

**Abstract:**

**Aims:** To explore how patients with CHF describe their experiences of breathlessness, the pattern of their breathlessness, how daily life is affected and how they adjust to and manage these symptoms.

**Background:** Chronic Heart Failure (CHF) is a highly prevalent syndrome often with poor outcomes and in a patient group who are predominately elderly. Breathlessness is the main symptom experienced by patients and often relates to decompensation and hospitalisation, yet subtle changes described by patients are often not discussed with health care professionals.

**Design:** A descriptive qualitative design

**Participants:** Twenty-five participants with heart failure with reduced ejection fraction (HF-REF) from a tertiary referral centre in England

**Methods:** Twenty-five semi-structured interviews were conducted and data was analysed through thematic analysis

**Findings:** All participants reported experiencing breathlessness daily. Four sub-themes were identified in their accounts: nature of breathlessness, emotional impact of breathlessness, impact of breathlessness on daily life and managing breathlessness.

**Conclusion:** Participants were able to give vivid descriptions of breathlessness and the way it affected their lives.

**Relevance to Clinical Practice.** Health care professionals need to take account of each patient's personal assessment of their own breathlessness and how this is having an effect on their life and ability to undertake activities of daily living. Self-care management strategies need to be developed so that subtle changes can be assessed by the patient and reviewed by the healthcare professional to avoid hospitalisation and increased mortality risks.

**Keywords:** chronic heart failure, breathlessness, patients' experience, qualitative.

### **Introduction:**

Chronic Heart Failure (CHF) is a life-limiting syndrome, which has poor outcomes for patients. Over the last decade there has been an increase in the incidence of CHF with the majority of people being first diagnosed falling into the older patient group (mean age at first admission 77.7 years). Furthermore, with CHF being present in an older population, many patients also present with a number of comorbidities (NICOR, 2013 and 2015). As with any syndrome, diagnosis can be difficult to 'pick up' as it is the accumulation of symptoms that is often the first indicator to both patients and health care professionals there is an underlying problem (Herr *et al*, 2014).

The most prevalent symptoms experienced by patients with heart failure are breathlessness and fatigue (Moser *et al*, 2014). The degree of breathlessness a person experiences has been closely linked to mortality, and has been found to be one of the first signs of undiagnosed heart failure (Van Riet *et al*, 2014) and acute decompensation (Mentz *et al* 2015). However, once diagnosed with heart failure, patients experience breathlessness on an increasingly regularly occurrence and as the syndrome progresses so does the degree of breathlessness. It is therefore important for health care professionals to understand breathlessness and particularly in patients who have been diagnosed and are living with heart failure.

### **Background:**

The American Thoracic Society (1999) defines dyspnoea as:

‘Dyspnoea is a term used to characterise a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological, social and environmental factor, and may induce secondary physiological and behavioural responses.’ (p.322)

What is significant in this definition is the multifactorial nature of breathlessness. Rather than just the physical symptom of breathlessness, it also encompasses subjective experience of breathlessness. Therefore, it is important breathlessness is not seen in isolation but rather in the context of a patient’s daily life, and is seen as different for each patient.

Breathlessness in CHF presents in two distinct stages in the disease trajectory, firstly as an acute presentation of heart failure, either on first presentation or as an acute decompensation of the disease and secondly as a known and managed symptom once a diagnosis has been made and the syndrome progresses into the chronic stages. .

Patel *et al* (2007) explored why CHF patients would seek acute and urgent care, and found 86% of patients stated the main reason was breathlessness, and would particularly seek help if they were breathless when lying down. Interestingly, 50% of these patients did not equate this breathlessness episode to problems with either their heart or lungs with only 4% linking this with worsening of their heart failure.

Johnson *et al* (2014) explored breathlessness in the acute clinical setting and found sudden breathlessness was a common reason for presentation to the emergency department in people older than 75 years. They also found this carried a poor clinical outcome. This finding was supported by a study undertaken by Mentz *et al* (2015) who explored the relationship of severity of breathlessness in heart failure on admission to acute care with the clinical outcome. The study (n = 48,616 ≥ 65 years) found a graded increase in the mortality rates of patients when comparing breathlessness to levels of activity. Patients who were breathless at

rest had a higher 30 day mortality rate and 30 day readmission rate than those with breathlessness on moderate activity and those with breathlessness on minimal activity. The authors reported that severity of breathlessness was an important prognostic marker for patients who presented with acute decompensation of heart failure. Patients appeared to try to manage their breathlessness rather than seek help earlier.

