

Knowledge and communication difficulties for patients with chronic heart failure: qualitative study

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Abstract

Objectives To explore patients' understanding of chronic heart failure; to investigate their need for information and issues concerning communication.
Design Qualitative analysis of in-depth interviews by a constant comparative approach.
Participants 27 patients identified by cardiology and care of the elderly physicians as having symptomatic heart failure (New York Heart Association functional class of II, III, or IV) and who had been admitted to hospital with heart failure in the past 20 months.
Results Participants were aged 38-94 (mean 69 years); 20 had a New York Heart Association classification of III or IV. All had at least one concurrent illness. Participants sought information from the research interviewer about their heart failure, their prognosis, and likely manner of death. They also described several factors that could inhibit successful communication with their doctors. These included difficulties in getting to hospital appointments, confusion, short term memory loss, and the belief that doctors did not want to provide patients with too much knowledge.
Conclusions Good communication requires the ability both to listen and to impart relevant information. Effective and better ways of communicating with patients with chronic heart failure need to be tested. Disease specific barriers to effective communication, such as short term memory loss, confusion, and fatigue should be addressed. Strategies to help patients ask questions, including those related to prognosis, should be developed.

Introduction

Heart failure is a common chronic disease that leads to disability and death. It is the only major cardiovascular disease that has increasing incidence and prevalence.^{1,2} Treatments for heart failure slow, but do not stop, the progression of the disease. The successful management of chronic heart failure may require changes in patients' diet, alcohol intake, and smoking behaviour and use of complex drug regimens to prevent episodes of acute decompensation.³ The limited available evidence suggests that, in some respects, quality of life is poor and often worse than that experienced by patients with other chronic conditions.⁴

Studies in the United States have shown that patients with chronic heart failure find it difficult to retain information and that patients may not appreciate the relevance of information provided by clinicians.⁵ Carers of people who have died from heart disease have reported that, although many patients believed that they were dying, few had been told this or discussed it with their doctors.⁶

In this paper we report findings from a qualitative, interview based study that investigated the experience of patients with heart failure. We focus particularly on their experience of communicating with health professionals.

Participants and methods

Participants were identified and recruited from outpatient clinics in cardiology and care of the elderly and from hospital wards. Patients with a diagnosis of symptomatic heart failure (New York Heart Association functional class II and above) and who had been admitted to hospital because of heart failure in the past 20 months were eligible for inclusion. Initially, every eligible patient was asked to participate in the study. After the first 15 interviews, however, we sought interviews with older and female patients to ensure that a wide range of views was represented. Participants were invited to take part in an open ended interview to discuss the effect heart failure had on their everyday lives. The study was approved by the local ethics committee and written informed consent was obtained from study participants.

Interviews

Thirty seven patients were approached to take part in the study and 30 agreed to be interviewed. Respondents and non-respondents did not differ in terms of age, sex, or New York Heart Association functional class. All but one of the interviews took place in the patients' homes; three were conducted jointly by AR and AA (non-clinical research fellows) and the remainder by AA alone. Three interviews were lost because the tape recorder failed and have been excluded from the analysis. Patients interviewed were aged 38-94 (mean 69) years; 20 were men and 21 classified themselves as white. The mean left ventricular ejection fraction was 33.1% (SD 14.8). The mean number of hospital admissions for heart failure in the past 24 months was 1.7 (range 1- 8) and mean number of

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inpatient admissions for any reason 3.5 (range 1-8). Seven were in New York Heart Association functional class II, 12 in class III, and eight in class IV. All patients had at least one concurrent illness.

Interviews started with the open question, "can you tell me how your heart failure started?" and various ideas and issues were pursued as they occurred in the patient's narrative. A constant comparative approach, in which data are collected and analysed concurrently, was adopted. This approach allows both expected and emergent themes and ideas to be incorporated and explored in subsequent interviews. Interviews lasted between 30 and 90 minutes.

Analysis

All the interviews were tape recorded and transcribed verbatim. The transcripts were read and re-read and the data organised into initial codes, and then into higher codes that encompassed these initial codes and provided insight into identified themes. Deviant cases (those that contradicted ideas or concepts) were sought and contributed to the analysis. Fifteen interviews were coded independently by two researchers (AR and AA); areas where coding differed were reconsidered and an interpretation agreed on. Analysis of the data was aided by the computer package QSR NUDIST 4.0 (non-numerical unstructured data indexing search and theory building).

Results

In this paper we discuss two key areas that emerged from the data. The first is patients' knowledge and understanding of heart failure in general, including their likely prognosis. The second focuses on barriers to effective communication with doctors.

Knowledge about heart failure

Patients generally gave accurate descriptions of the mechanisms associated with acute episodes of heart failure. These patients reported that their heart had failed to pump properly and water collected in their lungs causing acute breathlessness. Most patients felt that their symptoms were a result of growing older and, at least before diagnosis, something for which nothing could be done.

The main thing is coughing. A good old cough and I go [demonstrates breathlessness] puffing away. That's the only effect of it. I don't know why I'm sure. I'm not used to having coughs and things, but there we are: old age.

Many patients gave accounts of the type of person they thought would be likely to get heart disease. However, most lacked a clear understanding of why they had developed heart failure, what it was, and what this implied for them. As one patient stated:

And while I just accepted the fact that I'd got it, to me, it was news that you could have heart failure and go on living.

Patients asked questions about their condition, with interest focused on the nature of their illness and its likely prognosis. These included:

I mean, if your heart is damaged and it's not working as well as it should be working ... But if your heart's damaged does it deteriorate more over the years or does it remain at that level? Do you know what I mean?

