The lived experience of end-stage cardiac failure

CPD

Taylan Gurgenci, Phillip Good

Background
Clinical trials rarely explore the patient's lived experience. Qualitative research bridges the gap between evidence-based medicine and the patient's journey.

Objective
The aim of this article is to explore key aspects of the lived experience of patients with end-stage heart failure (ESHF). This will allow clinicians to better engage with patients and carers faced with this condition.

Discussion
Psychological and spiritual distress are common in ESHF. Patients with ESHF often feel socially isolated. Inadequate communication from clinical staff is a common negative experience for patients to which they frequently resign themselves. The ambiguous illness trajectory in advanced heart failure makes both general practitioners and cardiologists uncomfortable initiating advance care planning and less sure of their roles in these discussions. Patients have spiritual concerns that they reportedly feel awkward raising during consultation. Attention to these concerns will help build rapport and provide more personalised care for patients with ESHF.

HEART FAILURE can be described in different ways. A cardiologist may describe it as a complex clinical syndrome with typical symptoms and signs that generally occur on exertion but can also occur at rest. An epidemiologist may describe it as a burdensome condition primarily of the elderly that accounts for a disproportionately large amount of healthcare spending. The description least frequently presented in the clinical literature is in the patient's own words.

What follows is an outline of the lived experience of patients with end-stage heart failure (ESHF), which relies heavily on qualitative studies. Qualitative studies are conducted through direct patient interviews and present quotations within their results. Recurring themes in the interviews are identified, and interview segments are collated within these themes. Qualitative studies add a richness to the clinical literature and are increasingly embedded within randomised controlled trials (RCTs). The search strategy used was 'heart failure' [MeSH Terms] AND 'qualitative research' [MeSH Terms], which yielded 342 results. Titles and abstracts were reviewed for relevance. Specifically, the articles of interest ideally had patient/carer or clinician interviews and quotes directly included or made reference to such articles in articulating their key messages. A total of 31 articles were retrieved for full text review.[1–31] The reference lists of these full text articles were analysed for other potential articles. The reference lists of a few articles were particularly useful as a guide to locating literature not captured by the search. Many additional articles were considered in this fashion.

Considered broadly, the major themes that emerged were physical symptoms, psychological and spiritual distress, interactions with the health system (with advance care planning as subtheme), the carer's experience of all of the above and the clinician's experience of all of the above.

Diagnosis and treatment are not discussed except insofar as to articulate the burden of medicalisation as cardiac function worsens. These authors interpret ESHF as the point in illness trajectory at which available active management has been exhausted, and so historical studies with different standard pharmacological management may still help us understand how patients feel when they have no further active management options. The focus is on common themes that arise through interviews of patients with worsening heart failure and their families, namely:

- psychological and spiritual distress
- burden of symptoms
- advance care planning.

There were a number of other themes that could have been chosen. These particular themes were selected because, in the authors' experience, they are often the most neglected of the themes that were commonly presented in the literature. Many important aspects of the patient journey will necessarily be omitted. The authors have chosen to highlight aspects of the lived experience they felt were least represented in traditional clinical trials and those most relevant to general practice palliative management. The authors conducted additional searches in an effort to locate and include studies from other nations and cultures after the key themes were identified.

Psychological and spiritual distress in end-stage cardiac failure

Many studies have examined the nature of psychological and spiritual distress in ESHF. Participants frequently volunteered a quite profound unhappiness.[32] The word unhappiness is used here advisedly; there are many traditional clinical investigations into 'depression' in heart failure. For instance, one large prospective RCT evaluated the benefit of sertraline for depression in heart failure.[33] They found sertraline was safe but no better than placebo. Strict ineligibility criteria call into question the clinical relevance and reproducibility of this conclusion.