In a study in 2015, Reeder *et al* explored how patients perceived their symptoms and managed heart failure through self-care strategies. They found most patients would seek acute care due to breathlessness, fatigue or oedema, however, they also found that the majority of the patients (n=37) had these symptoms for anything up to 14 days before presentation. When questioned why they had not sought help earlier, many reported they did not realise the symptoms were showing their heart failure was worsening. Patel *et al* (2007) also found patients did not relate a worsening of breathless with deterioration in heart failure.

Gysels and Higginson (2011) explored the lived experience of breathlessness in CHF and found patients often could not say when the breathlessness started and described breathlessness was a slow process which crept up on them. Patients had learnt to 'live' with breathlessness and described how they had to adapt their lives and activities to what breathlessness 'allowed' them to do. The patients also expressed how they often under-reported the episodes of breathlessness or its severity to health care professionals.

In support of this finding Edmonds *et al* (2005) study found patients structured breathlessness in 3 ways; firstly, everyday breathlessness (including night time breathlessness); secondly, worsening breathlessness and thirdly, uncontrollable breathlessness. Patients reported seeking help only if their own strategies of breathlessness did not work. The researchers reported a discord between health care professional's language and patients' descriptors of breathlessness which may impact on effective communication

between the two groups on the management and presentation of breathlessness. Simon *et al* (2013) found patients described breathless in types of episodes triggered by something. Heart failure patients described four types of episodes of breathlessness. 93% of CHF patients found breathlessness was triggered with a predictable response (type 2) and 60% found breathlessness was not triggered by anything and was unpredictable in its cause. The 4 types of breathlessness episodes described by Simon *et al* do appear to represent the trajectory of the disease progression within heart failure.

An interesting finding reported by Shoaib *et al* (2014) was that breathlessness at rest was more alarming for patients and so would trigger them to seek help, yet patients who were comfortable at rest but breathless on slight exertion (CARBOSE) had a worse prognosis. This suggests patients are not seeking help to manage their breathlessness at the right stage of deterioration.

The findings above suggest a number of areas to be explored with patients in relation to their experience of breathlessness in CHF. Firstly, how chronic breathlessness is managed and secondly, how acute exacerbations are recognised in patients. A better understanding of these issues is essential for health care professionals to collaborate with their patients to optimise treatment and ultimately quality of life.

### **Aims and Objectives**

The purpose of this study was to explore how patients themselves describe their experiences of breathlessness, how breathlessness affects their daily lives and how they adjust to and manage it.

### **Method:**

### **Design**

An exploratory qualitative approach was used. The use of semi-structured interviews facilitated exploration of the patient's experience of living with heart failure and enabled them to tell their own story of living with CHF and to discuss their perception of breathlessness in the context of the syndrome and in their daily lives.

### **Data Collection**

Participants were recruited from a large tertiary care centre in England. All had been diagnosed with Heart Failure with Reduced Ejection Fraction (HF-REF).

The specialist heart failure team identified patients who had been hospitalised with heart failure in the previous year and invited them to take part in the study. The potential participants were posted a research information pack, which included an invitation letter, an information sheet and a reply slip with a stamped return envelope. Eligibility criteria were a diagnosis of HF-REF, ability to speak and read English (or supply a translator) and assessed as cognitively competent at the last clinical assessment. The current status of each patient was checked prior to posting to ensure that no invitation letters were sent inappropriately.

Participants who wanted to partake returned the reply slip with their name and contact details to the lead author, who then contacted them to answer any questions on the research and arrange a convenient time and place to interview them. Written informed consent was given by all participants prior to commencement of the interview.

The interviews were conducted with patients in their own homes, between November 2012 and June 2013. All interviews were conducted by the lead author, and took between 45 and 90 minutes. Participants were invited to tell their own story of being diagnosed and living with heart failure. A topic guide was designed to explore their experience of breathlessness and was piloted with five patients who were members of the study's Advisory Group.

Although a topic guide had been prepared, in most cases topics were covered with minimal prompts, through the natural development of the patient's narrative. All interviews were digitally recorded and transcribed verbatim.

