copy of this letter will be provided, if you require the original signed letter please contact the Research Office and we will be happy to provide this.

Should you have any queries about your project please contact the Research Office, Tel: (02) 8382-2075, email SVHS.Research@svha.org.au. The HREC Terms of Reference, Standard Operating Procedures, *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice* and standard forms are available on the Research Office website found at: www.stvincents.com.au/researchoffice or at http://svhnet.svh.stvincents.com.au/researchoffice (internally).

Yours sincerely,

Production Note:
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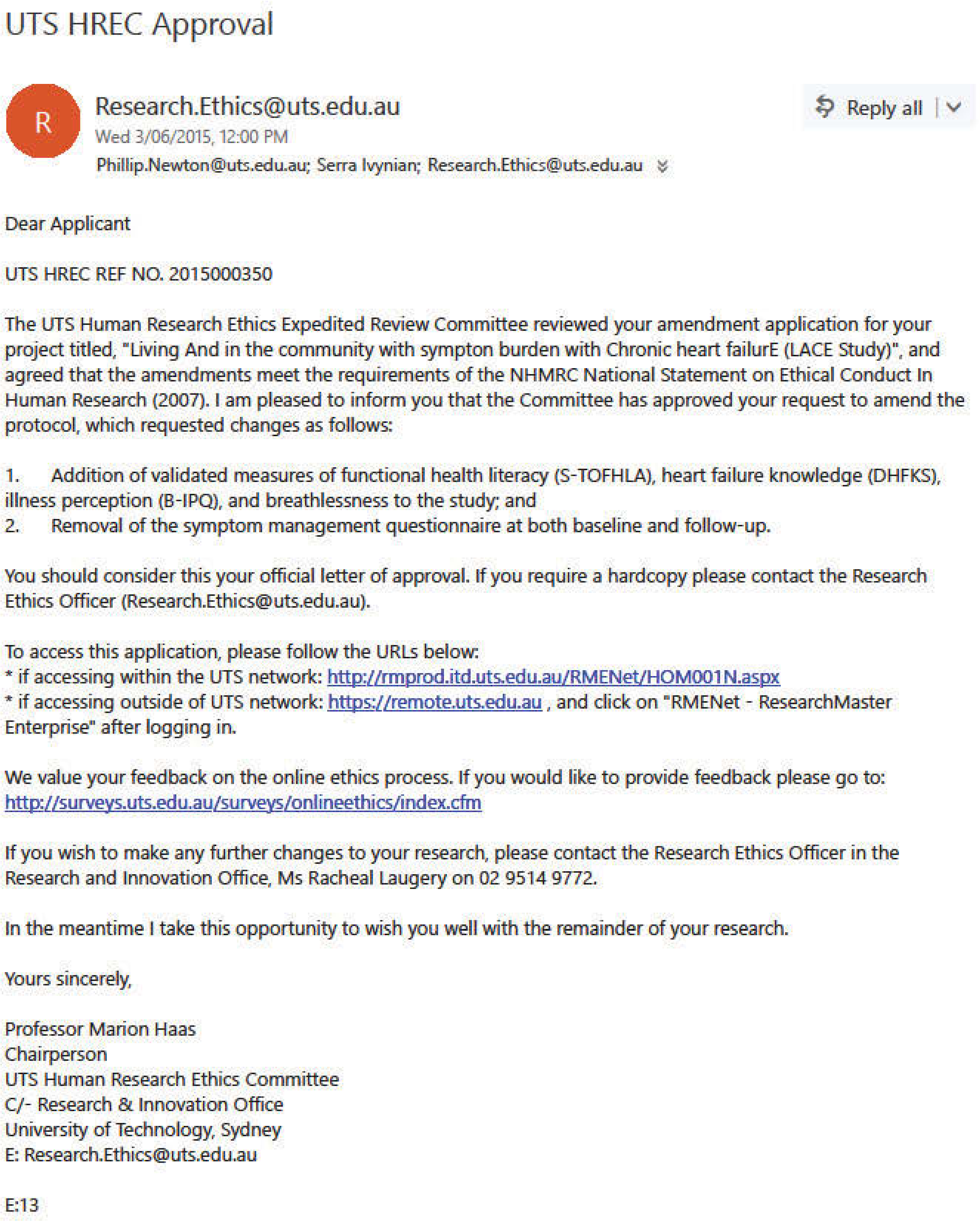
Sarah Charlton
**HREC Executive Officer**
**St Vincent's Hospital Research Office**
**Level 6, de Lacy Building**

cc: Philip Newton
TRIM REF: D/2015/25245



# UTS HREC Approval

Research.Ethics@uts.edu.au
Wed 3/06/2015, 12:00 PM
Phillip.Newton@uts.edu.au; Serra Ivynian; Research.Ethics@uts.edu.au

Dear Applicant

UTS HREC REF NO. 2015000350

The UTS Human Research Ethics Expedited Review Committee reviewed your amendment application for your project titled, "Living And in the community with sympton burden with Chronic heart failurE (LACE Study)", and agreed that the amendments meet the requirements of the NHMRC National Statement on Ethical Conduct In Human Research (2007). I am pleased to inform you that the Committee has approved your request to amend the protocol, which requested changes as follows:

1. Addition of validated measures of functional health literacy (S-TOFHLA), heart failure knowledge (DHFKS), illness perception (B-IPQ), and breathlessness to the study; and
2. Removal of the symptom management questionnaire at both baseline and follow-up.

You should consider this your official letter of approval. If you require a hardcopy please contact the Research Ethics Officer (Research.Ethics@uts.edu.au).

To access this application, please follow the URLs below:
* if accessing within the UTS network: http://rmprod.itd.uts.edu.au/RMENet/HOM001N.aspx
* if accessing outside of UTS network: https://remote.uts.edu.au , and click on "RMENet - ResearchMaster Enterprise" after logging in.

We value your feedback on the online ethics process. If you would like to provide feedback please go to: http://surveys.uts.edu.au/surveys/onlineethics/index.cfm

If you wish to make any further changes to your research, please contact the Research Ethics Officer in the Research and Innovation Office, Ms Racheal Laugery on 02 9514 9772.

In the meantime I take this opportunity to wish you well with the remainder of your research.

Yours sincerely,

Professor Marion Haas
Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office
University of Technology, Sydney
E: Research.Ethics@uts.edu.au

E:13