

Title: Patient preferences for heart failure education and perceptions of patient-provider communication

Abstract

Objective: For people managing chronic illness, such as heart failure, adequate health literacy is crucial to understand the complex information that underpins self-care, yet evidence suggests poor understanding in this patient population. To better understand patients' heart failure comprehension and why knowledge gaps may exist, this study sought to explore perceptions of patient-provider communication and ascertain unmet educational needs and preferences.

Methods: Semi-structured in-depth interviews were conducted with 15 symptomatic in-patients with heart failure. Data collection and analysis occurred simultaneously until saturation was reached. Transcripts were analysed using thematic analysis.

Results: Participants relied heavily on providers for HF information and support, expressed numerous unmet educational needs, and had mixed feelings about quality of communication. Participants expressed the need for credible, tailored heart failure information that accounted for comorbid conditions, and preference for face-to-face information delivery. Knowledge gaps included heart failure pharmacotherapy, symptom appraisal and management, cause and chronicity of heart failure, and a specific action plan for heart failure symptom exacerbation. Barriers to effective patient-provider communication included providers using complex medical terminology, lack of adequately detailed information, relationships that did not foster open communication, and participants' memory problems.

Conclusion: Gaps in knowledge and poor communication may indicate inadequate availability of multidisciplinary heart failure management programs, and/or fidelity to guideline recommendations.

Practice Implications: Evaluating heart failure management programs is important to ensure consistent delivery of best-practice education and care. Nurses play a key role in the delivery of patient-focused health information.

Keywords

Heart failure, patient-provider communication, patient education, health literacy

Introduction

More than 23 million people worldwide live with heart failure (HF). It is an irreversible chronic condition most prevalent in older people and the leading cause of their hospitalisation worldwide. Almost 50% of patients with HF are re-hospitalised at least once within 6 months,⁽¹⁾ which accounts for most of the cost associated with HF management. In the UK and Switzerland, hospitalisations account for approximately two thirds of total healthcare spending on HF⁽²⁾, and in Australia, approximately 85%.⁽³⁾

Many HF hospitalisations are considered preventable with proper self-care.⁽⁴⁻⁶⁾ Self-care in HF involves a range of behaviours carried out by patients, often with the help of family members or caregivers, to actively manage their condition.⁽⁷⁾ Self-care involves complex decision-making processes that are often difficult for patients to grasp. Whilst there are many factors that influence a patient's capacity to self-care,⁽⁷⁻⁹⁾ adequate disease-specific knowledge and understanding form the basis of effective self-care. Knowledge of the general concepts of HF, pharmacological and non-pharmacological therapy, as well as symptom recognition, appraisal, and appropriate response to exacerbations is essential to avoid preventable re-hospitalisations. Despite HF guideline promotion worldwide,⁽¹⁰⁻¹²⁾ many patients remain confused about basic aspects of their condition and its management.⁽¹³⁾

Delivery of self-care information may contribute to gaps in patient knowledge and understanding. Almost 40% of HF patients have low health literacy,⁽¹⁴⁾ which impacts on their ability to understand and use health information. Health literacy is dependent on exposure to different information/health messages and how these are delivered.⁽¹⁵⁾ Health literacy is therefore inextricably linked with patient-provider communication. Adequate access to, and quality of, health communication is vital to improve health literacy in HF. Poor communication can lead to major gaps in knowledge and confusion about how to apply information to real life circumstances. Low health literacy is associated with poorer health outcomes and use of healthcare services (greater use of emergency care and hospitalisation, lower probability of the use of preventative services).⁽¹⁶⁾ A recent study also confirmed health literacy as an independent predictor of self-care behavior in HF.⁽¹⁷⁾ Health literacy is therefore a key

outcome in health education, not just in HF, but across all populations. Moving from inadequate to adequate health literacy levels is inherently dependent on cognitive skills,⁽¹⁵⁾ which is also problematic in HF. Prevalence of cognitive impairment in HF varies from 25%⁽¹⁸⁾ to 80%⁽¹⁹⁾ depending on cognition assessment.⁽⁸⁾ Memory, attention, and problem solving are areas of concern in patients with HF and have been shown to have direct negative consequences on self-management capacity.^(20, 21)

