

TITLE:

Patients experience of fatigue in advanced heart failure

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ABSTRACT

Aims: To explore the experience of fatigue and living with fatigue in persons with advanced heart failure.

Design: Single-setting, qualitative interview study.

Methods: In-depth in-person interviews were conducted with participants from November 2012 to June 2013. Participant responses to open-ended questions were analysed using thematic content analysis.

Inclusion criteria were: 18 years and older, diagnosis of New York Heart Association class III-IV heart failure with reduced ejection fraction by a consultant cardiologist, and able to participate in conversational-style interviews in their own language. Major exclusion criteria was cognitive deficit identified by Abbreviated Mental Test Score. Twenty-three adults participated in the study.

Results: Participants (age 72.5 ± 9.5 years, 10/23 female, 17/23 New York Heart Association class III, and 6/23 class IV) identified experiencing fatigue almost daily with over 14/23 reporting it as their worst symptom or combined worst symptom with breathlessness. 9/23 identified fatigue as their second-worst symptom. Three key themes were identified: fatigue as a physical barrier, psychological response to fatigue, and living with fatigue as a part of daily life. The three themes however combine to influence a patients well-being and we suggest need to be acknowledged when planning self-care management.

Conclusion: As heart failure progresses fatigue influences patients' daily life and may negatively affect self-care abilities however patients strive to adapt to these limitations. Understanding the patient experience of fatigue and living with fatigue is important to optimize health management strategies.

Impact:

- **What problem did the study address?**

How fatigue is experienced by patients with heart failure as their condition progresses.
This is currently unknown

- **What were the main findings?**

14/23 patients reported fatigue as their worse symptom

Patients reported feeling fatigue every day

Fatigue affects physical and psychological health in patients with advanced heart failure

- **Where and on whom will the research have impact?**

This research will add to the evidence pertaining to patients experience of fatigue in advanced heart failure. The pattern of fatigue presented could inform patient centred care, including self-care management strategies for patients in this stage of disease progression. Routine monitoring of fatigue must include assessing patient perceptions which may lead to timely recognition of progression and appropriate action taken to improve patient outcomes.

Key words: fatigue, heart failure, patients, lived experience, qualitative, symptoms.

Main paper

INTRODUCTION

Heart failure is a complex clinical syndrome that has been increasing in prevalence for many years (National Institute for Cardiovascular Outcomes Research [NICOR], 2017) and has been described by Savarese and Lund in 2017 as a ‘global pandemic’ which is affecting at least 26 million people worldwide. It is a life-limiting condition however management of heart failure may slow progression and reduce symptoms. Patients have identified a number of symptoms and clusters of symptoms which they experience on a regular basis, with fatigue being one of the worst (Williams, 2017). Physiologic contributors to fatigue in heart failure are known (Williams, 2017). However, less is known about the personal experience of fatigue, that is, how patients perceive, describe, and respond to fatigue in their daily lives, especially as heart failure progresses to advanced stages. To date, research examining fatigue as experienced by patients with heart failure has predominately focused on quantitative assessments to measure physical outcomes, quality of life, and anxiety levels (Yu et al., 2016). Qualitative reports in the last decade are few in number but provide a base of knowledge of which we aimed to focus on fatigue as experienced during advanced heart failure (defined by New York Heart Association (NYHA) classification system categories III-IV (American Heart Association, 2017)). As heart failure worsens and progresses to NYHA III and IV so do fatigue levels (Nepomuceno et al, 2018), yet little is known about the patient’s perception of fatigue as a symptom and how it is experienced by the patient. A richer

focus is needed from the perspective of the patient progressing into advanced heart failure stages to better understand the fatigue experience during this period. The patterns of fatigue at this stage of disease trajectory as experienced by patients is important to enable recognition of deterioration and guide health care professionals to implement effective interventions to support self-management of this symptom. Fatigue has previously been identified as a predictor of heart failure outcome with increased fatigue over time being related to heart failure deterioration (Tsai et al, 2013; Perez-Moreno et al 2014).

