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Symptoms and fear in heart failure patients approaching end of life: a mixed methods study

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Abstract

Aims and Objectives—The purpose of this study was to consider how fear and symptom experience are perceived in patients with heart failure at the end of life.

Background—Heart failure is a burdensome condition and mortality rates are high globally. There is substantive literature describing suffering and unmet needs but description of the experience of fear and the relationship with symptom burden is limited.

Design—A convergent mixed methods design was used.

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Contributions

Study Design: MA, JX, DM, MH, MN; Data Collection: DM, JK, MH, MN; Data Analysis: MA, JX, PD, MN; Manuscript preparation: MA, JX, CDH, PD, JK, MH, MN, DM, JK.

Conflicts of interest

The authors do not have any conflicts of interest.

Methods—Data from the McGill Quality of Life Questionnaire ($n = 55$) were compared to data from in-depth interviews ($n = 5$).

Results—Patients denied fear when asked directly, but frequently referred to moments of being afraid when they were experiencing symptoms. In addition, patients reported few troublesome symptoms on the survey, but mentioned many more symptoms during interviews.

Conclusions—These data not only identify the relationship between psychological issues and symptom experience but also elucidate the benefit of a mixed method approach in describing such experiences from the perspective of the patient. Future research should examine relationships between and among symptom experience, fear and other psychological constructs across the illness trajectory.

Relevance to Clinical Practice—Conversations about the interaction of symptom burden and fear can lead to both a more robust assessment of symptoms and lead to patient centred interventions.

Keywords

end of life; fear; heart failure; mixed methods; symptoms

Introduction

Heart failure (HF) prevalence is estimated between 2–8% of the world's population and it is a leading cause of the cardiovascular disease-related deaths globally (Hogg *et al.* 2004). A HF hospitalisation more than doubles the likelihood of mortality within 2 years for an individual patient (Ahmed *et al.* 2008). While it is unknown how many patients with HF understand their prognosis, studies have shown a range of 23–40% of patients living with HF make a resuscitation preference known (Dev *et al.* 2012). Unlike diseases such as amyotrophic lateral sclerosis and lung cancer, which have a predictable course allowing patients to anticipate symptom increase and understand the value of palliation, the trajectory of HF is unpredictable (Murray *et al.* 2005). Patients experience cycles of acute decompensation with life-threatening symptoms, but are sometimes able to recover with hospitalisation, appropriate medication adjustments and lifestyle management. This makes the recognition of 'end-stage disease' challenging for patients living with HF, caregivers and their providers (Murray *et al.* 2005, Hupcey *et al.* 2009).

Background

Symptom burden, the number and severity of symptoms leading to a worsened disease outcome, is one method of increasing awareness among patients and caregivers of the seriousness of HF (Gapstur 2007). Dyspnoea and pain are common symptoms reported by patients with advanced HF near the end of life. (Selman *et al.* 2007, Annema *et al.* 2009). Recent studies are beginning to address additional symptoms such as depression and sleep disturbance (Johansson *et al.* 2006, Yu *et al.* 2008, Casida & Parker 2012). However, the best methods for eliciting patient-reported symptoms in end-stage HF are poorly understood. This is particularly important within the context of advance care planning and symptom management.

Although the experience and burden of symptoms is being studied in HF patients, less is known about how individuals and their families interpret symptoms and act accordingly (Leeming *et al.* 2014, Strachan *et al.* 2014). Fear is a common emotion that involves the intense anticipation of threat to a person, accompanied by a desire to escape the situation or defend oneself (fight or flight response; Ohman 2010). A metasynthesis by Clark *et al.* (2012) found fear to be a main barrier to HF help-seeking behaviours. Ryan *et al.* identified a common theme that all of their participants lived with a pre-eminent sense of fear particularly in relation to episodes of nocturnal breathlessness, a common symptom of advanced heart failure (Ryan & Farrelly 2009). Understanding this response is critical in developing management plans for HF patients. One study, for example, found connections between religious comfort and fear of death in patients living with HF (Edmondson *et al.* 2008). Fear of death has also been conceptualised as existential distress, a term describing a sense of meaninglessness or death anxiety. Existential distress is common as patients living with HF struggle with loss of personal identity and worry about the end of life (Leeming *et al.* 2014).