A focus on the patient's perspective of health communication in HF is important to understand how to best provide *usable* information to empower patients to become more engaged in self-management.⁽²²⁾ Studies to date have not focused on patients' needs and preferences for HF information, which can provide patient-centered targets for intervention. Understanding what type of information is most useful, from the patient perspective, is key in facilitating high quality patient education and fostering adequate health literacy.

Aims

This study aimed to explore HF patients' perceptions of patient-provider communication, highlighting barriers and facilitators of effective health information delivery, preferred sources of HF information and perceived gaps in HF knowledge to ascertain unmet educational needs.

Methods

Study design

This article reports on the qualitative portion of a mixed-methods study exploring delayed care-seeking in HF.

Recruitment

Participants were recruited from June 2015 – August 2016 using inpatient lists from the cardiothoracic ward at a teaching hospital in Australia. The study site is a centre of excellence for cardiology and national leader of cardiac service provision, including cardiac transplantation. People are often referred to this site from across Australia, resulting in an array of patients with varying demographics and sometimes unique and

severe clinical characteristics. Symptomatic HF patients (New York Heart Association class II-IV)⁽²³⁾ with at least one previous HF-related hospitalisation (not including the current HF admission) were considered eligible for the study. Sufficient English language reading and speaking skills, and the ability to provide written informed consent were also necessary. Patients were excluded if they were unable to provide informed consent or had documented dementia. Eligible patients were invited to participate, provided verbal and written explanation of the study, and given the opportunity to ask questions. Interviewees were a convenience sample of participants recruited into the larger study, including those who expressed an interest in discussing HF knowledge and patient-provider communication. Interviewees had to have the physical capacity to participate in a conversation for up to an hour without significant deterioration (e.g. breathlessness and fatigue) and be available and willing to speak at length in a busy clinical setting. This study was approved by the hospital and university human research ethics committees (ETH:12/052) and conducted within the principles of the Declaration of Helsinki.⁽²⁴⁾

Data collection

Semi-structured interviews were primarily conducted in-person in hospital (n=11) in a private interview room on the cardiology ward or at the bedside when patients were less mobile. The interviewer was a PhD candidate with a Medical Science (Honours) degree and prior clinical research experience in a HF population. Prior to study commencement, participants had no relationship with the researcher, as she was uninvolved with their care. Interviews were conducted by telephone in cases where participants had been discharged (n=4). Interviews lasted from 31-95 minutes, were audio-recorded with permission of participants, and transcribed verbatim. All transcripts were de-identified with pseudonyms replacing names and identifying information removed.

Interviews began by asking participants to talk about their experience with their heart condition and how they dealt with it. Additional questions asked where participants sourced HF information, in what way they perceived the utility of the information, and what types of information they needed. Participants were then asked about their perceptions and experiences with patient-provider communication and in what way

this informed their preference for information delivery style. The interviewer periodically summarised participants' accounts during interviews and asked for confirmation or clarification of meanings.

Data collection and analysis occurred simultaneously. When new themes ceased to emerge from transcripts, it was deemed that saturation had been reached and recruitment for interviews ended.

Data analysis

Descriptive thematic analysis of transcripts was undertaken.⁽²⁵⁾ Transcripts were each read multiple times and initial notes were made to describe proceedings. Transcripts were then coded line-by-line to represent each segment of the data. Codes were applied to summarise concepts and then grouped into larger categories. Emerging themes were listed at the bottom of each transcript and supporting information (quotes) added. To enhance rigour and credibility of findings, two additional authors independently parallel coded a selection of transcripts.⁽²⁶⁾ Emergent themes were discussed to check for consistency of interpretation and disagreements deliberated until consensus was reached. A conceptual map was developed to reflect perceptions of HF education and patient-provider communication across all transcripts and then refined.