Background

Fatigue is a common symptom presenting in nearly all patients with heart failure including reduced left ventricular function and preserved left ventricular dysfunction. Witte and Clark (2007) suggest fatigue in heart failure is due to systemic changes in muscle bulk, metabolism and blood flow to cardiac and skeletal muscles and not simply due to reduced cardiac output, which supports the symptom being present in all classifications of heart failure. Fatigue often presents in patients as a cluster of physical symptoms including chest pain, oedema and breathlessness (Smith et al, 2007; Moser et al, 2014 & Park et al 2017) and recently has been linked in the advanced stages of the disease with a debilitating cluster of symptoms also seen in other chronic illness as the disease progresses (Yu et al 2016). Much research has linked depression and fatigue and how the two symptoms happening synonymously suggesting each symptom could worsen the other (Williams, 2017). This clustering of symptoms seem to suggest fatigue plays a role in the well-being of patients from both a physical and psychological perspective as heart failure progresses.

Fatigue has been described by patients with heart failure as a lack of energy and strength (Martensson et al, 1998; Martensson et al, 1997) which impacts their ability to perform activities of daily living, and often leaves them with a feeling of overdependence on other people (Hagglund et al, 2008). Smith et al. (2010) explored the physical component of fatigue in heart failure patients and further classified it as exertional and general, where exertional fatigue referred to the direct impact of fatigue on a person's

ability to undertake activities of daily living, and general fatigue referred to an overpowering feeling of exhaustion that is not essentially linked to physical activity or exertion.

While there is evidence that fatigue is a significant symptom for people living with heart failure, little attention has been given to the voice of the patient with advancing heart failure and how they experience fatigue in their daily life. Of the few qualitative studies in the advanced heart failure population, none provides a robust picture of experiences of living with fatigue (Hagglund et al, 2008; Jones et al, 2012.). Jones et al (2012) explored fatigue as a distressing symptom of heart failure for patients. They found that patients perceived fatigue as a symptom related to the nearing of the end of their life and thus tried to preserve what they could do as a consequence. However, in the other evidence the majority of participants were either NYHA class II or III, with less than 8% of samples represented by class IV. Additionally, the demographic profile of the study population was not representative of the current profile of community-dwelling individuals with advanced heart failure. Hagglund et al (2008) explored fatigue in older Swedish women with heart failure and identified two important themes in their sample (N=10) pertaining to loss of physical function and striving to adapt. However, no males were represented in the sample and the NYHA classification level was not adjudicated through provider or records review, thus it questions if the sample was representative of class III and IV patients, as the authors described. Recently, Schjoedt et al (2016) reported Hagglund et al's findings along with findings from four other studies in their systematic review of qualitative data on fatigue. The five studies had a combined sample of 61 with an appropriately spread for gender and age for the heart failure population. However, it was not clear how many in the sample were classified as NYHA III-IV as two studies did not report this data and of the three remaining, one included patients classified II-IV and thus not allowing accurate reporting of patients within our required sample. On further investigation of this systematic review, we found the study offered very limited information related to NYHA III/IV and some of the findings were unable to be substantiated as they were not available from peer review publication. Furthermore two of the papers had small sample sizes for qualitative work questioning the rigour of the presented data analysis. However,

the recommendations of the systematic review were that further qualitative work was warranted and a more culturally diverse sample was required. Only three countries were represented in the included studies and the sample presented here in our study is not currently represented in the systematic review.

Thus there is a critical gap in understanding the experience of fatigue in persons with advancing heart failure and from differing cultures. Thus our study sought to explore patient perceptions of fatigue as a symptom as heart failure progressed to an advanced stage and offer rich, narrative accounts of living with fatigue associated with heart failure. The aim of our study was to explore how fatigue impacted on participants with heart failure as it advanced. Our findings we hope may inform a more patient centred approach appropriate to progressive heart failure symptom management to enable fatigue to be better managed for the patient. Furthermore, we aim to add to the limited evidence base of patients who are classified as NYHA III/IV and from a new cultural perspective.

THE STUDY

Aims

The aim of this study was to explore the experience of fatigue and living with fatigue in persons with advanced heart failure

Design

This analysis is part of a larger study to develop a patient reported outcome measure (PROM) for patients with heart failure. In accordance with PROM development (Jenkinson et al 2012) we used an exploratory qualitative research design with thematic content analysis focused on those patients with NYHA classifications III and IV.