### *Data Analysis*

Data analysis was undertaken using Braun and Clarke's (2006) framework for thematic analysis. This framework has 6 stages which enabled the identification of common codes, searching for themes and final themes to emerge from the data. The six stages described by Braun and Clarke include; familiarisation with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; producing the report. The process was inductive and was led by the data, and common threads of breathlessness emerged from the transcripts and similar descriptions and patterns of breathlessness connected the transcripts together. The research team independently read each transcript in its own context and then all transcripts were read together to get a feel for the interconnectedness of the data.

Each transcript was coded for breathlessness individually and emergence of themes. Once this was completed there was discussion within the research team to agree the themes to ensure credibility and transparency of the data (Braun and Clarke, 2006). Any discrepancies in the interpretation of data were discussed with the research group and agreement was reached by everyone.

### *Ethics*

The study was approved by the National Research Ethics Service and the investigation conforms to the principles outlined in the Declaration of Helsinki (WMA, 1964)

### **Results**

Eighty-six patients were sent a research information pack, and twenty-six returned the reply slip, a response rate of 30%. Unfortunately, one participant died before interview.

The characteristics of the study are presented in Table 1.

Participants reported they were often asked how short of breath they were, or to rate their breathlessness on a scale (usually of 1-5). However, they reported finding it difficult to respond in a meaningful way as they were unclear how or on what basis they should rate their breathlessness. All 25 participants reported experiencing breathlessness daily, with eighteen (72%) participants identifying breathlessness as the most limiting symptom. Participants with different underlying aetiologies experienced symptom severity differently.

Breathlessness was seen as the most limiting symptom in patients with ischaemic heart disease, cardiomyopathy and mixed aetiology. In contrast participants with valve disease or hypertension, breathlessness and fatigue had equal limitation on their daily life.

The themes that emerged from analysis of the data were; the nature of breathlessness, the emotional impact of breathlessness, the impact of breathlessness on daily life and managing breathlessness.

#### **Nature of breathlessness:**

Most participants were able to describe the feeling of breathlessness very vividly. The nature of breathlessness was described by participants often in two stages, firstly when heart failure symptoms started and were very acute and then secondly, how breathlessness affected them in their daily lives. Most referred to the feeling of not being able to breathe. Some described difficulty getting breath into their lungs, or the feeling of not being able to breathe in at all. This is a participant sharing what an acute episodes of breathless felt like for him before he had been diagnosed with heart failure:

*'I had extreme shortness of breath and I felt I couldn't breathe at all. I felt rather as if I was drowning. I really thought that I was not, you know, going to survive without some form of treatment.... It just felt, no matter what I did, I couldn't oxygenate my body. I couldn't breathe properly at all and it was just becoming more and more difficult to breathe at all' (56-year-old male with cardiomyopathy CHF NYHA III).*

This is a participant describing what living with breathlessness was like for him once he knew he had heart failure, but did not equate the worsening of his breathing to his heart failure:

*'Very unpleasant, very wearing and tiring. I was for ever trying new things like opening the window and standing there and trying to breathe, even go out and try and get more oxygen in, which failed miserably. I had no idea what the problem was, it gradually got worse over a period of 3-4 days...All of a sudden I couldn't cope, I was desperate for oxygen now. I asked my wife to call an ambulance' (77-year-old male with hypertensive CHF NYHA IV).*

Once heart failure was known and participants were living with breathlessness they described the nature of breathlessness in the context of their daily lives.

*'I woke in the early hours of the morning and I couldn't breathe.....I was breathless all the time...[I]am lacking breath, getting out of breath.. [you] can't breathe out, [you] can't breathe in but [you] feel you can't breathe out.....like running for a bus but I haven't run for a bus' (75-year-old male with IHD CHF NYHA IV).*

*'Going up stairs most of the time [well you know], I have to stop, or if I walk a distance, then I start to feel breathless... I can just be sat here and I have to go like that, sort of fill [your] lungs up.' (76-year-old male with IHD/hypertensive CHF NYHA IV).*

Participants often described this scenario as 'gasping for air' but also feeling like they were 'suffocating' or 'drowning'.

In both examples participants described how they tried to manage the breathlessness with the need to breathe more quickly with shorter breaths in an attempt to get more air in or by changing behaviour.

### **Emotional impact of breathlessness:**

The inability to breathe left participants feeling ‘very frightened’ or ‘terrified’ and extremely distressed. The emotional impact was also different if participants were describing the acute exacerbation or the chronic living with heart failure.

One participant described the panic she felt during an acute exacerbation.

