

Removing the boundaries: palliative care for patients with heart failure

Gillian Horne Doncaster and Bassetlaw Hospitals NHS Trust, Doncaster and **Sheila Payne** Trent Palliative Care Centre, University of Sheffield, Sheffield

Aim: This study aimed to explore the experiences of patients with severe heart failure and identify their needs for palliative care. **Method:** A qualitative design was chosen. Semi-structured interviews were used for data collection and patients were interviewed in their homes. The sample consisted of 20 patients with a confirmed diagnosis of heart failure. Patients were between 60 and 83 years. **Results:** Patients reported difficulties in walking, extreme fatigue and problems managing daily activities. Having to rely on family, friends and neighbours was common, causing feelings of being a burden, loneliness and isolation. Patients talked about dying as well as their fears and frustrations in living with heart failure. Barriers to accessing information and social services were identified. None of these patients had been referred to specialist palliative care services. **Conclusions:** Patients' experiences were similar to those of patients living with advanced cancer and yet they received little support. Comprehensive routine assessment of the palliative care needs of patients living with severe heart failure is recommended. *Palliative Medicine* 2004; **18**: 291–296

Key words: heart failure; lived experience; palliative care; qualitative research

Introduction

Heart failure has become a major cause of morbidity and mortality in the UK,¹ with a mortality rate suggested to be 31–48% at one year from diagnosis of heart failure and 76% at three years.² Incidence is speculated to rise by 70% over the next decade.³ These mortality figures are higher than some cancers and yet there is little research about the palliative care needs of this patient population.

The topic of palliative care for heart failure has gained increasing interest both in government and statutory bodies.^{4,5} This interest comes as a result of an increasing and ageing population of patients surviving heart disease related events.

Research on the care of patients dying from heart failure has mainly been conducted through retrospective studies. Evidence suggests that patients have experienced barriers to obtaining information about their condition and choices in care.^{6–8} Patients with severe heart failure are dying with significant symptom burden that is similar, or in some instances greater than, patients dying from cancer,^{9–11} and yet they are rarely referred to specialist palliative care teams.⁹

Methods

A prospective qualitative design was used because the literature suggested that there is a lack of descriptive knowledge on the needs and experiences of patients living with end-stage heart failure.^{11,12} The use of a qualitative design would therefore help discover the meanings and characteristics of living with heart failure from the patient's perspective. Open semi-structured interviews enable patients to elaborate on their experiences and views. The local Research Ethics Committee granted approval for this study.

Setting

The study was conducted in Doncaster, one of three areas in the South Yorkshire Health Action Zone. Doncaster has a population of approximately 300 000 people with urban and rural communities situated in former coal mining areas. As part of the Modernisation agency, a Coronary Heart Disease collaborative project began there in April 2001.

Sampling

We used purposive sampling to recruit patients, who had a clinical diagnosis of heart failure confirmed by echocardiogram. They were recruited either by the consultant cardiologists, care of the elderly consultant or the heart failure nurse specialist from two teaching hospitals in the north of England. Twenty-four patients were identified; two declined participation and a further

Address for correspondence: Gillian Horne, Doncaster and Bassetlaw Hospitals NHS Trust, Armthorpe Rd, Doncaster DN2 5LT, UK.
E-mail: gillian.horne@dbh.nhs.uk

two died before they could be interviewed. Of the 20 who consented, 11 patients had New York Heart Association¹³ (NYHA) classification 4; seven patients were class 3 and two were class 2. Six of the sampled patients died within six months. Of the six who died, five were classed as stage 4, and one as stage 3.

Patients were not excluded because of comorbidities as older patients are recognised as likely to have associated diseases.¹⁴ In total 20 patients were interviewed aged 60–83 years (mean 73 years), of whom fourteen were men and six were women. Thirteen patients reported owning their own homes and seven lived in rented accommodation. Fourteen patients were married and lived with their spouse, one patient lived with her brother and five patients lived alone.

Collection of data

Data were collected between October 2001 and March 2002. Semi-structured interviews were used. Key questions helped to obtain information about the needs and concerns of patients. Questions were carefully selected and approved by the local ethics committee to limit potential distress to participants. Patient interviews were conducted by the first author in their own homes and audiotaped with their consent. Field notes were also taken (GH). Interviews lasted on average 30 minutes. Informed consent was obtained before each interview started. Sampling of patients continued until no new themes were identified.

