

# Care-seeking decisions for worsening symptoms in heart failure:

## A qualitative meta-synthesis

Ivynian, S.E., DiGiacomo, M. & Newton, P.J.

**Affiliation:** University of Technology Sydney, Faculty of Health, Centre for Cardiovascular and Chronic Care

**Address:** PO Box 123, Ultimo NSW 2007

**Corresponding author:** Serra E Ivynian, [serra.e.ivynian@student.uts.edu.au](mailto:serra.e.ivynian@student.uts.edu.au), (phone) +61 2 9514 2858, (fax) +61 2 9514 4474

### Abstract

**Purpose:** Over 50% of heart failure (HF) patients delay seeking help for worsening symptoms until these reach acute levels and require emergency hospitalisation. This metasynthesis aimed to identify and explore factors influencing timely care-seeking in patients with HF.

**Methods:** Electronic databases searched were Medline, EMBASE and CINAHL. Studies were included if they were peer reviewed journal articles written in English, and reported perspectives of HF patients following qualitative data collection and analysis. Forty articles underwent analysis following the approach of Thomas and Harden. Leventhal's self-regulatory model (SRM) was used to organise the literature.

**Results:** Much of the literature fit within the SRM, however this model did not account for all factors that influence patients' care-seeking for worsening symptoms. Factors not accounted for included patients' appraisals of previous care-seeking experiences, perceived system and provider barriers to accessing care, and the influence of external appraisals. When added to factors already represented in the model, such as misattribution of symptoms, not identifying with HF diagnosis, cognitive status, lack of understanding information provided, adaptation to symptoms, and emotional responses, a more comprehensive account of patients' decision-making was revealed.

**Implications:** This metasynthesis identified factors, as yet unaccounted for, in a prominent model, and has suggested a more comprehensive framework for addressing care-seeking in HF patients. This information can be used to tailor education, communication, and service initiatives to improve HF patients' responses to worsening symptoms, and target those most at risk of delay.

### Keywords

Meta-synthesis; Qualitative review; Care-seeking; Symptoms

## 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)[1-3]. Worsening symptoms are frequently noted as the main reasons for seeking professional care [1-4], however, over 50% of patients delay seeking help when these signs and symptoms manifest, to the point of requiring emergency medical attention [3].

Delay is associated with increased risk of hospitalisation and readmission [5,6], 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 [7-9]. With up to 50% of patients re-hospitalised at least once within six months [10], HF management carries a heavy economic burden, whilst dually affecting patient quality of life due to frequency of re-admissions [11].

It has been proposed that these admissions are largely preventable, as the majority of HF re-hospitalisations can be attributed to ineffective self-care [12-20]. 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 [21]. 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 [22], to be a factor influencing decision-making, affecting patients' ability to understand and act on health information [23].

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[24,25]. Leventhal's self-regulation model (SRM) of illness behaviour highlights the impact of personal attitudes and perception of condition and symptoms on processing physical stimuli [24,25]. 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 [24,25]. (Figure 1)

### Fig. 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 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 [26-35]. 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% [36,37], yet research has scarcely focused on this component of self-care. Research into adherence to medications is well established, yet, understanding how HF patients 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 [38-43], rather than care seeking decisions specifically, or do not go beyond summarizing what is already reported in the literature [44]. This metasynthesis goes beyond aggregating findings and offers a new understanding of professional care-seeking decisions in HF.

## Aims

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

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

## Methods

A qualitative metasynthesis 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.

## 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).

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.

### 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.

### 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 [45]. With no single widely accepted appraisal tool suited to compare all forms of qualitative research [46], questions developed by Kitto and colleagues [47] 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.

### Data synthesis

Studies were analyzed using the approach of Thomas and Harden [45]. 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.

## Results

### Selected studies

Following retrieval of 582 unique articles, forty studies were included in the synthesis (Figure 2).

#### Fig. 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 [48] or long-term care [49]. 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 [50-52]. Two articles explored self-care in an ethnic minority population [53,54] and one in a rural community [55]. 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 [1,56]. 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 [57], and another conducted both focus groups and interviews [58].

#### Table 1

Characteristics of included studies

### 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 [47].

### Metasynthesis 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.

## 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*" [49,59-62]. 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*" [63,61]. 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*" [64]. 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 [51,65,63]. 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.