Findings

Of the fifteen participants, ten were male and median age was 55 years. Most participants did not live alone and were NYHA class III (53%). Participants were managing, on average, five co-morbidities. Characteristics of the fifteen participants are presented in Table 1.

Perceived barriers and facilitators of patient-provider communication

Memory problems and complex medical language impede effective communication

Limited executive function was a barrier to remembering vital health information, particularly clinical terminology. Difficulty recalling events and names including those to label symptoms, treatment, test and diagnosis led to gaps in knowledge and

impacted communication with providers, where participants were not able to effectively communicate their concerns to their doctors. Note-taking during consultations was described as an effective way of addressing this. This participant explained how note-taking also helped relay important facts to other health providers, facilitating management continuity.

'This time around we (husband and I) are writing things down so... then you can back track...it's a bit like when they said ok, your defibrillator can go through the MRI scanner, but one of my leads can't. It's good to know in future that if you were in a situation, my husband and I both know that I can't have an MRI because of the lead. (Participant 13, female)

Complex medical language also impeded patient-provider communication and affected understanding. Conversely, plain language was linked to effective provider communication where understanding was clear and shared, as in the following example.

'...because she just speaks...she doesn't speak in long words or anything, she just speaks so that anybody would understand what she was saying' (Participant 3, female)

Whilst medical language was identified as a potential barrier to effective communication, asking for clarification was an effective way of mitigating this issue.

'He's usually pretty clear, I think. If I don't like the answering, I tell him to dumb it down a bit so I can understand. It's always good to do. They come up with these words like thoracic and all that sort of stuff and I say, well, what the hell is that? (laughs)' (Participant 15, male)

Incoherent information leads to confused representations

Information delivered consistently by all providers was most effective in clarifying uncertainty. One participant described the strong coherence of a message when delivered from multiple providers. The participant did not have to weigh viewpoints because they were all the same. He had a clear, well-articulated, consistent strategy.

'...it's good that there's that support there and I now realise, coming from the doctor, the specialist and the nurse, that any problems - just ring an ambulance. They can decide whether it's a problem or not.' (Participant 12, male)

Heart failure information that was inconsistent, incomplete, or lacked detail led to gaps in patient understanding. As a result, patients connected pieces of information themselves, often from different providers, to construct bigger pictures. Lack of clear information in relation to pharmacotherapy and side-effects was frequently described.

'I don't think they do enough explanation of the drugs they are giving you. They come in and they say oh we'll give you this, this, and this. I've only really seen a pharmacist maybe... twice or three times come in and actually explain to me what the drugs are. It's normally the nurses who come in and say, "the doctor has prescribed this and this" and you ask the nurse and she says "oh, it's just for that". But they don't actually explain to you what 'that' is. That's been another one of my ongoing sagas with the hospitals. They don't explain to you enough what tablets they are giving.' (Participant 11, male)

Lack of perceived effort to keep patients informed about the details of management contributed to participants' overall negative healthcare experience. Getting information was perceived as a *'long process'*, often leaving patients unclear about their condition. It was frequently noted that HF information delivered by providers was inadequate, not thoroughly explained, or not communicated at all. Some participants perceived doctors lacked time to talk to patients so instead relied on nurses as a first point of call for advice.

Patient-provider relationships impact communication

Patients described varying levels of comfort in openly communicating and asking questions during patient-provider consultations. This was largely dependent on the nature of the relationship between patient and provider either being positive and supportive, or paternalistic. Relationships incorporating trust, compassion, flexibility

and effective two-way communication made participants more comfortable to reach out to their trusted providers, namely those who made themselves easily accessible.