Analysis

The audiotapes were transcribed verbatim. The data were anonymised. Data were coded independently by the researchers (GH, SP) using a grounded theory approach.¹⁵ This approach allowed identification and labelling of the main themes and categories. Field notes and a research diary (GH) also contributed to the analysis. Concurrent analysis and data collection enabled refinement of the focus of the study on emergent issues. In the last three patient interviews theoretical sampling was employed using a revised interview schedule, which served to confirm or refute the emerging themes. This systematic process of analysis was guided by grounded theory.¹⁵ Strategies to ensure validity or trustworthiness were employed throughout the study.¹⁶

Results

Three main themes describe the patients' experiences in living with heart failure, 1) 'can't do', 2) difficulties in walking and 3) relying on others. Seven subthemes were also identified: concept of disease; talking about death; keep taking the tablets; feelings and attitudes; hope and hopelessness; symptoms and information needs.

Main themes

1) '*Can't do*'. Not being able to do even small tasks or get out of the house pervaded many of the patients' lives and influenced changes and experiences of loss in every aspect of their daily living.

I just aint got the guts and strength to do anything. I'm well I don't lose interest in it, I mean I want to do something but I can't. (No 7, Male, Age 60)

Simple activities like maintaining their own personal hygiene, walking, standing or bending may become impossible. The ability to drive the car, climb stairs, pick up prescriptions, shop or cook for themselves became more difficult and had meant a loss of the life and enjoyment they once knew.

The difficulty is getting to the doctors to get my tablets, you know. I can't get out and I've got to pay a girl to go and get them for me. (No 6, Female, Age 75)

Living with heart failure meant that patients often could not get out of their house and therefore found it difficult to access services.

I think the only way to describe my days, day by day, is just getting up sitting here and looking at that fish tank. (No 7, Male, Age 60)

2) *Difficulties in walking*. This theme was identified as a difficulty or major challenge for patients. Many had been very active but now were limited to walking around the house or short distances only. Difficulties in walking were related to breathlessness or loss of energy.

But er, I don't get out a lot cause walking just used to shatter me. (No 15, Male, Age 68)

Walking was seen as important to a sense of wellbeing and again presented a significant loss to the sampled patients.

It's me life and sole love. I can't say no more. That's how important it is. (No 18, Male, Age 81)

3) *Relying on others*. Patients needed to rely on those around them for help. This meant relying on their spouse or family members but for those living alone this also meant relying on friends and neighbours. Relying on people was needed for basic living activities such as washing, cooking, personal care and maintaining their home. Patients expressed feelings of being a burden, which was enhanced sometimes by having to ask for help. Having to be dependant on others impacted on their role and those of carers, often causing an emotional impact on patients' lives.

Oh the thing that gets me, this destroys me, she (wife) now has to do the gardening. I mean I can't even bend down. This destroys me. (No 15, Male, Age 68)

Difficulties were expressed in accessing social services for support and aids for bathing, home help or financial advice. Spouses requested guidelines in caring for their partner and did not know how to access support. Those living alone relied on neighbours' goodwill.

It takes me all my time to change me bed, well my neighbour does it...the most important thing cos using a commode at night when I'm on my own you want a clinical nurse to clean and everything you know. You can't, can't do it yourself. I can't expect, couldn't expect my neighbours to do it. (No 1, Male, Age 83)

Subthemes

1) *Concept of disease.* Patients used words such as 'dead', 'rubbish', 'diseased', 'gone completely' or 'scarred tissue' to describe the condition of their heart. They often related their disease to the effect it had on their lives

It's hard to put into words in't, but what I understand about it is it puts me out of breath and I can't walk and can't do owt. (No 13, Male, Age 70)

Some patients had worked out for themselves that something was wrong, but others talked about being told by their doctors 'we can't do anything for you'.

2) *Talking about death.* Patients were asked how they saw their future and they all talked about death and dying. Many had thought about death daily and shared their concerns with the interviewer (GH), but found it hard to discuss with their families. Patients had mixed views about wanting to know their prognosis. Wives also expressed fears in watching their spouse die. For some patients fears were about the dying process and others worried about the family they were leaving behind.

But I'm, you get worried not er I'm not afraid of being dead but I'm worried about dying. I don't want to die and I don't want to know that I'm dying, I want to die in my sleep. (No 16, Male, Age 80)

3) *'Keep taking the tablets'.* Patients perceived the necessity to be on medication in different ways. For some they knew medication was crucial to their existence and felt that apart from tablets there was nothing else that could be done, so they heeded the advice of their physicians. Others felt their tablets were a nuisance and related this to unwanted side effects such as the constant need to void, which further restricted them to their home.