Sample/Participants

Participants were recruited from a cardiac centre in the south of England. Inclusion criteria were: 18 years and older, diagnosis of heart failure with reduced ejection fraction by a consultant cardiologist, and able to participate in conversational-style interviews in their own language. Major exclusion criteria was cognitive deficit identified by Abbreviated Mental Test Score (AMTS). An interpreter for participants was made available if required, however this service was not requested by any participant.

Nurses at a local National Health Service Trust in south England, UK identified potential participants and sent each an information packet with an invitation to participate in the study. Packets included an invitation letter, a participant information sheet (explaining the study requirements) and a reply slip on which the patient could express their interest in the study and provide their contact details for the research team. On return of the reply slip, the research team contacted the potential participant, answered any questions and arranged a suitable time and place to interview the participant. Written informed consent was obtained from all participants prior to interviewing. Packets were mailed and participants interviewed concurrently. Interview settings were primarily at a private place selected by the participant (e.g. home, library). Interviews continued until no new data emerged from the interviews (i.e. saturation was reached) (Fusch & Ness, 2015).

Data collection

Data were collected between November 2012 and June 2013. Participants were interviewed individually in a single visit by a trained nurse researcher (HW) with cardiac experience using an interview guide developed by the primary nurse researcher (HW). Participants were asked to describe their experience of living with heart failure and how this impacted their lives. Open-ended questions were asked including ‘Tell me about your heart failure’; after participants discussed fatigue or fatigue symptoms, the interviewer asked probing questions to further explore these symptoms. Additionally, if the participant identified fatigue, the interviewer also asked, ‘How has the fatigue you described affected your everyday life?’ Interviews lasted between 38 and 62 minutes (average 53 minutes) and were audio-taped and transcribed.

Ethical considerations

Ethical approvals were obtained from the sponsoring university, one hospital NHS Trust acting as a participant identification centre and the NHS Health Research Authority's National Research Ethics Committee.

Data analysis

Data analysis was undertaken using Braun and Clarke's (2006) six stage framework for thematic analysis. Each transcript was first read independently by two members of the research team, who then grouped common phrases. The third and fourth researchers reviewed all phrases and groupings on several occasions, providing additional feedback. Inductive coding was undertaken and common threads were identified from the grouped phrases. Finally, the four researchers reviewed the codes to identify themes, then collectively reviewed the themes, and through an iterative process came to agreement regarding the themes and sub-themes, ensuring credibility and transparency of the data (Braun & Clarke, 2006).

Rigour

To ensure thorough and accurate coverage of the topic, semi-structured interviews were conducted using an interview guide developed by one of the nurse researchers which had previously been pilot tested on 5 participants who were members of the PPI advisory group. All materials were reviewed and received ethical approval. We included patient and carer representatives on the study's advisory committee to review themes and provide feedback to our interpretation of themes, if necessary. Their feedback confirmed our final coding. This supported accurate interpretation of the data.

FINDINGS

Eighty-six information packs were sent with 26 participants responding (response rate of 30.2%). One participant died between returning the reply slip and the researcher contacting them. The final sample size was 23, as two other participants in the larger study were classified as NYHA class II heart failure and thus did not meet eligibility for this analysis. Participant demographics are presented in Table 1. All

participants were classified in NYHA III or IV, which is considered advanced heart failure. All but one participant described experiencing fatigue on a daily basis; this person was the youngest in the sample. Ten participants cited fatigue as their worst symptom, while four cited fatigue and breathlessness equally as their worst symptom. Nine participants stated fatigue was their second-worst symptom. Three key themes emerged from our qualitative analysis: *fatigue as a physical barrier, psychological response to fatigue, and fatigue as a part of daily life*.

Theme 1: Fatigue as a physical barrier

Almost all participants discussed the physical burden of fatigue. This first key theme related to the physical limitations or effects of fatigue reported by participants includes three distinct subthemes: physical debilitation, low energy levels, and sleepiness.

Physical debilitation. Participants discussed how fatigue affected their ability to perform activities of daily living and other physical activities. Walking was perceived as a problem for participants due to increasing fatigue levels during the day. A few participants indicated they could not finish chores. Others felt fatigue was the cause of aches and pain within their legs. These feelings caused participants to limit their physical activity engagement frequently.