*"If 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"*  
[58]

Quality of patient/provider communication and the resulting confusion was further compounded by patients' own cognitive deficits (memory loss, poor concentration) [58] and inconsistent language used by HCPs [66,52]. 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”* [66]

*“Every time I talk to somebody I feel like I get a different answer”* [52]

### **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 [59].

*“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”* [59]

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 [59].

*“... 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”* [59]

## **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 [66]. Lifestyle factors, such as smoking, were not generally linked with HF, nor were links made between preceding heart conditions and their current condition [66]. Lack of understanding and awareness of diagnosis was, in some cases, compounded by dementia [49]. A Swedish study showed that immigrants were more likely to be completely unaware of what was causing their condition as compared to locals [67].

### **Evaluating symptoms**

Attributing symptoms was problematic as some patients were completely unaware of what was causing their symptoms [58,51]. Some were able to feel or see a difference from normal, but were not able to attribute them to a cause [51,59,61,55]. Mechanisms involved with HF (eg fluid retention causing breathlessness) were complex and difficult for patients to understand [58]. 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 [55,62,67,49,66,59,68,56,51].

*“I thought getting winded and tired was part of getting old”* [51]

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 [59,66]. This misconception made it difficult for patients to link breathlessness with the heart [59]. Comorbid conditions with overlapping symptoms further

complicated the symptom evaluation process, making it difficult for patients to attribute symptoms to conditions [49,67,61].

*“Well I’m still having the shortness of breath. I don’t know whether it’s my heart or it is my pulmonary condition”* [61]

## 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 [60,51,61,69,68,70,63,62,67,66,71]. Unpredictable symptom onset prohibited patients from taking holidays or participating in spontaneous activity [60,51]. Increased dependence on family and spouses was a consequence of reduced mobility [72,64,60,69,71,70,65,63]. 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 [64,51,66,72,70,61].

*“..everybody wants to see me and I want to see them but I get so tired”* [51]

Patients instead described being housebound and isolated as a result of restrictive symptoms [72,60]. The loss of family, gender, and employment roles, were additional consequences of HF described by many [55,51,64,70,73]. 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 [60].

*“Terrible, really, because we used to enjoy life, didn’t we”* [60]

### *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 [55,59].

*“My heart – it runs fine...There is a little bit of damage to it on the outside, but that is all”* [55]

*“for some reason I seem to feel that this is lesser of all the heart conditions”* [59]

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 [70].

*“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”* [70]

## 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 [55,59].

*“(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”* [55]



A focus on symptoms led patients to conceive HF as an acute illness, rather than a chronic condition [59]. 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” [59]*

### *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?” [66]*

*“as far as what the long term prognosis should be, I have no idea...” [59]*

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” [60]*

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 [66].

*“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” [66]*

### **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 [62,48,66], attributed the unpredictable nature of symptoms to fate [55], or believed HF was inevitable due to a genetic predisposition [53]. 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 [53].

*“All my people have bad hearts” [53]*

### *Active vs. 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 [55,59], family members [59,68,63], and/or partners [63]. 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 [74,59]. 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 [55,59]. Some patients were completely unaware of their responsibility to take control and call for help when symptoms worsened [74].

*“If the clinic wants to know how I’m doing and that’s part of their job, then they should call me” [74]*

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 [48], and took control even when access to professional care presented itself with barriers [64].

## **Emotional responses to HF**

### *Uncertainty and frustration*

Unclear cognitive representations of HF led to widespread feelings of confusion and uncertainty [62,59]. 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 [72,70]. 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[72].

*“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” [72]*

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 [74,58], as were perceptions of being unnecessarily coddled by overprotective family, which encumbered patients’ independence and freedom [70,72].

*“At the start, they explained everything to me. Now, I sometimes find that they just don’t explain things” [74]*

*“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” [72]*

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

Physical limitations often caused patients to feel worthless and not capable of much [69]. Inability to spend quality time with family [51,70], and being forced to give up hobbies that once brought great pleasure and meaning, caused feelings of surrender, sadness, grief and longing [60,51,69,61,68,70,63].