*I just couldn't breathe..... As long as I sat here and didn't do anything, I seemed to be alright... I sat on the stairs because I thought I can't get upstairs....I thought you know, just relax, forget, you know, try and thinking of something else. Because I think you tend to panic too -why this is happening...’ (70-year-old female with IHD CHF NYHA IV)*

Whereas when living with breathlessness participants found they were embarrassed by the degree of breathless when in the company of other people and indicated that it caused further anxiety, stress and panic which in turn exacerbated their difficulties in breathing or brought on more breathlessness.

Several participants also reported they could not identify a cause for episodes of breathlessness and this itself caused further worry, why it was happening and when it would happen again. Other emotions experienced by participants included anger and frustration at the limitations breathlessness imposed on their life. Night time seemed to be a particular difficult time for the participants. Participants found sleep was affected particularly by breathlessness or a related cough, but also by the medications taken for CHF, resulting in the need to get up in the night to use the toilet, sometimes many times at night.

*‘I was unable to sleep at night. I just sit down here downstairs coughing, trying to get my breath. I was struggling getting upstairs; I had to crawl upstairs to get to the toilet.’ (56-year-old female with cardiomyopathy CHF NYHA III)*

Participants also described how they feared going to sleep, how they woke up thinking of how to breathe and how they experienced nightmares or ‘weird dreams’ which disrupted their

sleep. A common experience for many was ‘lying awake with my mind wandering, thinking of things and what will be’.

*‘I also have to get up during the night as well as sometimes because I can’t sleep...things start going through my head and that does it...my mind wanders...it does that and it goes mad...I find I have to get up and watch some television...it seems to take my mind off it a bit.’ (66-year-old male with IHD CHF NYHA III)*

Participants felt the quality of sleep they could get was affected by breathlessness and their inability to breathe comfortably at night made their mind wander and become fearful.

*‘Well breathlessness overnight tends to wake one up panicking that I can’t, can’t breathe. I mean there is this sensation of drowning that I do get, less so now actually than previously. But I have had quite long periods where I would wake up and I would really you know be quite disturbed by it...’ (56-year-old male with cardiomyopathy CHF NYHA III).*

*‘These times in the middle of the night when you’re really frightened...oh am I going to die now you know...because you’ve nothing else to do during the night, just lie there and think.’ (86-year-old female with hypertensive CHF NYHA III).*

Participants felt the emotional distress was considerable and had significant consequences for both themselves and those around them. Many participants described a sense of dejection at what the future held for them: they lacked motivation, felt beholden to others, sensed that ‘the fight has gone’ and generally felt that their life was over.

*‘When I think of the tiredness and the breathlessness I feel....well the only thing I could say .... I feel as if my life is over....I want my life back, I have no life when I feel like this...(75-year-old female with IHD CHF NYHA III)*

Some participants also felt anger, shock and panic at the diagnosis and the prospect of living with debilitating symptoms which could not be cured and would get progressively worse.

*‘I know I can’t really have any effect on things in general, certainly around the house...I find it very difficult to do anything, which means I’m not a person, I’m just a mouth to feed.’ (75-year-old male with IHD CHF NYHA IV)*

The feelings for the future or the journey they were on were not positive, with a sense of despair amongst many participants. This was seen across all ages and both genders.

### **The impact of breathlessness on daily life:**

Breathlessness impacted on a wide range of activities. Many described how breathlessness affected activities such as sleeping, eating, walking and talking, particularly in an acute exacerbation.

*'breathlessness was dreadful..... I fought for breath...I couldn't eat because I couldn't eat and breathe, I couldn't talk to you because it would take too much energy up and I couldn't walk, I couldn't go shopping. My life was it was dreadful.'*  
(75-year-old female with IHD CHF NYHA III)

Whereas in daily living with breathlessness participants described activities that were just related to normal life and the impact breathlessness had on these. Participants talked about not being able to take a shower because of the steam or the need to stand up would bring on their breathlessness, whereas others were unable to take a bath because they could not get in or out of the bathtub.

Many participants were unable to function fully in their own home, or undertake activities such as hovering, cleaning or gardening, because they could not walk up stairs or found that bending down, reaching up or lifting would bring on their breathlessness.

*'It has changed my life considerably because I hate seeing someone come in ... I just feel so useless and helpless ..... when you go to do something and you realise you can't do it and you mustn't do it.... I feel mainly frustrated and disappointed. It's mainly the lack of the normal life I suppose and not being able to do, looking after myself properly and the housework and the cooking'* (84-year-old female with IHD CHF NYHA IV).