Any tablets what they give me I'll take em and half the time I think they're no good, but then again I think they know what they're doing so leave it to em and I still carry on taking em. (No 13, Male, Age 70)

Patients told of how they bartered with their doctor to reduce dosages or independently stopped taking medication. They talked about constant changes in dosages and expressed anxiety about when further increases would no longer be an option.

But everything keeps changing and they get one tablet sorted out and then something else'll happen and I'll drop back again. (No 7, Male, Age 60)

4) *Feelings and attitudes.* Patients used descriptive words such as 'terrible', 'absolutely unreal', 'miserable', 'shattered' and 'rotten', to describe the effect heart failure had on their lives. They talked about being imprisoned by their illness, depressed and sad.

Here I am, I am lounging about in chairs. Wife's getting onto me, and ee it does make me sad. (No 2, Male, Age 82)

Ten participants felt frightened, which caused sleeplessness and anxiety. They related this emotion to fear of death, pain, having another heart attack, going out alone, and readmission to hospital or medical procedures. Feelings of frustration, loss of self-esteem and confidence was common. They struggled to discuss their feelings with family from fear of further burdening their carers. Lack of emotional support compounded a sense of loneliness and isolation for those living alone. Getting older was felt to be the reason for a lack of response to cries for help.

It (illness) knocks the hell out of me. Cos I'm sat in this chair like a dummy. I get up to mend me fire, I have it in buckets...so I aven't got to go. They (family) get it in buckets and I just throw it on fire and I sit back here. So it's forced to be a burden in't it. I'm a burden to me self love. I can't say no more, and nobody coming to see me, well little lady next door, she's 70 odd, she comes every day or every other day for about 10 minutes and that's it. (No 18, Male, Age 81)

No I'm not really worried (pause) I mean there's people er young who need more treatment than I do I mean I'm getting old and it doesn't matter. (No 6, Female, Age 75)

5) *Hope and hopelessness.* The object of patient's hope was often to be able to go for a walk, get out of the house and gain back some independence. Some patients hoped

for a longer future, to have some of their 'normal' life back or bargained for even a portion of what they once had.

Well my future at the moment, all I can say, I'm hoping to get a bit of strength so that I can walk about again and enjoy a bit of life. (No 1, Male, Age 83)

And getting back on my feet, being able to get out a bit. If, if I only go for a walk around the block for 10 minutes, you know. (No 14, Male, Age 78)

Hopelessness was also experienced, sometimes alongside feelings of hope but for others it was the predominant feeling that they just saw their lives as finished or 'simply going'.

6) *Symptoms.* Although this study did not seek to quantify patients' symptoms, participants talked about their symptoms to the interviewer (GH). The most common symptoms reported were: having no strength, constantly feeling tired and lacking the energy to do anything. Patients felt mentally able to tackle tasks but after repeated failure to achieve them they complained of feeling too tired to even try. Simply getting washed, dressed and walking downstairs in the morning would take them several hours.

Other symptoms were shortness of breath (14) or sleeplessness (5). Not being able to breathe was the main reason patients called the doctor or an ambulance to be admitted to hospital. In an analysis of the six patients who did not complain about experiences of breathlessness two were classed as NYHA stage 4, three as NYHA stage 3 and one at NYHA stage 2. Other symptoms were loss of weight (6), loss of appetite (4), pain (3), having 'swollen legs' (4), nausea (1) and constipation (1).

7) *Information needs.* Patients expressed needs for better communication from their physicians in the form of explanation, education and information. Typical comments were 'nobody ever tells you' and the 'doctor didn't explain'.

That's something that has not been explained to me, you know, how bad the condition is...If what, you know, how far can I look in front and what I can look forward to or not...I've not been told, you know, up to now what the effects are likely to be. (No 9, Male, Age 65)

Explanation was requested to gain a better understanding of the disease process, the practical limitations, how to get help and how to cope in living with heart failure. Some sense of prognosis and wanting to be told the truth was also important to these participants.

Discussion

This is a small qualitative study undertaken in one area of England. The intention of this study was to identify issues and concerns from the perspectives of patients, but we make no claims about the ability to generalise these results. A limitation of this study is that it was a cross-sectional design and 11 of the 20 patients were NYHA class 4; therefore, 9 of the sampled patients may not have started to recognise end-of-life issues. In future a quantitative study could be utilised in combination with qualitative methods to determine relationships between concepts and variables identified.