For this study, we conceptualised the relationship between fear and symptoms based on the Theory of Unpleasant Symptoms. The Theory of Unpleasant Symptoms suggests that there may be many factors that influence symptoms including psychological factors, such as fear (Lenz *et al.* 1997). In this theory, a feedback loop exists between the factors that influence symptoms and the actual symptoms. Fear may influence symptom experience and symptom experience may influence certain fears, particularly as patients become more symptomatic approaching end of life. The purpose of this mixed methods study was to explore and describe the relationships between perceptions of symptoms and fear among patients living with HF who are nearing end of life.

Methods

Study design & description

The Natural History of End-of-Life Decision Making was a longitudinal exploratory study that examined the role that patients with advanced illness wanted their family and physician to play in health care decision-making (Nolan *et al.* 2005, Sulmasy *et al.* 2007). The sample included patients in the terminal stage of one of the three disease groups that were characterised by different illness trajectories from diagnosis to death: amyotrophic lateral sclerosis (steady decline), stage IV lung cancer (rapid decline) and advanced HF (uncertain trajectory of decline). Participants from each disease group were recruited from the outpatient specialty clinics and inpatient units of two large, urban, medical institutions in north-eastern USA. Patients were screened and excluded for altered mental status at each interview using the Short Portable Mental Status Questionnaire and the Confusion Assessment Method. Surveys and qualitative interviews were continued every 3 months for up to 2 years or until death, whichever came first. The study was approved by the Johns Hopkins Institutional Review Board (IRB 99-06-18-01), and written consent was obtained from participants. For this study, only participants with HF were included and the focus of the analysis was on quantitative and qualitative data related to symptoms and fear. Data on symptoms and fear were summarised using the data collected at baseline in the study, and

qualitative–quantitative comparisons used quantitative data collected at the same time period as the qualitative data. A convergent mixed methods design was used wherein the quantitative and qualitative data were analysed individually and then integrated during data interpretation (Creswell & Plano 2011).

Sample

A convenience sample was used to collect both the quantitative ($n = 55$) and qualitative ($n = 5$) data. Eligible persons with HF who were inpatients and outpatients were referred to the investigators if they met the inclusion criteria of: aged 18 and older, spoke English or Spanish, could be interviewed within 8 weeks of being hospitalised for New York Heart Association functional class III or IV congestive HF (characterised by decreased mobility with limiting symptoms such as shortness of breath and increased oedema; The Criteria Committee of the New York Heart Association, 1994). Patients were excluded if they were eligible for a heart transplant, as these patients did not perceive themselves to be at the end of life. Of the 106 persons who met these inclusion criteria and were referred to the research team, 55 (52%) participated while 33 (31%) declined to participate, 10 (9%) were unable to be contacted and 8 (8%) were too sick, had died or family declined to have them interviewed. Of the 55 HF patients enrolled in the study, 19 were also asked to participate in a qualitative interview. These 19 were originally selected to provide the greatest diversity in gender, race and age. Seven (37%) of the 19 participants agreed and five participants (26%) provided completed interviews.

Quantitative measurement

The McGill Quality of Life Questionnaire was used to measure quality of life. This 17-item, 10-point Likert scale includes four subscales: physical symptoms, psychological symptoms, support and existential well-being. This tool is reliable (Cronbach's alpha 0.83) and has been validated in the palliative care setting (Cohen *et al.* 1995, Robin Cohen *et al.* 1997). For this study, we examined data from the physical symptom subscale and one question from the psychological symptoms subscale.