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 [74,68,63]. Role loss in particular, negatively impacted patients’ self-identity and self-worth. This included the loss of family roles, gender roles, and employment roles [73]. 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 [73,70]. A sense of unfamiliarity and feeling lost due to the life changes caused by the HF diagnosis were difficult to cope with for some [65,70].

*“life has totally changed, and obviously... I don’t know quite how I’ll build round that”[70]*

### *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 [55]. Patients were increasingly aware of the burden HF may cause their partners as their condition progressed [60].

### *Fear and anxiety*

Expecting death was always frightening [69,70], and many patients expressed a sense of ubiquitous fear when little was known about how much time was left [72].

*“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” [72]*

Lack of support [69], 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 [72].

*“In the interval then I'd be fine but I am all the time worried—worried when this breathing will attack me again” [72]*

For other patients, making decisions about the practicalities of what to do in a crisis caused feelings of anxiety [58]. 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 [67].

*“seeking care puts too much strain on me” [67]*

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.

### **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 [51,59,74].

*“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” [51]*

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 [55]. Patients reporting depressive symptoms were also more likely to respond to symptom exacerbations by “*taking to bed*” and “*waiting it (symptoms) out*” [54]. These patients delayed seeking professional care until symptoms led to an emergency situation [54].

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 [72,63].

*“You grab a cigarette and it helps to calm you down”* [63]

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 [59].

Determination to lead a full and active life despite suffering symptoms drove patients to overexertion and consequent emergency hospitalisation [61,70].

*“Once, I said, ‘I am going to church if it kills me.’ I passed out, and they [had to take] me to the hospital”* [61]

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 [64]. 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?”* [70]

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 of 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”* [71]

*“Maybe I was kind of tired but it just didn’t seem to be anything out of the ordinary”* [59]

Adapting daily routines to accommodate symptoms by limiting/pacing activities in order to conserve energy was common [62,64,66,72,70]. Such responses to symptoms made it difficult to gauge physical condition and led to function decline/decreased mobility that often went unnoticed [49]. 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 [55,51,67,59,56,72,74]. Frightening attacks of acute breathlessness were the most common reason patients sought professional care [51,49,56,74].

*“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” [51]*

For a number of patients, fear of death motivated care-seeking behaviours [51,72].

*“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” [51]*

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 [59].

*“...well, all these things seem to happen in the middle of the night so I don’t call doctors” [59]*

When symptoms were perceived as minor, patients were reluctant to call for help [51]. Some patients avoided voicing concerns to doctors or nurses until their symptoms were severe, as anything less was perceived as unjustified [49].

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 [55,53] or was perceived as a way of protecting loved ones by “putting on a front” [64]. 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 [53,70].

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 [71,53,49,65,70,63].

## **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 [49].

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” [51]*

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 [59].

*“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”* [59]

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.

### **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 [67,59].

*“My wife and family noticed the worsening, Home care personnel recommended me to seek acute care”* [67]

It was not uncommon for others to help appraise a patient’s health situation when patients were uncertain [59,63]. 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 [59].

#### *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?’* [60]

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” [63]. Previous negative hospital experiences provided further reason to avoid seeking care, with patients preferring to suffer with symptoms at home as a result [51,72].

*“I hate the hospital, I would rather tough it out as long as I can at home”* [51]

*“I felt wretched—I didn’t care quite seriously if I died—I felt wretched—stuck in that little ward—that CELL! God!”* [72]

Patients also described previous negative hospital experiences with unskilled HCPs and expressed a sense of frustration and loss of confidence [63]. 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 [60,48,68], and long wait times [59,68] 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”* [60]

Patients reported consciously allowing their condition to deteriorate merely to avoid the confusion associated with ambulatory care, preferring instead emergency care in the ED [68].

*“In the time it takes to call them, I’m in good hands in the ER”* [59]

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 [68]. In other cases, patients perceived the ability of local physicians was inadequate for HF specific management [56]. 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 [67,59,56].

## **Discussion**

This metasynthesis 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 [58]. 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 [22]. Higher health literacy levels are consistently correlated with higher HF knowledge [22]. 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 [67], thus suggesting the role of language barriers in patients’ communication with providers [51,65,63]. 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 [55,59]. This is evident through patients preferred coping methods (ie wait and see) in response to worsening symptoms, rather than seeking immediate professional care [51,59,74]. 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 [59,67,63]. 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 [51,72], disorganized care [60,48,68], long wait times [59,68], and even perceived negligence of GPs and nurses [56]. 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 [59,68]. 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 [3]. 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.