The results of this study revealed that despite expert medical care the most common symptoms experienced were an extreme lack of energy and breathlessness.

These data reveal that fatigue is the predominant symptom. Previous research has indicated fatigue is a problem,¹⁷ but has not elicited the major impact of fatigue on patient's lives. A recent review of exercise training and heart failure suggests that there may be positive effects on quality of life as well as physiological benefits and reduction in hospital readmission rates at least in the short-term.¹⁸ The need for further research and trials of exercise programmes for patients with end-stage heart failure may offer hope. The development of strategies to manage fatigue and trials with palliative treatments used for fatigue with cancer patients is also worthy of further research.

Breathlessness was often associated with fear and the primary reason for calling out the doctor or an ambulance. Accurate assessment and interventions such as those devised for the management of breathlessness in patients with cancer may be worthy of evaluation in this context.¹⁹ Interestingly, 6 out of the 20 patients interviewed did not discuss experiences of breathlessness. This could be accounted for by patients being accustomed to breathlessness and not regarding it as a concern within the context of the interview or alternatively fatigue was construed as their main concern.

Patients in this study had experienced significant losses in their life related to the inability to carry out many activities previously done with ease. Difficulties in performing simple tasks had changed patient's roles in family and society, which caused them to be housebound and led to isolation and loneliness. Social isolation can lead to an increased risk of fatal and nonfatal cardiovascular events.²⁰

The emotional impact on these participants was expressed in sadness, fear, frustration, loneliness and sometimes depression. Ten patients expressed fear, which supports the study by Murberg and Bru.²¹ The impact of loss on the participants caused emotional suffering. Palliative care seeks to help people acknowledge their grief and assist them to discover ways of coping.²²

Relying on others was necessary but compounded feelings of hopelessness and fears of being a burden were common. Walking became a major challenge or impossibility and was for many a significant loss. The need to facilitate choices for those who are dying from heart failure is desirable to give some sense of control and to promote hope.⁸ Moser and Worster suggest that management of heart failure has not yet addressed psychological support of patients despite the research evidence showing an association between lack of emotional support and increased cardiac-related events and morbidity.²³ The findings of this study have indeed highlighted a need for more psychological support. Heart failure nurse specialists have had a role in reducing readmission of patients to hospital and titration of medications,²⁴ and they may have a role in providing psychological support especially to patients who are emotionally and socially isolated. The provision of training in counselling skills and palliative care for heart failure nurses would be of benefit.

This study also revealed that despite the patients' perceived lack of information regarding the significance of heart failure and little evidence of their having explicit discussion with their doctors, they all had thoughts about dying. The thoughts and fears expressed in this study are similar to those expressed by patients living with cancer. For example, in McCarthy *et al.*, carers reports that of the 26% of patients who knew they were dying, 82% patients had to work it out for themselves.⁸ Rogers *et al.* reported 50% of their sample of 30 patients with severe heart failure discussed death in the context of their illness,⁶ while the findings from our study were significantly higher.

Our study highlights the need for someone to listen to patients' life stories and be comfortable in talking to them about dying including discussions on what gives meaning to their life. Feelings of guilt and the need to affirm faith were also found. With the palliative care approach, the assessment of spiritual needs is an important part of patient-centred care and therefore should be considered by all health professionals.

The findings from this study highlighted patients' needs for prompt access to social services. This would answer the need for home help and a variety of aids to assist in bathing and toileting. For older informal caregivers, assisting their spouse out of the bath was difficult and they wanted to know how to access help and information including contact numbers. Early referral to community and social services through relevant health professionals is needed.²⁵ Financial assistance to access benefits, respite or provision of day care will also benefit patients and assist carers to provide informal care in their homes.

Conclusion

The palliative care needs of patients living with heart failure are similar to those living with cancer and yet there are fewer services available to them. Physicians and other health professionals need to be aware that these patients may benefit from referral to specialist palliative care services.

Acknowledgements

GH was the principal researcher, designed and managed the overall project, collected and analysed the data. SP assisted in the design, coding and the analysis of the data, providing the academic supervision of GH. SP also assisted GH in editing of this paper. The authors would like to thank Gill Scott, lecturer/practitioner who was a critical companion to GH during the study; Dr Keith Doran, Palliative Medical Consultant; John Cornell, Public Health Officer and Brigid Cain, HAZ project manager who both supported the study; Sharon Lambert and Jenny Hardwick who helped with transcribing and the patients who participated. Source of funding: NHS Health Action Zone fellowship. Source of support: The first author conducted this study whilst reading for a Masters in Medical Science in Clinical Nursing, Midwifery and Public Health Nursing Practice at the University of Sheffield, UK.