'...I can just ring up and the girls (at reception) will just say come straight in, we'll fit you in... and she'll just fit me straight in. She's very good like that. She's very, very good. Very caring.' (Participant 3, female)

In some cases, patients' embarrassment to ask questions was a barrier to effective communication. Patient-provider consultations were not perceived as an appropriate time for asking questions if one did not already possess a high level of understanding. It was perceived that doctors were not open to being asked questions and expected compliance, overlooking the patient's right to know and make decisions of their own volition.

'Doctors are a funny group. They don't like to be questioned on decisions...they should realise too, it's your life they are dealing with, not their own...' (Participant 2, male)

The perception of doctors' lack of openness to discussion was a barrier to effective communication, and a reflection of the perceived social and cultural norms of being subordinate to those in the medical profession.

'...see this is the other thing 'I'll do as I'm told' because in our day... it's rude to ask the doctor something, you know, you just accept it.' (Participant 8, female)

Heart failure information needs and preferences for information delivery

Perceived gaps in knowledge

Participants openly acknowledged that they did not fully understand their condition, despite living with it daily. Specifically not well understood were clinical terminology, pharmacotherapy, symptom recognition, appraisal and management, and the cause and chronicity of HF. As an example of unmet need for information, the following participant explained the clinical term for her condition was learned only through attending cardiac rehabilitation after suffering multiple myocardial infarctions, resulting in a sense of shock when hearing her diagnosis.

'...she (cardiac rehabilitation nurse) said, 'you're here because you've got chronic cardiac failure'. 'Ahh no sorry, I'm probably in the wrong room'. No, sit yourself down, that's what you've got'. That just really, just REALLY blew me away. Totally.' (Participant 8, female)

Others needed more information about pharmacotherapy, wanted clear information to help identify warning signs and symptoms of HF exacerbation, and a specific action plan recommended by a perceived credible entity.

'Yeah I want to have a plan. Because I need to know, when I do get a symptom, what do I do? And not what do I do, what does the hospital recommend that I do?' (Participant 9, male)

Most participants expressed the need for practical self-care information to help understand different aspects of their condition, however, one participant expressed the need for information about how to cope emotionally. This participant suffered fatigue daily and wanted to develop skills to help accept the consequences of fatigue and manage the feelings of frustration that ensued.

Preferences for information delivery

Most participants expressed a preference for information to be delivered face-to-face and periodically to facilitate information retention.

*'...information could be disseminated over a period of time (in hospital) instead of one hit...you're going to take in only that much and the rest will just go *shunk* over your head...if you were able to address bits in chunks, it would be easier.'* (Participant 13, female)

A combination of verbal, visual, and written information was suggested as the most effective way of communicating HF information, with emphasis on the importance of written information to refer back to post-discharge. Visual communication was described as an effective strategy to deliver health messages clearly in a population who may not be well educated.

'Well, if it's not clear they should have something in writing...with drawings... and explain on that, exactly what they are going to do, and what they plan to do.... A visual would be ideal. Not only for me. I'm mediocre educated, but to get someone less (than) me that's not educated, then you got a problem.'

(Participant 5, male)

Participants stressed the need for HF information to be tailored, relating specifically to aetiology, medical history and comorbidities, and thus, preferred information to be delivered by treating doctors. A number of participants did not identify as the 'typical' patient with HF and felt general information was not relevant or adequate. For example, this participant wanted to know how HF affected him in the context of his pre-existing conditions.

'...To be related to me specifically, as in, to do with my cancer... how does it affect my cancer...I'm not your typical patient because of the cancer.'

(Participant 9, male)

The need for more self-care information and support on discharge was described, highlighting the value of relational continuity in this population, as in, the value of being provided links to future care.

'...if you were discharged and they said look, if you've got any questions here's our website or this is what we put out, would be useful.' (Participant 13, female)

Sources of information

Providers were the preferred source of HF information as they were considered trustworthy and could offer the most tailored HF information. Participants did not, however, exclusively rely on providers for information at all times. Post-discharge from hospital, online and telephone services offered by disease-specific organisations were noted as credible sources of information. The following participant suggested written information produced by a reliable source to avoid internet searching.