I am definitely tired when you're doing physical things as well you know, if you're emptying the cupboards and things, you do get tired. I don't get breathless but I do get tired. (64-year-old female; NYHA IV)

I can't walk too far because my legs start aching..... if my legs didn't ache I could walk further. (76-year-old male; NYHA IV)

One participant described how walking was a problem yet cycling was not, raising the question of whether weight-bearing may be an additional or separate contributor to aches and pains in this population.

I've got muscle pains in my legs, which is a nuisance, well more than a nuisance....I am as active as I can be you know....for some reason I can get on a bike and cycle but I can't walk. (70-year-old male; NYHA III)

Almost all participants reported noticing reduction in their physical strength that they did not attribute to their age. They felt this lack of strength was debilitating and they expressed frustration because of it.

I can't lift anything heavy. I used to have good upper strength because I used to play netball years ago and I've always retained my sort of strength, but I haven't, it's gone I haven't really got anymore, it's been squashed. (56-year-old female; NYHA III)

I mean I've lost so much of my strength, I'm as weak as a kitten in many respects. All too often I'm asking [wife] to tighten nuts up for me because I can't hack it, it's dreadful. (75-year-old male; NYHA IV)

Low energy levels. Many participants described how their energy levels were much lower than they had previously experienced. They described the low energy levels in terms of exhaustion and not just as a feeling of not wanting to do something.

Just a feeling of total exhaustion. The fatigue that one feels is indescribable to anyone who hasn't experienced it themselves. I think there are other people who are ill who have that kind of fatigue, but this is not like being tired. This is something of a complete order of magnitude of difference, it is a feeling of complete and utter exhaustion and it can come after doing very, very little, and it is very, it's very soul destroying that you feel quite that tired and you haven't actually done anything. There are times when just sitting in a chair is exhausting. (56-year-old male; NYHA III)

I am worn out really. I feel as if I want a day in bed, that's how I feel...the tiredness is all the time really. I am miserable. (75-year-old female; NYHA III)

Others attempted to clarify their energy levels, by relating it to physical tasks and their ability to do what they want to do.

I want to do things and all I want to do now is get out and help [my wife], but I stand up to go out there and I think oh no and sit down. And that's the way I am at the moment, it's an effort to do anything, really an effort. (87-year-old male; NYHA III)

Sleepiness. Participants described difficulties sleeping and often felt tired and not refreshed. They also felt at times during the day they would have no control over falling asleep spontaneously.

[more tired] Oh yes, more tired now. It's like I'll drop off to sleep in the chair, whereas sort of years ago I would never, if I had been watch anything I would never have fallen a sleep, never. (76-year-old male; NYHA III)

I fall asleep a lot. You don't get to see many end of programmes. Because in the evening I just, after I've had something to eat, that's it I'm just, I'm falling asleep or day time after I've had something to eat, fall asleep ... you just get very, very tired. (56-year-old female; NYHA III)

Theme 2: Psychological response to fatigue

Participant responses within this theme were in-depth, individualized, and emotional. We constructed three sub-themes: variations in mood, social consequences, and worries for the future.

Variations in Mood. There were variations in how participants described mood as a response to fatigue. Most responses involved negative feelings about the impact of fatigue on their lives. Participants described emotional and psychological effects with terms such as frustration, depression, helplessness, and lack of motivation.

It's frustration a lot I think, that you feel as I say, you are well but then you go to do something and you realise you can't do it and you mustn't do it. (84-year-old female; NYHA III)

It does take me a long time to decide to do something, like getting dressed. And then having got dressed and got up and gone downstairs, you know, kind of lulling around on the sofa, nodding and watching television. So you know, that sort of kind of boredom, lack of interest, again

difficult in terms of, so you'll either say I was tired, knackered, inactive or you could say I was bored, but I certainly wasn't doing what I would normally have. (66-year-old male; NYHA III)

I think it is inevitable that one goes through periods of, I supposed what might be called depression, you know or whatever because you actually have a fair bit to be depressed about. I felt overnight I had my life taken away from me really. (56-year-old male; NYHA III)

I don't try for it [help], I'm too tired. I mean if anything went wrong I used to ring and shout and do something until they did it. Now I just sit back and wait. All the fight's gone out of me...I'm tired, I'm tired of fighting the world. (86-year-old female; NYHA III)

Though a majority of responses regarding feelings were negative, a few participants discussed positive thinking strategies to manage their fatigue and get through the day.