Others talked about the impact on their life and the need to feel a purpose.

*I've nothing to get up for in the morning if I, no incentive to get up.... So I make myself do it [cooking] ...and I can cope with that and I feel that I'm doing something useful and cooking is useful. And psychologically if you don't do that you'd give up 79-year-old female with IHD CHF NYHA III).*

As the participant population were older, many of the participants talked about the impact their breathlessness had on their ability to be a grandparent or undertake the social activities they wanted to, and had previously done. There was also a feeling of isolation and loneliness, which participants attributed to the limitations their breathlessness had placed on 'going out' or 'doing things'. The impact on the participants to work was not discussed in great detail as the majority of the participants were retired. Of those who were of working age (4 out of 25) all had given work up do to the impact of heart failure on their daily life. There was also a feeling of isolation and loneliness, which participants attributed to the limitations their breathlessness had placed on 'going out' or 'doing things'.

Many participants experienced significant changes in their roles as a consequence of the degree of breathlessness they experienced. Male participants, saw their wives take on roles they had previously perceived as theirs, (e.g. mowing the lawn or doing heavy work around the house), and female participants saw they could no longer do the roles in the home they perceived as theirs.

*'I am fairly limited to what I can do now...I can't get on the floor and play with my grandchildren, we can't go on holiday as we can't get insurance...Yes it has impacted on my life.'* (66-year-old male with IHD CHF NYHA III)

The diagnosis of CHF and subsequent symptoms affected their lives so much they found coming to terms with the changes difficult. This often left participants frustrated, angry and questioning what their role was.

### **Managing breathlessness:**

Many participants felt able to manage their breathlessness themselves, through taught deep breathing exercises, used regularly to overcome episodes of breathlessness. Others knew 'their breathlessness' well and so knew when it would happen and when it was 'coming on'. In both of these examples, patients would rest before or during the episode and then complete what they were doing. Some participants explained that they would 'slow down' rather than stop what they were doing, as this meant they did not allow the 'breathlessness to win'. Others avoided any form of activity that would cause them to be breathless. Many participants reported using mobility aids such as a walking stick or wheelchair because they got breathless after walking even short distances.

The majority of participants were unable to lie supine, many managing their breathlessness at night by sleeping on three or four pillows or on a bed that would raise their upper body.

Others found sleeping in bed too uncomfortable and so would 'sleep' in a chair.

*I'm lying in bed and unable to sleep, then I start getting stressed. I'm uncomfortable, my mind's wandering all over the place and I just generally don't like it....but if I come and sit down here [in the chair]and got my dressing gown, I've got a rug I put over my legs and feet and everything, then I am a lot more comfortable and relaxed to lying in bed.' (77-year-old male with hypertensive CHF NYHA IV)*

Nearly all participants recognised the relationship between the degree of breathlessness they were experiencing and how they managed their weight/fluid retention. While some sought guidance from their HCP, others took their own decisions to take an extra diuretic to reduce their breathlessness.

*'I can't lie flat as I feel like I am suffocating. You really can't breathe; you know it's as if somebody's got something over your face. So I sit up and have a drink of water, put my pillows back together again and lie down again... Some nights, when I go to bed, I can't breathe no matter what's going on. And I tend to take an extra water tablet and that manages it...'* (65-year-old female with cardiomyopathy CHF NYHA III)

In general it was evident people living with CHF were able to recognise the differences in how they felt and could do, and developed strategies, often their own, to overcome the level of breathlessness they were feeling.

Participants described an acceptance of the limitations placed on their lives. They had gradually changed their lifestyle, adapted it to live within these limitations, and described this in terms of taking control and making choices to manage their life. They would plan and organise how they could go out; the best way to travel, the best seats for them in the cinema/theatre or when to visit friends or family.

*'If we were going to for dinner we made sure we left in plenty of time to get there. If we were going to a concert we made sure we left in plenty of time to get there. We always made sure we got an end seat on the row for me....so I could get outside without disturbing people.'* (77-year-old male with hypertensive CHF NYHA IV)

Some participants described how they would research where hospitals or support services were if they were leaving their home, either for a holiday or for the day. Many also described the need to identify tasks and set goals, as achieving them was rewarding and seen as a positive motivator to carry on. One participant described how he would choose to climb stairs rather than take the lift, as he felt he had achieved something and his illness wasn't 'getting the better of him'.