'...if it was general information that you could get in booklet form or even through the website would be quite useful that you could go to and it's not Dr

Googling it. If it was put out by an institution so you can rely on the information being accurate would probably be really useful because there isn't anywhere to go to when you're thinking 'I don't understand why this is happening but it doesn't feel right' and you can't put your finger on it. (Participant 13, female)

In most cases, the internet was perceived as untrustworthy and to be avoided. Others were not completely averse to using the internet, but interpreted information sourced online with caution, recognising how it could easily be taken out of context. Participants perceived few opportunities to communicate meaningfully with trusted providers and felt the internet was their only choice when questions arose outside scheduled visits.

I either ask the GP or I ask the cardiologist when I see him but I only see him usually twice a year...So I would google it (laughter)... you understand that the information you may get you can't take that as the gospel, you need to check that up... (Participant 13, female)

Attendance at cardiac rehabilitation programs was noted as a major contributor to improved HF knowledge and understanding.

'We had about 30 people who had battery (ICD) or open heart and they explained to you and you ask all the question. Any stupid question or good question. Yes, it change your life.' (Participant 14, male)

Discussion

Participants perceived gaps in knowledge relating to HF pharmacotherapy, symptom appraisal and management. Providers were participants' preferred source of information, as they were perceived to be the most trustworthy (as opposed to information sourced from the Internet), and able to provide the most tailored and useful information. Perceived facilitators of patient-provider communication included: patient note-taking during consultations, which facilitated information retention and ensured management continuity; consistent health information from providers so that health information was clear and not conflicting; and positive

patient-provider interpersonal relationships involving trust and support, which facilitated open communication. Perceived barriers to effective patient-provider communication included: participants' memory problems; the use of complex medical terminology by providers; lack of adequately detailed health communication or simply no communication at all; and negative patient-provider interpersonal relationships involving lack of trust and paternalism, which did not allow for open communication.

Heart failure education and multidisciplinary care

HF guidelines globally clearly state that HF patient education should include pharmacotherapy, signs indicating deterioration (i.e. symptom recognition and appraisal), and include an a-priori action plan for symptom exacerbation.⁽¹⁰⁻¹²⁾ Despite being guideline recommended topics of education, participants expressed uncertainty and confusion in these areas.

Lack of access to multidisciplinary HF management programs may explain participants' unmet educational needs. From 2005-2006, only 6.3% of hospitals nationwide in Australia provided a HF multidisciplinary management program, which should be available for all who have experienced HF hospitalisation.⁽²⁷⁾ During this time, 8000 patients in total were managed by multidisciplinary HF programs, which represented only 20% of those who needed it.⁽²⁷⁾ Efficacy of multidisciplinary care also relies on adherence to guideline recommendations in real-world population and settings.⁽²⁸⁾ Heart failure guidelines state that a multidisciplinary approach is recommended, but do not mention a specific model of care or specify who the multidisciplinary team should include. Australian investigators showed that, in reality, a multidisciplinary 'team' was comprised of between one nurse to at least four providers.⁽²⁷⁾ Only 39% of programs included a pharmacist, and level of training and education of HF nurses that acted as sole practitioners varied.⁽²⁷⁾ Heterogeneity amongst programs and the inadequate number of programs available to support and educate HF patients makes delivering best-practice patient education challenging.^(27, 28)

Symptom appraisal and management were key areas of uncertainty, further complicated by comorbidities with overlapping symptoms. Participants expressed the need for information that was tailored to their clinical situation and comorbidities,

and felt that general heart failure information was not relevant or adequate. This may be related to the site of recruitment, as participants represented a cohort of the most sick and sometimes atypical cases. Participants with comorbid conditions perceived themselves as distinct, yet the 'typical' heart failure patient does, in fact, suffer multiple comorbidities. This is something that needs to be considered in patient education. Whilst current multidisciplinary guidelines advocate for a holistic approach to HF management, this approach may not transfer to educational strategies. It is fruitless to educate patients on one body system when multiple are failing. Efforts must be made to take a more holistic approach, viewing patients as an entire being rather than focusing on a single condition in isolation. The relationship and interaction between comorbidities makes treatment and patient education challenging. Nurses play a vital role in addressing these challenges and delivering patient-focused, rather than disease-focused, health information.