I just feel so useless and helpless but I have to think of the things I still can do (84-year-old female; NYHA III)

I think I've just got to remain positive like I've always been you know. I don't want to sit and drift away. (84-year-old female; NYHA IV)

Social consequences. Many participants described feeling isolated as a consequence of fatigue. Some were concerned about their shrinking 'social circle' as their ability to navigate outside the home environment became limited.

...and I used to go out every night... and then come home again and that was it, my social intercourse don't do that these days because I can't really face the walk. Because I know by the time I get down to the local I'd be dying for a rest. (75-year-old male; NYHA IV)

I feel very isolated. Loneliness is the biggest problem. (86-year-old female; NYHA III)

It's the social life that you miss, but I am lucky that I've got friends that come to see me. (84-year-old female; NYHA III)

Worries for the future. Fatigue and how participants were experiencing fatigue was also a source of fear for the future. Some found themselves panicking over symptoms and what this meant for the future.

Fatigue is, I think, is the worst thing, apart from the [diagnosis], obviously sheer panic of it all but mainly the symptomsyes it's tired, fatigue is the biggest thing. (56-year-old female; NYHA III)

...times in the middle of the night when you're frightened, you think you've got a little pain somewhere or a niggle somewhere else and you think oh am I going to die now. ' (69-year-old female; NYHA III)

Theme 3: Fatigue as a part of daily life

Descriptions of living with fatigue were interwoven throughout participant responses. We constructed two subthemes of learning to live with fatigue and striving for resilience.

Learning how to live with fatigue. Participants described how they adapted their daily life in response to fatigue.

I've come to terms with it and I'm trying to live within my means. Well not rushing about anyway, and just taking it steady and doing what I want to do in the time. (86-year-old female; NYHA III)

If I'm going to do something for the day, I have to plan ahead, you have to manage and think about what you're going to do the next day. (56-year-old female; NYHA III)

So we gradually changed our lifestyle so that, you know, we just took time doing everything, going anywhere, so that it was more done at my pace and not on my wife's. (77-year-old male; NYHA IV)

Striving for resilience every day. Participants discussed not letting fatigue beat them. While they accepted their condition and the way it impacted them, they also discussed how to minimize the negative feelings regarding effects of fatigue.

You do what you can and you don't give up. It's important to do what you can even if what you can do is very, very little and often it is very, very little. But you do feel very much better for doing what you can. (56-year-old male; NYHA III)

I just very much take one day at a time and just think, yes, you know, just live life really. And I will push myself as well, that's the other bit of me, you know I don't sit down thinking, oh I'm not very well. I just want to get up and do things. (64-year-old female; NYHA III)

DISCUSSION

Our study findings highlight fatigue as a significant problem for patients with advancing heart failure. Participants clearly described their experiences of fatigue and how it impacted their lives. Similar to Smith et al (2007), the majority of our participant descriptions centred on physical and psychological characteristics, within three distinct themes: fatigue as a physical barrier, psychological response to fatigue, and fatigue as a part of daily life. Participants not only described their feelings of fatigue, but also defined fatigue in terms of what exacerbated it or how it caused further symptoms, such as leg pain, low mood and inability to sleep. However, they did not discuss the significance of worsening of fatigue in relation to deterioration of their heart failure. Yu et al (2016) in their study clustered fatigue with other debilitating symptoms such as drowsiness, reduced appetite and nausea within a decondition symptom cluster, and aligned this to findings in other life-limiting disease advanced stages. This was not found in our study. What we showed was fatigue is a complex and multidimensional symptom of heart failure and may not be able to be seen or treated in isolation (Conley et al, 2015; Williams, 2017). In contrast, Heo et

al (2019) found symptoms of heart failure should be explored individually to enable symptoms to be addressed effectively in heart failure management.