For the physical symptom subscale, participants are instructed to fill in the blank and then rate the severity of the symptom from no problem (0) to tremendous problem (10). They are given the opportunity to list and rate up to three symptoms, answering the following question: 'Over the past two (2) days, one troublesome symptom has been: _____ (write symptom)'. From the psychological symptoms subscale we used the item: 'Over the past two (2) days, when I thought of the future, I was not afraid (0) to terrified (10)'. For this study we focused only on fear and did not include other items from this subscale.

Qualitative interviews

Qualitative interviews were conducted by research team members with end-of-life care experience using an interview guide that started out broadly asking about the illness experience before focusing on decision-making. The main topics in the interview guide included the history of the illness, symptoms, decision-making, fear and religious coping. To ensure participants were comfortable during the interview, research nurses conducting the interviews frequently assessed patients for breathlessness and distress. Interviews were

conducted either at the participant's home or in the hospital. All interviews were transcribed verbatim and validated by the interviewer.

Sample interview questions

1. Can you tell me where you are in terms of your illness and how things have been going for you the last couple of days?
2. Tell me about any particular fears that you have.

Analysis

Demographic and clinical data were analysed using descriptive statistics. Age, gender and race (black or white) were explored for their relationship with fear using Pearson's Correlation or *t*-test for independent groups as appropriate. Qualitative transcripts were analysed using an iterative process, where two nurse researchers with expertise in HF and end-of-life care independently reviewed the interviews, created a codebook, and identified and discussed emerging themes. Discrepancies in codes, interpretations of data, and/or themes were resolved by consensus with the research team. Themes were drawn from codes both within and across cases. A clear audit trail was maintained through the use of memos and notes. The quantitative and qualitative results were interpreted together and are presented in the discussion section. Qualitative findings are presented according to the following themes: 'You aren't comfortable' (symptoms) and 'Not having fears, just having hopes' (fear).

Results

Sample characteristics

Fifty-five HF participants completed surveys and a subset of seven completed interviews. Two interviews were excluded because they did not substantively answer interview questions. Five interviews were included in the study. The sample for this study had a similar number of black and white participants. Female participation was 29%. The interviewees were representative of the overall sample with respect to age and race; however, there were more female interviewees (3 of 5) than is represented in our quantitative data sample. Other sample characteristics may be seen in Tables 1 and 2.

Symptoms – quantitative results

Despite having end-stage HF, the 55 participants reported few symptoms on the McGill QOL questionnaire. Although given the opportunity to list three troublesome symptoms, the mean number of symptoms reported was 1.7 (range 0–3 symptoms) and 18% did not list any troublesome symptoms. Mean symptom severity for reported symptoms was 5.9 ± 3.6 (see Table 3). Among participants who completed the qualitative interviews, the mean number of symptoms reported was 1.2 and one person did not list any troublesome symptoms.

Symptoms: qualitative results – 'You're not comfortable'

In the interviews participants described their symptoms in terms of acute and chronic experience. Various symptoms were reported prior to hospitalisation, in everyday life, and

during the hospitalisation. Shortness of breath was commonly mentioned as a symptom participants experienced prior to hospitalisation.

‘...allows fluid to build up in my lungs. When that happens it doesn’t, it doesn’t get cleared up and I lose my breathing, ability’. –Participant 88

Symptoms were described in clusters, in which one symptom would exacerbate or cause a different symptom. For instance, shortness of breath and fluid overload resulted in symptoms of general discomfort and difficulty sleeping.

‘You’re not comfortable. You can’t sleep. When you go to sleep, you have to prop up a lot of pillows, you know, so that you sit up. You don’t lay flat because you feel like you’re suffocating or your heart is skipping beats and stuff’. –Participant 40

Physical symptoms that worsened gradually over time were difficult for participants to understand and interpret. This was particularly true when the symptom was not related to shortness of breath.