Such RCTs are instrumental in facilitating evidence-based practice, but when they compress patients into discrete statistical units, the unique experience of each patient is lost. On the other hand, qualitative studies are designed to capture how each patient with heart failure may be uniquely unhappy.[34] One qualitative interview study of patients with heart failure and their carers sought to understand how their lives were affected by the disease. Joint interviews were conducted, transcribed and then sorted into themes and subthemes. The social isolation volunteered by the participants was striking. For instance:[35]

> *It's heart breaking, I don't want to be sat here, I'm fed up with that. I've been painting by numbers, but you get bored with that … that's what I miss, somebody to talk to, I mean, I don't want to sit and look at a paper, I want to be out there.*

This was echoed by other participants:[35]

> *Most days I sit [facing the street] – if I see anybody I know, I go to the gate and have a chat.*

Participants in a Swedish study felt similarly:[36]

> *When you're ill you're not interesting anymore. Before I used to go visiting friends and they used to visit me and that was nice and fun but these days hardly anyone drops by.*

Social isolation is compounded by the difficulty of having to do activities of daily living (ADLs) either alone or with only one other person to help. A 2011 study that compared the experience of ESHF to other terminal diseases found frustration at a new state of dependence to be at the forefront of the patient experience. As one participant noted:[37]

> *[S]ometimes it depresses me coz you feel […] useless, incompetent, you can't do a simple task, like I try to put me socks on and I'm struggling and I might get one on with a bit of luck and I go to get the other one and I have to give up and I'm upset.*

The difficulty of managing these ADLs robbed patients of the desire to engage in recreational activities:[36]

> *I haven't managed anything today; I haven't even read the newspaper* (in a situation when ADL is described as taking a long time) … *I've lost the will. I look out of the window and think no, the weather is too bad today. I won't go out today and before that didn't used to matter.*

Some patients were described to have adopted a more stoic attitude. Patients able to adapt to their change in functional ability were identified as more able to enjoy each day.[32]

Spiritual distress is also seen in ESHF. A reasonable definition may be distress when contemplating a transcendent meaning to existence or a lack thereof. When asked, patients confided their attempts to hide spiritual concerns:[38]

> *The staff are too busy, and you have to learn to look at for yourself … I try to hide my grief and be nice to others. That's what they want to see, someone coming in who's cheerful and doesn't complain.*

Importantly, patients were explicitly reluctant to ask professionals about spiritual concerns because they were worried that such questions may be inappropriate:[38]

> *I wouldn't know what I wanted counselling on. I wouldn't know why I'd want to phone [the counsellor] up.*

Reading such passages, one cannot help but wonder what private turmoil has been missed for want of asking. It would clearly redound to the patient's benefit for their distress to be understood by their doctor. Attending to such details may help physicians too. They might avoid what JD Sapira called 'apple-sorter medicine', such that, 'After a few years of seeing the apples only in the single dimension of size and ignoring their colors, tastes … your medical practice will become one-dimensional, causing boredom and burnout in your life's work'.[39]

Burden of symptoms

The symptoms of ESHF are burdensome, as is the attendant medicalisation of life.[3] Clinicians struggle to balance their innate desire to help with the recognition that more care, even if evidence based, is not always helpful.[40] Each visit to the doctor can remind patients of their declining health:[22]

> *Currently, they're up titrating my medication, lowering my blood pressure. I've tried that once before and that didn't go so well. I nearly fainted then and that made me feel tired and scared.*

Symptoms remind patients that they are unwell, and yet, familiar symptoms can reassure patients that things are not changing for the worse. In a qualitative study of Thai patients with heart failure, one participant evocatively expressed this notion:[41]

> *There is a machine inside of me that controls my heart function. It is ticking inside of me as if it is a clock. At first, I did not like it because it's like having a bomb inside my body ... Now, I am feeling great when it is ticking regularly. It is my life.*

The consequences of symptoms can be burdensome too. One patient with fatigue lamented:[13]

> *They see me, they cannot see how ill I am, and they seem to think I exploit my wife by letting her carry the bags.*

These studies suggest there is a difficult balance that clinicians need to aim for. On the one hand, methodically listing all the signs and symptoms of disease will heighten patient anxiety. On the other hand, to not mention them so as not to scare the patient would be dismissive of what is a central concern in their lives.