*'You develop kind of strategies for avoiding extra effort, you know, so by using reasonable tactics you can, not disguise, but mitigate.'* (67-year-old male with hypertensive CHF NYHA III)

Participants made choices to give themselves a degree of control and enable them to manage their breathlessness.

## **Discussion:**

This paper has reported how 25 patients diagnosed with HF-REF described their experiences of breathlessness and how this had an effect on how they lived their daily lives.

Participants discussed breathlessness in relation to a number of dimensions: the way they experienced their symptoms, their emotional response to them, the impact in practical and psychological terms and the ways they had developed to manage symptoms and minimise impact. These findings support the definition put forward by the American Thoracic Society where breathlessness was defined as multi-factorial which had a degree of subjectivity and could not be seen in isolation, but had to be seen in the context of a person's daily life.

Similar findings were reported by Bosworth et al (2004) and Edmonds et al (2005), although in Bosworth's study of 15 participants, all were male and two-thirds were classified as NYHA class I/II. Our study demonstrates findings in a mixed gender population with a greater mean age and severity of illness, highlighting the experience of breathlessness as chronic heart failure progressed.

In this study it was found many participants felt they were left to manage on their own with little support or guidance from health professionals with regard to progression of the symptoms and what that meant. Self-management strategies for patients and caregivers appears to improve quality of life, especially when symptoms such as breathlessness are assessed using patient descriptors and in language patients understand, demonstrating the need for relevant education (Ekman *et al* 2011). However, a study by Wilkinson *et al* (2015) exploring nurses' attitudes, views and beliefs about their role with patients who have long term conditions and self-management found a difference between what nurses believed and what they actually did. This discord suggests that nurses' ability to work with patients as absolute partners was hindered by their own sense of professional accountability. Although

this was not explored during this study, it may well be similar finding to what the patients are experiencing.

The manner in which patients experience breathlessness is often an important component of successful management of the symptom. It is often the first symptom that develops in acute heart failure and important components of this deterioration can be subtle and need careful assessment (Van Riet *et al*, 2014). This study has shown that listening to how patients describe changes in their daily life, and their perceptions of symptom changes is significant in how health professionals work with patients to manage breathlessness, and could lead to a greater degree of self-care (Reeder *et al* 2015).

This study has shown that breathlessness had caused changes to participants' lives; including their role within the family unit and the loss of valued activities. Breathlessness had also caused a number of emotional responses in participants including feelings of dejection, resignation, fear and anger. Thus, showing that the importance of psychological support for patients with heart failure. This is supported by findings from Heo *et al* (2014) study, where they identified the need for greater awareness amongst health care professionals regarding the risk of depression and appropriate support offered

This study has explored the experience of breathlessness for patients with CHF. It has identified that many patients are unaware of what worsening of symptoms means in relation to their disease progression. They tend to learn to live within their limitations and accept change rather than looking at how strategies through self-care could optimise the symptom. Furthermore, they identified how breathlessness affects them emotionally and has a negative effect on their quality of life, demonstrating the need for health professionals to play a key role in psychological support.

## **Limitations**

A potential limitation of the study is that all participants were recruited from one tertiary care centre in England and all were white British. Had patients from other ethnic or cultural groups and other geographical areas been recruited, they may have described different experiences. However the sample is representative of the national picture of HF-REF in terms of age and gender.

## **Relevance to Clinical Practice**

The impact of breathlessness on patients with CHF has been evident by their own descriptions. It is clear this symptom not only affects daily life and how life is managed, but also has broader consequences for both physical and emotional well-being of patients. It was also evident from patient narratives they developed strategies to overcome and manage breathlessness, however greater intervention from health professional was required to enable patients to know when to manage it themselves and when to call for help. As a consequence there needs to be a more robust method of assessment available for both to ensure subtle changes in the nature and severity of breathlessness are detected, and a strategy of how best to manage self-care in this group of patients.

Summary box:

What does this paper contribute to the wider global clinical community?

1. This paper is relevant to all nurses who care for patients with chronic heart failure in any clinical context
2. It helps nurses to understand the experience of breathlessness from a patient's perspective which may help the nurse and patient to work in partnership to manage breathlessness.

**Contributions:**

Research team: Dr Helen Walthall, Professor Mary Boulton and Professor Crispin Jenkinson.

All were involved in the designing of the study, analysing data, and identifying themes and contributing to writing the paper. Dr Walthall took primary responsibility for reviewing the literature and drafting the paper.

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