## **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.

## **Acknowledgements**

S.E.I. is supported by the University of Technology Sydney Doctoral scholarship.

## **Conflict of interest**

The authors have no conflicts of interest or financial ties to disclose.



## References

1. Welsh JD, Heiser RM, Schooler MP, Brockopp DY, Parshall MB, Cassidy KB, Saleh U (2002) Characteristics and treatment of patients with heart failure in the emergency department. *J Emerg Nurs* 28 (2):126-131
2. Patel H, Shafazand M, Schaufelberger M, Ekman I (2007) Reasons for seeking acute care in chronic heart failure. *Eur J Heart Fail* 9 (6-7):702-708
3. Altice NF (2010) Factors associated with delayed care-seeking in hospitalized heart failure patients. *Heart and Lung: Journal of Acute and Critical Care* 39 (4):360
4. Parshall MB, Welsh JD, Brockopp DY, Heiser RM, Schooler MP, Cassidy KB (2001) Dyspnea duration, distress, and intensity in emergency department visits for heart failure. *Heart & Lung* 30 (1):47-56
5. Kociol RD, Hammill BG, Fonarow GC, Klaskala W, Mills RM, Hernandez AF, Curtis LH (2010) Generalizability and longitudinal outcomes of a national heart failure clinical registry: Comparison of Acute Decompensated Heart Failure National Registry (ADHERE) and non-ADHERE Medicare beneficiaries. *Am Heart J* 160 (5):885-892
6. Giamouzis G, Kalogeropoulos A, Georgiopoulou V, Laskar S, Smith AL, Dunbar S, Triposkiadis F, Butler J (2011) Hospitalization epidemic in patients with heart failure: risk factors, risk prediction, knowledge gaps, and future directions. *J Card Fail* 17 (1):54-75
7. Whellan DJ, Zhao X, Hernandez AF, Liang L, Peterson ED, Bhatt DL, Heidenreich PA, Schwamm LH, Fonarow GC (2011) Predictors of hospital length of stay in heart failure: findings from get with the guidelines. *J Card Fail* 17 (8):649-656
8. Takahashi M, Kohsaka S, Miyata H, Yoshikawa T, Takagi A, Harada K, Miyamoto T, Sakai T, Nagao K, Sato N (2011) Association between prehospital time interval and short-term outcome in acute heart failure patients. *J Card Fail* 17 (9):742-747
9. Lee CS, Moser DK, Lennie TA, Riegel B (2011) Event-free survival in adults with heart failure who engage in self-care management. *Heart & Lung: The Journal of Acute and Critical Care* 40 (1):12-20
10. Krumholz HM, Chen Y-T, Wang Y, Vaccarino V, Radford MJ, Horwitz RI (2000) Predictors of readmission among elderly survivors of admission with heart failure. *Am Heart J* 139 (1):72-77
11. Rodríguez-Artalejo F, Guallar-Castillón P, Pascual CR, Otero CM, Montes AO, García AN, Conthe P, Chiva MO, Banegas JR, Herrera MC (2005) Health-related quality of life as a predictor of hospital readmission and death among patients with heart failure. *Arch Intern Med* 165 (11):1274-1279
12. Moser DK, Doering LV, Chung ML (2005) Vulnerabilities of patients recovering from an exacerbation of chronic heart failure. *Am Heart J* 150 (5):984. e987-984. e913
13. Hope CJ, Wu J, Tu W, Young J, Murray MD (2004) Association of medication adherence, knowledge, and skills with emergency department visits by adults 50 years or older with congestive heart failure. *Am J Health Syst Pharm* 61 (19):2043-2049
14. Michalsen A, König G, Thimme W (1998) Preventable causative factors leading to hospital admission with decompensated heart failure. *Heart* 80 (5):437-441
15. Vinson JM, Rich MW, Sperry JC, Shah AS, McNamara T (1990) Early readmission of elderly patients with congestive heart failure. *J Am Geriatr Soc* 38 (12):1290-1295
16. Bennett SJ, Huster GA, Baker SL, Milgrom LB, Kirchgassner A, Birt J, Pressler ML (1998) Characterization of the precipitants of hospitalization for heart failure decompensation. *Am J Crit Care* 7 (3):168-174
17. Tsuyuki RT, McKelvie RS, Arnold JMO, Avezum Jr A, Barretto ACP, Carvalho ACC, Isaac DL, Kitching AD, Piegas LS, Teo KK (2001) Acute precipitants of congestive heart failure exacerbations. *Arch Intern Med* 161 (19):2337-2342
18. Opasich C, Febo O, Riccardi PG, Traversi E, Forni G, Pinna G, Pozzoli M, Riccardi R, Mortara A, Sanarico M (1996) Concomitant factors of decompensation in chronic heart failure. *The American journal of cardiology* 78 (3):354-357
19. Opasich C, Rapezzi C, Lucci D, Gorini M, Pozzar F, Zanelli E, Tavazzi L, Maggioni AP (2001) Precipitating factors and decision-making processes of short-term worsening heart failure despite "optimal" treatment (from the IN-CHF Registry). *The American journal of cardiology* 88 (4):382-387
20. Morgan AL, Masoudi FA, Havranek EP, Jones PG, Peterson PN, Krumholz HM, Spertus JA, Rumsfeld JS (2006) Difficulty taking medications, depression, and health status in heart failure patients. *J Card Fail* 12 (1):54-60
21. Jurgens CY, Hoke L, Byrnes J, Riegel B (2009) Why do elders delay responding to heart failure symptoms? *Nurs Res* 58 (4):274-282
22. Cajita MI, Cajita TR, Han H-R (2014) Health Literacy and Heart Failure.