Improved patient knowledge of their condition may help to lighten these burdens.[42] Unfortunately, many patients with heart failure often lack even a rudimentary understanding of the condition.[43] A Japanese study showed less than 50% of patients with heart failure had a basic understanding of the disease trajectory.[44] Other studies have shown that when the patient lacks understanding, external manifestations of the disease rather than the underlying condition become the principal focus:[43]

> Participant [asked about hopes for the future]: *Not keep coming in. It's just water retention, innit. Once they can master that, the other half I can live with.*
>
> Interviewer: *If the water retention was sorted you think everything else would be fine?*
>
> Participant: *Yeah.*

This ignorance exacerbates anxiety during heart failure exacerbations. Results from many studies support forthright discussions of prognosis, even when poor:[43]

> *Honest is important. If you say, 'This is going to happen,' I say, 'Okay, fine', quite willing to accept it, but I think if you don't know anything ... you start panicking and it starts mucking up your sleep ... It does ... play on your mind psychologically.*

It is well described that culture can affect preferences regarding prognostic disclosure.[45] Clinicians may be reticent to discuss prognosis if they suspect the patient does not want to hear it. The aforementioned Japanese study took a pragmatic approach and simply asked patients whether they wanted to discuss prognosis or not.[44]

Advance care planning and the fear of dying

Advance care planning has been shown to improve the quality of life of patients with heart failure.[26] Patients with heart failure want to discuss advance care planning,[46] and tools to guide these discussions exist.[47] Yet in one large American study, advance care planning was discussed with less than half of enrolled patients with heart failure.[48] Qualitative literature is filled with examples of patients and carers wanting forthright discussions to facilitate planning:[46]

> *Well, if they think that you are not going to get better, they should give you the choice and let you know. I think it's their duty to tell you. I mean, there is no sense in going to the doctor and he saying, 'You're okay', and you're going to die tomorrow. I would rather they tell me that. At least then I know what they think.*

There is a significant body of research investigating the barriers that prevent advance care planning discussion in heart failure. A British study by Schichter et al of general practitioners (GPs) and their implementation of advance care planning in heart failure identified barriers that are echoed across much of the literature:[26]

> *My biggest fear was getting it wrong and upsetting the person and not being able to recover that and damaging the relationship and not being able to go there again.*

> *With cancer, I actually find it much easier ... And therein lies the problem with [heart failure] and why my [advance care planning] experience with [heart failure] is limited because I find it much harder to predict and getting harder.*

A lack of time as well as uncertainty about roles and responsibilities of the GP versus the cardiologist were also common themes. One GP said it was impossible to have many two-hour conversations regarding advance care planning. Though there are unique cases in which very long discussions take place, these authors' experience is these represent a small minority. There may be a role for education to improve the efficiency of such discussions.

GPs were also concerned they may give the impression there is no further treatment when the cardiologist is still advocating the benefits of an active approach. Interestingly, cardiologists identify similar barriers and express hope that other health professionals who know the patient better may be having these conversations for them even during active management.[40] The end result is a lived experience of ambiguity and loss of control for the patient with heart failure and their family.

Clinicians may read the foregoing passages and think to themselves that they sound applicable to all terminal conditions, not just ESHF, and so question whether it has any special relevance to this illness. In some ways this is true, but as alluded to previously, in one important way it is not: designating a patient with ESHF as terminal or palliative is much less consistent and often delayed when compared with other conditions.

Conclusion

Clinical trials and guidelines rarely give the patient a voice. Qualitative studies provide a means for patients to speak across RCTs and guidelines to the clinicians who read them. Patients with heart failure have a set of unique challenges that, along with their support structures, make up part of their healthcare journey. Australian GPs provide excellent evidence-based management of heart failure as a medical condition. The themes derived from qualitative studies that are reproduced in this article may be useful in truly understanding the patients' lived experience. Future interview-based research could explore the impact of cultural background on how individuals and families make decisions about residential aged care in the context of ESHF. The benefits of explicitly recognising social isolation as well as providing repeated education on their diagnosis and treatment cannot be overemphasised.

Authors

Taylan Gurgenci FRACGP, MBBS, Palliative Care Research Fellow, Mater Research Institute – University of Queensland, South Brisbane, Qld; General Practitioner, Capalaba Medical Centre, Capalaba, Qld

Phillip Good FRACP, PhD, MBBS, Director of Palliative Care, St Vincent's Private Hospital, Brisbane, Qld; Palliative Care Physician, Mater Research Institute – University of Queensland, South Brisbane, Qld

Competing interests: None.

Funding: None.

Provenance and peer review: Commissioned, externally peer reviewed.

Correspondence to:
t.gurgenci@uq.edu.au

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correspondence **ajgp@racgp.org.au**