Different from Smith et al's (2010) study, our study participants did not identify their fatigue as general versus exertional. However, their disease severity may have caused limited engagement in higher levels of physical activity which is often associated with exertional fatigue. Previously fatigue has been shown to impact on a patient's ability to undertake activities of daily living and an ability to self-care (Falk et al, 2009; Kessling et al, 2016). Patients who are able to effectively self-manage heart failure symptoms have been shown to have lower mortality and admission rates (Lee et al 2018). Effective self-management does require regular symptom monitoring (Lee et al 2015), and with this comes symptom recognition, accurate interpretation, ability to undertake self-care and importantly know when to call for help (Reeder et al, 2015).

Psychological responses to fatigue were also evident in participant discussions and were focused on low mood/depression, change in social consequences, and worries for the future, which caused participants to feel emotionally debilitated. Our study did not directly measure depression scores, but participant self-reporting of it cannot be ignored. Fatigue and depression have been linked previously (Heo et al, 2016; Graven et al, 2018) and have been associated with further physical symptoms and reduction in quality of life, leading to poorer health outcomes (Heo et al, 2016). Depression in heart failure has also been linked to poor self-care adherence (Auld et al 2018). Although a few participants in our study described strategies to stay positive in light of fatigue, the majority expressed negative feelings related to the effects fatigue had on their abilities to continue their lifestyle. Loss of contact, or shrinking of social circles was a frequent cause for distress, as was increased dependence on family. Fatigue has previously been found to significantly affect emotional and social functioning of the family (Whitehead, 2017). Descriptions from our study participants related to both negative and positive feelings may provide insight for support

strategies related to psychological effects of worsening fatigue in later stages of heart failure. Alleviation of fatigue through social interaction has been seen previously (Falk et al 2007; Matura et al 2018)

Participant narratives elucidated differences in how they managed periods of fatigue and adapted their daily life to accommodate chronic or worsening fatigue. Although most participants discussed negative emotional feelings regarding fatigue, very few said it was easier to “give up” or “withdraw” from activities; the majority focused on ways to manage their self-care. Daily adaptation included mobility aids, going at a slower pace and structuring their day around rest periods. These strategies are similar to strategies identified by participants with NYHA class II-III heart failure (Jones et al, 2012), and older women with heart failure (Hagglund et al, 2008), and show that even people in advanced heart failure continue to strive for quality of life, thus supportive interventions should be continued to promote health outcomes during all stages.

Participants did not discuss fatigue in relation to the progression of their heart failure suggesting they perceived it as a consequence rather than a symptom that may indicate deterioration. Fatigue has been shown to cause delay in health seeking behavior (Okada et al 2019), as patients appear to lack knowledge about symptoms and do not monitor them regularly. Regular symptom monitoring, aligned with symptom recognition and interpretation is required for self-management and effective self-management is linked with improved outcomes (Reeder et al, 2015; Lee et al, 2015; Lee et al 2018). This requires partnership working with health care practitioners to increase knowledge and confidence to manage symptoms (Lee et al, 2018; Rice et al, 2018; Okada et al, 2019).

Our results show that fatigue is complex and an inter-play between the three themes identified from our patients' narratives is evident. Our study's findings gives a better understanding of the dimensions of fatigue in advanced heart failure and further supports the need for patients to recognize a deterioration of fatigue so that heart failure can be managed more effectively.

Limitations

We acknowledge that our interviews relied on the participant's ability to accurately recall details about their fatigue experience and thus we cannot confirm these perceived experiences. We also did not share the definitions of general and exertional fatigue with participants nor ask questions specific to exercise and physical activity thus this may have limited description of exertional fatigue by participants.

Additionally, though we utilized an interview guide, presence of the researcher and dynamics of the relationship during data gathering may have affected individual participant response. Our qualitative findings from this convenience sample are not generalizable, nor can causality be inferred, however the purpose of the study was to provide further description of fatigue in advanced heart failure.

Conclusion

The significance of fatigue levels and how people manage this in their everyday lives has potential to affect the management of their heart failure. The findings of our study have provided further evidence of the patients' perspective into the significance of fatigue as a symptom, especially in advancing heart failure. The narratives have clearly shown the impact of fatigue on daily life and how it is a complex, multidimensional symptom of heart failure. Despite its negative impact, patients learned and adapted their lifestyle to best manage this symptom in their everyday life. Open communication with patients regarding their perceptions of the impact of fatigue is essential to support management strategies through the progression of heart failure.