References

- 1 Gibbs C, Davies M, Lip G. *ABC of heart failure*, second edition. London: BMJ Books, 2001.
- 2 Gibbs C. Heart disease. In Addington-Hall J, Higginson I eds. *Palliative care for non-cancer patients*. Oxford: Oxford University Press, 2001: 30–37.
- 3 Murray C, Lopez A. Global mortality, disability, and the contribution of risk factors: global burden of disease study. *Lancet* 1997; **349**: 1436–42.
- 4 Department of Health. *National service framework for coronary heart disease: modern standards and service models*. London: Stationery Office, 2000.
- 5 National Council for Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative Care and Cancer Care. *Reaching out: specialist palliative care for adults with non-malignant diseases*. Occasional paper 14. USA: Sage, 1998.
- 6 Rogers A, Addington-Hall J, Abery A, *et al.* Knowledge and communication difficulties for patients with chronic heart failure: qualitative study. *BMJ* 2000; **321**: 605–607.
- 7 Levenson J, McCarthy E, Lynn J, Davic R, Philips S. The last six months of life for patients with congestive heart failure. *J Am Geriatr Soc* 2000; **46**: S101–109.
- 8 McCarthy M, Addington-Hall J, Lay M. Communication and choice in dying from heart disease. *J R Soc Med* 1997; **90**: 128–31.

- 9 Anderson H, Ward C, Eardley A, *et al.* The concerns of patients under palliative care and a heart failure clinic are not being met. *Palliat Med* 2001; **15**: 279–86.
- 10 Lynn J, Teno J, Russell P, *et al.* for the SUPPORT investigators. Perceptions by family members of the dying experience of older and seriously ill patients. *Ann Intern Med* 1997; **126**: 97–106.
- 11 McCarthy M, Addington-Hall J. Dying from heart disease. *J R Coll Physicians Lond* 1996; **30**: 325–28.
- 12 Gibbs L, Addington-Hall J, Gibbs J. Dying from heart failure: lessons from palliative care. *BMJ* 1998; **317**: 961–62.
- 13 Braunwald E. *Heart disease: a textbook of cardiovascular medicine*, fifth edition. Philadelphia, PA: WB Saunders Co, 1997.
- 14 Friesinger G, Butler J. End-of-life care for elderly patients with heart failure. *Clin Geriatr Med* 2000; **16**: 663–75.
- 15 Strauss A, Corbin J. *Basics of qualitative research: grounded theory procedures and techniques*. Thousand Oaks, CA: Sage, 1990.
- 16 Lincoln Y, Guba E. Establishing trustworthiness. In Bryman A, Burgess R eds. *Qualitative research*. London: Sage, 1999: 397–444.
- 17 Bennett S, Baker S, Huster G. Quality of life in women with heart failure. *Healthc Women Int* 1998; **19**: 217–29.
- 18 Lloyd-Williams F, Mair F, Leither M. Exercise training and heart failure: a systematic review of current evidence. *Br J Gen Pract* 2002; **52**: 47–54.
- 19 Twycross R, Wilcock A. *Symptom management*, third edition. Oxon: Radcliffe Medical Press, 2002.
- 20 Krumholz H, Butler J, Miller J, *et al.* Prognostic importance of emotional support for elderly patients hospitalized with heart failure. *Circulation* 1998; **97**: 958–64.
- 21 Murberg T, Bru E. Coping and mortality among patients with congestive heart failure. *Int J Behav Med* 2001; **8**: 66–79.
- 22 Faul C, Woof R. *Palliative care: an Oxford core text*. Oxford: Oxford University Press, 2002.
- 23 Moser D, Worster P. Effect of psychosocial factors on physiologic outcomes in patients with heart failure. *J Adv Nurs* 2000; **14**: 106–15.
- 24 Blue L, Lang E, McMurray J, *et al.* Randomised controlled trial of specialist nurse intervention in heart failure. *BMJ* 2001; **323**: 715–18.
- 25 Murray S, Boyd K, Kendall M, Worth A, Benton T, Clausen H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002; **325**: 929–33.