‘When I was home, I didn’t gain weight particularly but I was eating less and less but I was taking on fluid. I mean I had a stomach out like this and I said there’s something wrong. You know, I shouldn’t be like this but nobody would tell me what was wrong’. –Participant 116

Everyday symptoms such as general fatigue and weakness were discussed in addition to acute symptoms. Although these daily symptoms did not cause acute distress, they lowered the baseline functional and activity level of the participants.

‘And I just, you know, just take it easy. Don’t do as much as I used to. Might clean up one room a day or something like that. Just relax and take it easy’. –Participant 40

Participants also described symptoms during their hospitalisation.

‘I, but I was miserable all night, all night...So, he got me Maalox, and that let me start to fall asleep, and I’ll be darned if I didn’t wake up again and it was hurtin’. And I said, I rang and I said, “I have to have something, something to stop this heart burn.” I mean it was burning, that was sittin’ up’. –Participant 106

Fear – quantitative results

Of the 55 participants, 29 (53%) indicated some level of fear. The median fear score was 2 out of 10, representing a low or mild level of fear and 26 (47%) selected 0 indicating that they had no fear when they thought of the future. There was no relationship among race, gender, and fear. There was, however, an inverse relationship between age and fear ($r = -0.29$, $P = 0.04$) indicating lower levels of fear among older persons with HF. Despite the low level of fear reported in the quantitative data, some fears were apparent in the qualitative data (as seen in Table 4).

Fear—qualitative results – ‘Not having fears, just having hopes’

In the qualitative interviews, fear was discussed both in regard to decision-control preferences and in response to a direct question from the interview guide, ‘Do you have any fears?’ For Participant 88, the only participant living alone, the only fear stated was ‘being a burden’. Many of the interviewees described moments of acute decompensation with pronounced shortness of breath, often when they presented to the hospital. In those moments patients were afraid. This fear was present as treatment decisions about direction of care and procedures had to be made. Fear was a factor in decision-making.

‘Really they’re wantin’ to get all the water off to start with, so, I don’t see why, you know, I should rush into it because actually I told him I was scared...I said, “If a blood clot’s in there I’d rather wait and if the heparin takes it away, then fine, I’ll go for it’. –Participant 106

Four of the interviewees spoke about the eventuality of death when asked about fear. The participant who did not discuss her own mortality was the youngest participant, 40 years old. Two participants took a very pragmatic approach, accepting the eventuality of death and denying fear.

‘I’ve lived around death and funeral directors and cemeteries, I mean I’m used to it (laughs) I, I, I, I’m used to death all around (laughs-voice breaking). You’re here today and gone today, believe me. And I can tell you that’s it’s many stories like that’. –Participant 88

Only one interviewee admitted there is fear when he thinks about the dying.

‘Well, when you’re dying it’s of course a fear, of course everyone will go there...’
–Participant 76

Most did not admit to a fear when they thought about dying and justified their lack of fear with acknowledgements of faith in God. They believed that faith mitigated fear or that they had made a decision to hope in God instead of let themselves consider fears. Those participants who were hopeful of their future often had unrealistic expectations of their longevity or a cure for their HF. One participant stated she believed she ‘can beat this’, meaning she thought she could be cured of her HF. Another participant indicated she was hopeful to spend another 15 years with her grandson.

‘I look at it as not having fears, just having hopes, you know, instead of fears...It makes me feel positive...Yeah, because if you had fear, you might think negative, and that can bring on something else, you know’. –Participant 40

Discussion

Mixed quantitative and qualitative results were interpreted and considered together. Although participants only listed an average of 1.7 symptoms out of 3 symptoms on the physical symptom subscale, the interviews elicited many more symptoms per individual. This suggests that the use of close-ended questionnaires to measure symptoms in patients with HF at the end of life has limitations. Different question formats should be included in the clinical assessment of symptoms – both closed-ended questions (i.e. Do you have

shortness of breath?) and open-ended questions (i.e. What symptoms have you been experiencing?).