Conflict of Interest statement

None declared.

References

American Heart Association. (2017). Classes of Heart Failure. Retrieved from:

http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/Classes-of-Heart-Failure_UCM_306328_Article.jsp#.Ww_tN4eouUk

Auld J, Mudd J, Gelow J, Lyons K, Hiatt S, Lee C (2018) Patterns of heart failure symptoms are associated with self-care behaviors over 6 months. *European Journal Cardiovascular Nursing*,17:543-551.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2):77-101.

Conley, S., Feder, S., Redeker, N.S. (2015). The relationship between pain, fatigue, depression and functional performance in stable heart failure. *Heart & Lung*;44, 107-112.

Falk K, Granger B, Swedberg K, Ekman I (2007) Breaking the vicious circle of fatigue in patients with chronic heart failure. *Qualitative Health Research*, 17:1020-1027.

Falk K, Patel H, Swedberg K, Ekman I (2009) Fatigue in patients with chronic heart failure – a burden associated with emotional and symptom distress. *European Journal of Cardiovascular Nursing*, 8:91-96.

Fusch, P.I. & Ness, L.R. (2015) Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20(9): 1408-1416.

Graven, L, Higgins M, Reilly C, Dunbar S (2018) Heart Failure Symptoms Profile Associated With Depressive Symptoms. *Clinical Nursing Research*: 1–21.

Hagglund, L., Boman, K. & Lundman, B. (2008). The experience of fatigue among elderly women in chronic heart failure. *European Journal of Cardiovascular Nursing*, 7: 290-295.

Heo, S., McSweeney, J., Tsai, P-F., Ounprasenth, S. (2016). Differing effects of fatigue and depression on hospitalizations in men and women with heart failure. *American Journal of Critical Care*, 25(6): 526-534.

Heo S, Moser D, Lennie T, Grudnowski S, Kim J, Turrise S (2019) Patients' Beliefs About Causes and Consequences of Heart Failure Symptoms. *Western Journal of Nursing Research*: 1–19

Jenkinson, C., Fitzpatrick, R., Peto, V., Dummett, S., Morley, D., Saunders, P. (2012). The Parkinson's Disease Questionnaires User Manual (3rd ed). Health Services Research Unit, University of Oxford.

Jones, J., McDermott, C. M., Nowels, C. T., Matlock, D. D. & Dekelman, D. B. (2012). The experience of fatigue as a distressing symptom of heart failure. *Heart & Lung*, 41(5):481-491.

Kessling, D., Denollet, J., Widdershoven, J., Kupper N. (2016). Fatigue and self-care in patients with chronic heart failure. *European Journal of Cardiovascular Nursing*, 15:337-344.

Lee K, Lennie T, Dunbar S, Pressler S, Heo S, Song E, Biddle M, Moser D (2015) The association between regular symptom monitoring and self-care management in patients with heart failure. *Journal of Cardiovascular Nursing*, 30:145-151.

Lee C, Bidwell J, Paturzo M, Alvaro R, Cocchieri A, Jaarsma T, Stromberg A, Riegel B, Vellone E (2018) Patterns of self-care and clinical events in a cohort of adults with heart failure: 1 year follow-up. *Heart & Lung*, 47: 40-46.

Martensson, J. Karlsson, J. E. & Fridlund, B. (1998). Female patients with congestive heart failure: how they conceive their life situation. *Journal of Advanced Nursing*, 28(6): 1216-1224.

Martensson, J. Karlsson, J. E. & Fridlund, B. (1997). Male patients with congestive heart failure and their conception of the life situation. *Journal of Advanced Nursing*, 25(3): 579-586.

Matura L, Malone S, Jaime-Lara R, Riegel B (2018) A Systematic Review of Biological Mechanisms of Fatigue in Chronic Illness. *Biological Research for Nursing*. 20: 410-421.

Moser D, Lee K, Wu J, Mudd-Martin G, Jaarsma T, Huang T, Riegel B. (2014). Identification of symptom clusters among patients with heart failure: an international observational study. *International Journal of Nursing Studies*, 51(10): 1366-72.