Is it terminal?

Prognosis

Although the research interviewer did not introduce the subject of death or dying, half of the participants discussed these issues in the context of their heart failure. In the light of both their advancing age and heart problems, most participants saw death as inevitable. Some discussed their desire to "plan" and make provision for their death.

But there are practical things: I mean I haven't made a will. You've got to start deciding, you know, what you want to happen for the sake of, you know, leaving things reasonably tidy.

Some patients were apparently unaware of their likely prognosis, with two reporting that "heart failure" sounded too terminal. Some patients' narratives suggested that they were aware of but had not (or did not wish to) openly acknowledged their prognosis. This illustrated their ambivalent attitude towards gaining greater knowledge of their condition.

Well sometimes I feel as if I'd rather not know anything. I'd rather let things take its course, you know. That's what I feel like, I'd rather not know, I'd rather not know because it might scare me, you know. I just keep taking the drugs and it all just ... I don't want to know. You know because sometimes I'm a bit worried to ask [doctor's name].

There was also a belief that doctors would not want to talk about the patient's likely death:

I think they like to keep things away from the patient. Like if I were to say to them, "will I see the millennium in?" they won't answer that sort of question.

Barriers to asking questions

Patients' narratives illustrated barriers to communication with doctors. Patients gave various reasons why they believed doctors did not tell them as much about their condition as they would have liked. Some felt doctors generally did not want to give patients too much or inappropriate information about their illness or its treatment.

But, er, the medical profession do not—even my own doctor and the doctor before that—they don't take you into their confidence. ... Either they think you are stupid ... or else not interested.

Some patients voiced concerns about their drugs and the possibilities for alternative interventions. Although some felt unable to raise these issues with their doctors, others believed that their doctors knew what was best for them and that they should not ask questions.

Other factors may have contributed to difficulties in communication with clinicians. Patients reported difficulties in getting to hospitals for appointments and to the outpatient clinic once inside the hospital. These were attributed to problems in walking over distance, using public transport, and intolerance of crowds.

I go to the [hospital] clinic, and sometimes I find it very difficult to get there. There isn't a direct bus service from here ... and then I've got to walk miles to get to the bus stop, you know, and I just can't do it.

Patients reported confusion or short term memory loss as symptoms or side effects of their illness. These may have contributed to their inability to remember to ask questions as planned of their clinicians.

Yes, that's the funny thing! Um, I go with all the intention, all the intentions, of asking for this, that, and the other. And

when I get there, it goes completely out of my mind. Like, um, taking all the tablets at once. . . . Could I have a drink?

Discussion

As suggested by two patients in our study, there seems to be little public understanding of chronic heart failure. Despite being able to describe coherent models of coronary candidacy⁷—that is, the type of people likely to have a heart attack or heart disease—these patients found it difficult to apply these models to their own experiences. This group of patients made sense of their illness in terms of increasing age and decreasing physical and mental capacities. This may have reinforced a belief that nothing could be done about their symptoms. This lack of knowledge of chronic heart failure serves to highlight the importance of patient education and information.

Chronic heart failure has a worse prognosis than many cancers.⁸⁻⁹ Patients in our study seemed to have been given little information about their likely prognosis. Some at least would have liked more information. Studies of patients with cancer have highlighted the positive effect of open communication about their likely prognosis.¹⁰ The high levels of depression found among people with chronic heart failure¹¹⁻¹² may partly be related to a lack of open communication with their doctors. Effective discussion about prognosis could have similar benefits to those shown for cancer patients. Because it is more difficult to predict prognosis in patients with chronic heart failure,¹³ the models of communication adopted in both cancer and palliative care may not be appropriate for this group of patients.

In order to optimise the effectiveness of consultations, the Royal College of Physicians has advocated that patients are provided with written information and audio and visual materials and that they are asked to bring a written list of questions to appointments.¹⁴ In addition, consultations should aim to optimise the perceived relevance of information to individual patients. For patients living with chronic heart failure, the disease specific barriers to communication, such as short term memory loss, confusion, and difficulties in mobility, warrant special consideration. Although doctors may not be best placed to provide patients with all the information they would like, heart failure nurses might be able to contribute if they used an appropriate communication strategy.

Unlike quantitative research, qualitative research does not aim to produce findings that are necessarily representative of a larger population. Findings from qualitative research can be generalised in certain circumstances.¹⁵⁻¹⁶ In our study, the wider concepts such as an absence of public knowledge about heart failure and difficulties inherent in doctor-patient communication underpin the reliability of our findings.

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Contributors: AER designed the qualitative component of the study; participated in data collection, led the data analysis and interpretation, and wrote the paper. JMA-H designed the original study, discussed the data and core ideas, and critically reviewed and edited the paper. JSRG designed the original study, contributed to data collection, discussed the data and core ideas, and critically reviewed and edited the paper. AJA participated in data collection and analysis. ASMMcC discussed core ideas and interpretation of the data and assisted in writing the

What is already known on this topic

Patients with heart failure often experience confusion, short term memory loss, and fatigue

These factors create barriers to doctor-patient communication

What this study adds

Patients tend to attribute symptoms of heart failure to advancing age and believe that nothing can be done about their symptoms

Patients have questions about their illness that they feel unable to ask their doctors

Patients believe that doctors are reluctant to talk about death or dying

Some patients would welcome timely and frank discussion about prognosis

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Endpiece

Advice from an American comedian

In one pocket keep a message reminding you that you are dust and ashes. In the other pocket keep a message telling you that the world was created just for you.