The divergence of reported symptoms may be related to participants feeling they should only list the worst symptoms they experience on the McGill questionnaire rather than the top three most troublesome symptoms. It may also be difficult for patients to have sufficient concentration to complete a questionnaire, particularly while in the hospital. Mild cognitive impairment, while not measured in this study has been reported to affect up to 73% of patients living with HF and significantly impair their ability to complete self-care-related activities (Cameron *et al.* 2010). Moving forward, future HF research may benefit from considering the impact of cognitive impairment on the study outcomes and should carefully consider the limitations and benefits of different symptom measurements.

From both the quantitative and qualitative data, it is evident that patients living with end-stage HF experience a wide spectrum of symptoms ranging from shortness of breath to daily fatigue. The HF literature, however, has primarily focused on pain and dyspnoea, even for patients at the end of life (Gadoud *et al.* 2013). Participants from this study reported acute symptoms, but they also reported chronic symptoms which influenced their daily lives (e.g. fatigue and weakness), and nonacute symptoms experienced during hospitalisations. Findings from the study affirm the need for clinicians to thoroughly assess for acute and chronic symptoms other than pain and dyspnoea in multiple question formats.

During qualitative interviews participants reported fear during symptom distress and treatment decision-making. Patients described fearful moments during symptom exacerbation characterised by pronounced shortness of breath and other symptoms, which often led to a hospitalisation. This confirms findings of previous qualitative studies linking fear and breathlessness (Ryan & Farrelly 2009). The interrelationships between psychological factors such as fear and multiple physical symptoms, as suggested by the Theory of Unpleasant Symptoms, is supported by our data (Lenz *et al.* 1997). This relationship between acute symptoms and fear brings to light the importance of understanding end-stage HF in two modes: acute decompensation and chronic care. In addition, these data provide additional support for the HF illness trajectory model (Murray *et al.* 2005, Davidson *et al.* 2007).

While interview participants articulated a heightened awareness of their own mortality, most did not communicate fear or existential distress. Social acceptability bias may play a role as the 'ideal' patient might be anticipated to be brave and uncomplaining. The denial of fear may be affected by the religious coping of some. Several participants who denied fear immediately began discussing faith in God. In addition, several participants had an unrealistic expectation of longevity, a finding which is supported by a growing body of literature in end-of-life HF research (Gadoud *et al.* 2013). As the HF population increases rapidly, it is critical for health care providers to have the training and skills to provide appropriate, realistic information to patients about living with HF and the HF disease trajectory.

Limitations and strengths

Fifty-two per cent of HF patients who were approached for this study and eligible, participated. While this may seem like a low level of participation, this is similar to the 31% and 63% participation rates of other studies of HF patients and advanced care planning in HF (Schellinger *et al.* 2011) and palliative care (Evangelista *et al.* 2014) respectively. Our sample of quantitative participants is reflective of the social and demographic characteristics of the HF populations served at the urban centres where the study was performed, but our results may not be generalisable to other populations due to sampling methods and study design. Individuals were surveyed during a period of clinical stability; however, most patients described fear occurring during acute states of clinical instability. Recall bias may have altered the reporting of symptom burden and the experience of fear in some participants. During this study, we did not interact with patients living with HF during an acute decompensation so our findings may reflect only fear experienced with chronic symptom management.

Also, while saturation was met for the primary aims of the parent study it is unclear if saturation was met for this secondary study. The quantitative data for this study is derived from a tool that is validated in several populations. The use of a disease-specific instrument may have produced results that would be more sensitive to HF-related issues affecting quality of life. The reliability and validity of the symptom subscale and the question regarding fear on the McGill Quality of Life Questionnaire has not been demonstrated in the HF population.

In spite of these limitations this study has several strengths. First, it elucidated the construct of fear – which can be both adaptive and maladaptive; second it described the utility of combining both quantitative and qualitative methods to paint a picture of symptom burden and reactions (Rosen & Schulkin 1998).

Conclusions

Findings of this study support the need for asking research questions in multiple ways to obtain a unique person-centred approach. Future research describing the relationship between symptom burden and fear should be undertaken with particular attention to identifying both acute and chronic states.