23. Moser DK, Watkins JF (2008) Conceptualizing self-care in heart failure: a life course model of patient characteristics. *J Cardiovasc Nurs* 23 (3):205-218
24. Cameron L, Leventhal EA, Leventhal H (1993) Symptom representations and affect as determinants of care seeking in a community-dwelling, adult sample population. *Health Psychol* 12 (3):171
25. Leventhal H, Brissette I, Leventhal EA (2003) The common-sense model of self-regulation of health and illness. *The self-regulation of health and illness behaviour* 1:42-65
26. Dracup K, McKinley S, Riegel B, Mieschke H, Doering LV, Moser DK (2006) A nursing intervention to reduce prehospital delay in acute coronary syndrome: a randomized clinical trial. *J Cardiovasc Nurs* 21 (3):186-193
27. Tullmann DF, Haugh KH, Dracup KA, Bourguignon C (2007) A randomized controlled trial to reduce delay in older adults seeking help for symptoms of acute myocardial infarction. *Research in nursing & health* 30 (5):485-497
28. Quinn JR (2005) Delay in seeking care for symptoms of acute myocardial infarction: applying a theoretical model. *Research in nursing & health* 28 (4):283-294
29. Horne R, James D, Petrie K, Weinman J, Vincent R (2000) Patients' interpretation of symptoms as a cause of delay in reaching hospital during acute myocardial infarction. *Heart* 83 (4):388-393
30. Noureddine S, Adra M, Arevian M, Dumit NY, Puzantian H, Shehab D, Abchee A (2006) Delay in seeking health care for acute coronary syndromes in a Lebanese sample. *J Transcult Nurs* 17 (4):341-348
31. McKinley S, Moser DK, Dracup K (2000) Treatment-seeking behavior for acute myocardial infarction symptoms in North America and Australia. *Heart & Lung: The Journal of Acute and Critical Care* 29 (4):237-247
32. MacInnes JD (2006) The illness perceptions of women following symptoms of acute myocardial infarction: a self-regulatory approach. *Eur J Cardiovasc Nurs* 5 (4):280-288
33. Dempsey SJ, Dracup K, Moser DK (1995) Women's decision to seek care for symptoms of acute myocardial infarction. *Heart & Lung: The journal of acute and critical care* 24 (6):444-456
34. Ryan CJ, Zerwic JJ (2004) Knowledge of symptom clusters among adults at risk for acute myocardial infarction. *Nurs Res* 53 (6):363-369
35. Zerwic JJ (1998) Symptoms of acute myocardial infarction: expectations of a community sample. *Heart & Lung: The Journal of Acute and Critical Care* 27 (2):75-81
36. Jovicic A, Holroyd-Leduc JM, Straus SE (2006) Effects of self-management intervention on health outcomes of patients with heart failure: a systematic review of randomized controlled trials. *BMC Cardiovasc Disord* 6 (1):43
37. Chin MH, Goldman L (1997) Correlates of early hospital readmission or death in patients with congestive heart failure. *The American journal of cardiology* 79 (12):1640-1644
38. Falk H, Ekman I, Anderson R, Fu M, Granger B (2013) Older patients' experiences of heart failure-an integrative literature review. *J Nurs Scholarsh* 45 (3):247-255
39. Hopp FP, Thornton N, Martin L (2010) The lived experience of heart failure at the end of life: a systematic literature review. *Health & Social Work* 35 (2):109-117
40. Yu DSF, Lee DTF, Kwong ANT, Thompson DR, Woo J (2008) Living with chronic heart failure: a review of qualitative studies of older people. *J Adv Nurs* 61 (5):474-483
41. Welstand J, Carson A, Rutherford P (2009) Living with heart failure: an integrative review. *Int J Nurs Stud* 46 (10):1374-1385. doi:10.1016/j.ijnurstu.2009.03.009
42. Oosterom-Calo R, Ballegooijen AJ, Terwee CB, te Velde SJ, Brouwer IA, Jaarsma T, Brug J (2012) Determinants of heart failure self-care: a systematic literature review. *Heart Fail Rev* 17 (3):367-385. doi:10.1007/s10741-011-9292-9
43. Siabani S, Leeder SR, Davidson PM (2013) Barriers and facilitators to self-care in chronic heart failure: a meta-synthesis of qualitative studies. *SpringerPlus* 2 (1):320
44. Clark AM, Savard LA, Spaling MA, Heath S, Duncan AS, Spiers JA (2012) Understanding help-seeking decisions in people with heart failure: A qualitative systematic review. *Int J Nurs Stud* 49 (12):1582-1597. doi:10.1016/j.ijnurstu.2012.05.010
45. Thomas J, Harden A (2008) Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 8 (1):45
46. Dixon-Woods M, Shaw RL, Agarwal S, Smith JA (2004) The problem of appraising qualitative research. *Qual Saf Health Care* 13 (3):223-225
47. Kitto SC, Chesters J, Grbich C (2008) Quality in qualitative research. *Med J Aust* 188 (4):243
48. Close H, Hancock H, Mason JM, Murphy JJ, Fuat A, de Belder M, Hungin AP (2013) "It's Somebody else's responsibility" - perceptions of general practitioners, heart failure nurses, care home