National Institute for Cardiovascular Outcomes Research (NICOR). (2017). *National Heart Failure Audit 2015-16*; Institute of Cardiovascular Science, University College London.

Nepomuceno E, Silva LN, Cunha DCP, Furuya RK, Simoes MV, Dantas RAS. (2018) Comparison of tools for assessing fatigue in patients with heart failure. *Rev Bras Enferm* [Internet];71(5):2404-10.

Okada A, Tsuchihashi-Makaya M, Kang J, Aoki Y, Fukawa M, Matsuoka S.(2019) Symptom Perception, Evaluation, Response to Symptom, and Delayed Care Seeking in Patients with Acute Heart Failure. An Observational Study. *Journal of Cardiovascular Nursing*, 34:36-43.

Park, J., Moser, D. K., Griffith, K., Harring, J. R. & Johantgen, M. (2017) Exploring symptom clusters in people with heart failure. *Clinical Nursing Research*, 1-17.

Perez-Moreno A, Jhund P, Macdonald M, Petrie M, Clelad J, Bohm M, van Veldhuisen D, Gullestad L, Wikstrand J, Kjekshus J, Lewsey J, McMurray (2014) Fatigue as a predictor of outcome in patients with heart failure. Analysis of CORONA (Controlled Rosuvastatin Multinational Trial in Heart Failure). *J Am Coll Cardio Heart Failure*, 2:187-197.

Reeder K, Ercole P, Peek G, Smith C (2015) Symptom perceptions and self-care behaviors in patients who self-manage heart failure. *Journal of Cardiovascular Nursing*, 30:E1-E7.

Rice H, Say R, Betihavas V (2018) The effect of nurse-led education on hospitalisation, readmission, quality of life and cost in adults with heart failure. A systematic review. *Patient Education and Counselling*, 101:363-374.

Savarese G, and Lund L. (2017) Global Public Health Burden of heart failure. *Cardiac Failure Review*, 3:7-11.

Schjoedt, I, Sommer, I, & Bjerrum MB (2016) Experiences and management of fatigue in everyday life among adult patients living with heart failure: a systematic review of qualitative evidence. *JBIM Database of systematic reviews and implementation Reports*: 68-115.

Smith, O. R., Michielsen, H. J., Pelle, A. J., Schiffer, A. A., Winter, J. B. & Denollet, J. (2007). Symptoms of fatigue in chronic heart failure patients: Clinical and psychological predictors. *European Journal of Heart Failure*, 9:922-927.

Smith, O. R., Kupper, N., de Jonge, P. & Denollet, J. (2010) Distinct trajectories of fatigue in chronic heart failure and their association with prognosis. *European Journal of Heart Failure*, 12:841-848.

Tsai M-F, Hwang S-L, Tsay S-L, Wang C-L, Tsai F-G, Chen C-C, Huang T-Y (2013) Predicting trends in dyspnea and fatigue in heart failure patients' outcomes. *Acta Cardiol Sin*, 29:488-95.

Whitehead, L. (2017). The family experience of fatigue in heart failure. *Journal of Family Nursing*; 13(1): 138-156.

Williams, B. A. (2017). The clinical epidemiology of fatigue in newly diagnosed heart failure; *BMC Cardiovascular Disorders*, 17:122.

Witte, K. K. & Clark, A. L. (2007). Why does chronic heart failure cause breathlessness and fatigue? *Progress in Cardiovascular Diseases*, 49(5):366-384.

Yu, D. S., Chan, H. Y., Leung, D. Y., Hui, E. & Sit, J. W. (2016). Symptom clusters and quality of life among patients with advanced heart failure. *Journal of Geriatric Cardiology*, 13:408-414.

Table 1: Characteristics of the Study Participants (N=23)

Characteristics	N (%)
Age, years, M \pm SD	72.5 \pm 9.5
Range	53-86
Sex, Female	10 (43.5)
Heart Failure Aetiology	
Ischaemic Heart Disease	11 (47.8)
Cardiomyopathy	5 (21.7)
Valvular	1 (4.3)
Hypertension	6 (26.1)
NYHA Classification	
III	17 (73.9)
IV	6 (26.1)

Key: NYHA: New York Heart Association