Relevance to clinical practice

These findings highlight the importance of having conversations that engage patients in discussing both their symptoms and the meaning that they attach to them. These conversations can lead to both a more robust assessment of symptoms and to important end-of-life discussions surrounding the topics of fear, death and dying (Pantilat & Steimle 2004, Pantilat 2009). This type of engagement is a common role of palliative care and multidisciplinary HF teams caring for patients living with HF at the end of life (Pantilat & Steimle 2004). Future research should assess the role of fear at the end of life through the development and use of instruments that engage patients in reflecting on this topic. Moreover, understanding the role of fear within other psychological constructs, such as

depression, anxiety and stress should be considered. Finally, comprehensively addressing symptom management in patients with HF at the end of life may help lessen the burden of fear that some experience, particularly in episodes of acute decompensated heart failure.

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

- A mixed methods approach including open- and closed-ended questions may elicit a richer understanding of the symptom experience of heart failure patients at the end of life.
- Heart failure patients at the end of life experience fears, particularly when experiencing severe shortness of breath, but minimally report other fears.

Table 1

Sample characteristics for interview participants (*N* = 5)

Participant	Gender	Race	Age	Primary Social Support	Lives Alone	Time since Dx (months)
116	F	Caucasian	75	Friend/Partner	No	130
88	M	Black	76	Sister	Yes	144
40	F	Black	42	Father	No	0
106	F	Caucasian	62	Daughter	No	132
76	M	Asian	67	Wife	No	1

Table 2Sample characteristics for all participants ($N = 55$)

Mean Age	62.3 years
Gender	
Female	29%
Male	71%
Race/Ethnicity	
Caucasian	42%
Black	42%
Hispanic	7%
Asian	7%
Other	2%
Mean ejection fraction*	23%
Mean New York Heart Association Class (NYHA) (class 3–4)	3.4
Mean time since HF diagnosis	7.6 years (50% of sample diagnosed in year prior to data collection)

* Mean ejection fraction is a measure of heart pump function found by echocardiogram. Normal is 60% or better.

Table 3**Quantitative Symptom burden (*n* = 55)**

Number of Symptoms reported	0–18%
	1–29%
	2–16%
	3–37%
Mean number of symptoms reported	1.7 ± 1.14
Mean Troublesomeness	5.9 ± 3.6
Symptom Frequency (Total of 93 symptoms reported for the 55 participants)	
Dyspnoea	26%
Pain	20%
Fatigue	24%
oedema	3%
Psychological Symptoms	11%
Other	15%
Fear when thinking about the future	53% some level of fear 47% no fear
McGill QOL score	mean = 5.98 ± 2.89, median = 6

Table 4

Mixed Results for Interviewees

Participant	Ejection Fraction (%)	McGill stated symptoms and severity (1–10, 10 = most severe)	Symptom descriptions from Qualitative interviews	McGill rating of fear/future (1–10, with 10 as most severe)	Fear descriptions from Qualitative Interviews
116	10	SOB - 5/10	Backache, decreased appetite, low energy, constipation, bloating, feeling of choking when eating, irregular rhythm	0/10	Did not state any fears
88	35	No symptoms reported	Difficulty concentrating	0/10	'being a burden'
40	25	1 back spasms - 3/10 2 sleepiness - 5/10 3 Getting used to medications/jittery - 4/10	Boredom Weakness, fatigue, uncomfortable, insomnia, SOB, arrhythmia	0/10	'When you can't catch your breath'
106	25	'water on my legs' - 9/10	Swelling, irregular rhythm, pain, depression, itching, heartburn, blood clot, decreased urine output, decreased mobility	0/10	Fear of procedures 'killing me', 'rushing into' decisions regarding health care
76	25	'nervous about heart' - 6/10	Fatigue, depression, weakness	4/10	Fear of 'stressing the heart', dying