Sources of heart failure information

Findings highlighted the importance of reliable information that can be easily accessed by patients at any time. Currently, the National Heart Foundation of Australia,⁽²⁹⁾ The American Heart Association,⁽³⁰⁾ and the European Society of Cardiology⁽³¹⁾ offer online resources for people living with HF written in plain language and covering topics such as diagnosis and symptoms of HF, monitoring fluid and symptoms, and lifestyle changes. Whilst these resources cover important information and are freely available, there is little evidence to suggest if/how people are using these online resources and tools, and how it impacts on self-care and coping.

The ability to reach providers easily through a secure online portal would help patients avoid the need to scrutinise reliability of information sourced from the internet. Providing a platform for patients to communicate with providers outside scheduled visits in situations of rapid deterioration, as in HF symptom exacerbation,⁽³²⁾ is an invaluable way of potentially reducing avoidable HF hospitalisation. Whilst the use of electronic health records with patient portals has been gaining traction in the US for the last decade, electronic health records have only launched in Australia since 2016, and do not offer a secure messaging portal.

Patient-provider communication

Communication strategies must be tailored to cater for the needs of those who may have difficulty understanding, using, and remembering vital health information – which in reality, is most patients with HF. Approximately 39% of people with HF have low health literacy,⁽¹⁴⁾ and even patients with adequate skills can experience stress-induced limited health literacy, where emotional response and physical symptoms interfere with the ability to pay attention and listen effectively during medical consultations.⁽³³⁾

Strategies to improve patient health literacy revolve around how health messages are conveyed. Using plain language to communicate information is vital, in written and spoken health messages.⁽³⁴⁾ Story-like formats help listeners predict what is coming in the conversation to enhance ‘listenability’ of health messages and improve health literacy.⁽³⁴⁾ This strategy can be adopted by nurses, given their key role in delivering complex HF self-care information through multidisciplinary HF management programs.

Strategies to improve patient-provider communication can also be used to enhance provider-provider communication to facilitate open and transparent communication styles.⁽³⁵⁾ Consistent information delivered by multiple providers, including nurses, physicians and paramedics, was perceived as a great facilitator of clarifying ambiguity. The potential for mixed messages and ambiguous coordination are a consequence of the very aspect of healthcare that offers strength – a multidisciplinary approach.^(36, 37) A multidisciplinary approach to HF management means that patients are cared for by a team of providers. It is essential that care is coordinated where goals of care are coherent between specialties and clinical areas to ensure management continuity.⁽³⁸⁾ Nurse engagement in the planning and delivery of HF management is crucial to ensure patients receive coordinated care and consistent information. Effective multidisciplinary team communication can help to ensure that HF patients receive care and education that is consistent and coherent.

Limitations

Participants recruited into this study may not be representative of the general Australian HF population. Participants were patients who volunteered to talk about gaps in knowledge and patient-provider communication. Furthermore, participants were recruited from a single site, caring for the most ill and atypical HF cases, who may have more specific information needs compared to the general HF population. For example, the need for tailored information and thus preference for information provision from treating providers to account for the nuances of their clinical situation may be exaggerated in this population. Heart failure, however, is typically associated with multiple comorbidities and thus the need for tailored information that accounts for this should not be discounted.

Conclusion

Adherence to guideline recommended education and focus on how information can be best delivered to this specific population with specific needs (with a focus on the quality of spoken health information) can help better support patient understanding, improve patient health literacy, and the capacity to self-care.

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Conflicts of interest

The Authors declare that there is no conflict of interest.

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