staff, and residents towards heart failure diagnosis and management for older people in long-term care: a qualitative interview study. *BMC Geriatr* 13:69

49. Kaasalainen S, Strachan PH, Heckman GA, D'Elia T, McKelvie RS, McAiney C, Stolee P, Lou van der Horst M, Lou Kelley M, Demers C (2013) Living and dying with heart failure in long-term care: experiences of residents and their family members. *Int J Palliat Nurs* 19 (8):375-382

50. Macabasco-O'Connell A, Crawford MH, Stotts N, Stewart A, Froelicher ES (2008) Self-care behaviors in indigent patients with heart failure. *J Cardiovasc Nurs* 23 (3):223-230

51. Gary R (2006) Self-care practices in women with diastolic heart failure. *Heart & Lung* 35 (1):9-19

52. Riegel B, Carlson B (2002) Facilitators and barriers to heart failure self-care. *Patient Educ Couns* 46 (4):287-295

53. Dickson VV, McCarthy MM, Howe A, Schipper J, Katz SM (2013) Sociocultural influences on heart failure self-care among an ethnic minority black population. *J Cardiovasc Nurs* 28 (2):111-118

54. Dickson VV, McCarthy MM, Katz SM (2013) How do depressive symptoms influence self-care among an ethnic minority population with heart failure? *Ethnicity & Disease* 23 (1):22-28

55. Clark AM, Freyberg CN, McAlister FA, Tsuyuki RT, Armstrong PW, Strain LA (2009) Patient and informal caregivers' knowledge of heart failure: necessary but insufficient for effective self-care. *Eur J Heart Fail* 11 (6):617-621

56. Retrum JH, Boggs J, Hersh A, Wright L, Main DS, Magid DJ, Allen LA (2013) Patient-identified factors related to heart failure readmissions. *Circulation Cardiovascular Quality & Outcomes* 6 (2):171-177

57. Bosworth HB, Steinhilber KE, Orr M, Lindquist JH, Grambow SC, Oddone EZ (2004) Congestive heart failure patients' perceptions of quality of life: the integration of physical and psychosocial factors. *Aging & Mental Health* 8 (1):83-91

58. Barnes S, Gott M, Payne S, Seamark D, Parker C, Gariballa S, Small N (2006) Communication in heart failure: perspectives from older people and primary care professionals. *Health & Social Care in the Community* 14 (6):482-490

59. Horowitz CR, Rein SB, Leventhal H (2004) A story of maladies, misconceptions and mishaps: effective management of heart failure. *Social science & medicine* 58 (3):631-643

60. Aldred H, Gott M, Gariballa S (2005) Advanced heart failure: impact on older patients and informal carers. *J Adv Nurs* 49 (2):116-124. doi:10.1111/j.1365-2648.2004.03271.x

61. Rodriguez KL, Appelt CJ, Switzer GE, Sonel AF, Arnold RM (2008) "They diagnosed bad heart": A qualitative exploration of patients' knowledge about and experiences with heart failure. *Heart & Lung: The Journal of Acute and Critical Care* 37 (4):257-265

62. Andersson L, Eriksson I, Nordgren L (2012) Living with heart failure without realising: a qualitative patient study. *Br J Community Nurs* 17 (12):630, 632-637

63. Zambroski CH (2003) Qualitative analysis of living with heart failure. *Heart & Lung: The Journal of Acute and Critical Care* 32 (1):32-40

64. Jones J, McDermott CM, Nowels CT, Matlock DD, Bekelman DB (2012) The experience of fatigue as a distressing symptom of heart failure. *Heart & Lung* 41 (5):484-491

65. Rerkluenrit J, Panpakdee O, Malathum P, Sandelowski M, Tanomsup S (2009) Self-care among Thai people with heart failure. *Thai Journal of Nursing Research* 13 (1):43-53

66. MacInnes J (2014) An exploration of illness representations and treatment beliefs in heart failure. *J Clin Nurs* 23 (9-10):1249-1256

67. Hedemalm A, Schaufelberger M, Ekman I (2008) Symptom recognition and health care seeking among immigrants and native Swedish patients with heart failure. *BMC Nursing* 7:7p

68. Skaperdas E, Tuepker A, Nicolaidis C, Robb JK, Kansagara D, Hickam DH (2014) Congestive heart failure self-management among US veterans: The role of personal and professional advocates. *Patient Educ Couns* 95 (3):371-377

69. Martensson J, Karlsson J, Fridlund B (1998) Female patients with congestive heart failure: how they conceive their life situation. *J Adv Nurs* 28 (6):1216-1224. doi:10.1046/j.1365-2648.1998.00827.x

70. Thornhill K, Lyons AC, Nouwen A, Lip GY (2008) Experiences of living with congestive heart failure: a qualitative study. *British Journal of Health Psychology* 13 (Pt 1):155-175

71. Brannstrom M, Ekman I, Boman K, Strandberg G (2007) Narratives of a man with severe chronic heart failure and his wife in palliative advanced home care over a 4.5-year period. *Contemp Nurse* 27 (1):10-22

72. Ryan M, Farrelly M (2009) Living with an unfixable heart: a qualitative study exploring the experience of living with advanced heart failure. *Eur J Cardiovasc Nurs* 8 (3):223-231

73. Dickson VV, McCauley LA, Riegel B (2008) Work-heart balance: the influence of biobehavioral variables on self-care among employees with heart failure. *AAOHN J* 56 (2):63-73; quiz 74-66

74. Schnell KN, Naimark BJ, McClement SE (2006) Influential factors for self-care in ambulatory care heart failure patients: a qualitative perspective. *Can J Cardiovasc Nurs* 16 (1):13-19

## **Appendix**