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# Representing the patient experience of heart failure through empathy, journey and stakeholder mapping

## **Cover Page Footnote**

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## Representing the patient experience of heart failure through empathy, journey and stakeholder mapping

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### Abstract

Heart failure is a long-term condition requiring those affected to manage numerous self-care related activities. People with heart failure report multiple challenges accommodating self-care activities in their every-day life. The aim of this study is to (1) understand the experience of people with heart failure and their caregivers in the local patient population, and (2) visually represent these experiences to inform the design of a mobile health intervention supporting self-care. Seven patients and four family caregivers were interviewed using an empathic approach. Data was collected using rapid design methods including an empathy map to uncover patient and caregiver perspectives and a journey map to document daily self-care activities. Content analysis resulted in a needs and insights summary, a journey map and stakeholder map. The needs and insights are summarised in five themes; controlling, trusting, concerned, symptom-laden and accepting. Negative experiences - restlessness, breathlessness and urination – occurred overnight as visualised in the journey map. Overwhelmingly the spouse and general practitioner were the personal and professional stakeholders involved in self-care activities. Understanding the experience of people with heart failure was the first step in the creation of a patient-centred mobile health intervention. Rapid design methods such as the three presented in this paper can give voice to the patient experience, their frustrations, challenges and existing support structures in a clear, visual format to aid empathic design.

### Keywords

Patient experience, patient- and family-centred care, qualitative methods, heart failure, self-care

### Introduction

Self-care is seen as the key to heart failure management but the understanding of how to operationalise the concept remains inadequate. The literature on heart failure self-care predominantly focusses on knowledge and skills as enablers since effective self-care improves outcomes and addresses the healthcare burden of the condition.<sup>1</sup>

However, living with heart failure is viewed by patients as a life-changing event<sup>2</sup> and the experience is expressed as being very challenging,<sup>1</sup> often with the presence of ambiguous symptoms.<sup>3</sup> The complexity of the patient experience poses challenges when attempting to advance care to improve clinical outcomes and quality of life.

The needs and views of patients and caregivers themselves are seldom included in the design of interventions for heart failure self-care.<sup>1</sup> Where experience information is considered it is broad and generic in nature which does not take into account the fact that perspectives differ with social, economic and geographical determinants of health

and the accessibility, quality and affordability of health services. This context-specificity needs to be considered in future interventions for the condition<sup>3</sup> to improve patient-centred healthcare that meets the requirements of healthcare consumers. Advancing methods for capturing rich experience data for healthcare intervention design is needed.

The aim of this study is to (1) understand the experience of people with heart failure and their caregivers in the local patient population, and (2) visually represent these experiences. Visual representation of experiences provides critical insight for the design team in the development of a self-management mobile health intervention for this patient population. This paper reports research findings and discusses the suitability of empathy, journey and stakeholder mapping in representing patient experience.

## Methods

A design thinking framework for innovation was used. Design thinking focuses on the human experience using empathy<sup>4</sup> to uncover contextual specifics as a novel approach to an existing, complex challenge.<sup>5</sup> Design thinking and other rapid design methodologies offer a set of tools that can help collect, analyse and incorporate experience into the design of health interventions.<sup>5</sup> Here, three rapid design methods generated from a single interview with each participant, are presented.

Semi-structured, face-to-face interviews were conducted with seven patients with heart failure and four family caregivers. Recruitment was via self-selection from recruitment posters and flyers displayed in common areas within the health service; an acute private hospital and co-located out-patient clinic in Sydney, Australia. Written informed consent was established prior to participant interviews which were conducted between May and August 2017. Ethical approval was granted by the University of Tasmania and the health service.

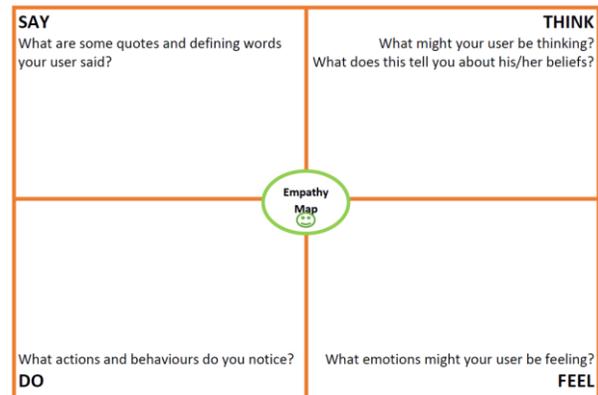
Interviews followed an interview schedule using empathy as a means to uncover participant experience data. An empathic approach to design, as defined by Wright & McCarthy<sup>6</sup> (537-8) begins with a ‘rich understanding of people’s experiences, dreams, expectations, and life contexts’. It is achieved through a meaningful emotional encounter between researcher and participant using dialogue and responding empathically.<sup>6</sup> The approach facilitated discussions that were highly flexible, allowing participants to speak of their experiences, share stories, reflect on healthcare interactions and raise the most salient issues in their daily lives. To represent research findings, the response to the participant experience data was the formation of a needs and insights summary uncovered from empathy map content, along with a journey map and stakeholder map. Each of these three processes are detailed below.

### Needs and Insights

Data collection during the interview involved the use of a four-quadrant empathy map as a way to document what was *said*, what the participant was *thinking*, what they *do*, and how they *feel* (Figure 1). The term ‘user’ was derived from the common application of empathy mapping in market research. Interview questions focussed around overall perceptions of health, how health is managed at home and involvement of others.

Following the interview, needs and insights were elicited via content analysis: *Needs* are verbs which relate to activities or desires and *insights* are interesting or surprising realisations often uncovered from data merged from two or more quadrants within the empathy map.<sup>7</sup> The individual needs and insights were combined to produce

Figure 1. Modified empathy map<sup>7</sup> used in participant interviews



themes in response to having, or caring for someone with, heart failure. Content analysis revealed the dominant characteristics. A table was created listing each dominant characteristic and described the needs and insights associated with this patient category (Table 1).

### Journey Map

The concept of customer journey mapping comes from the business world in respect of better understanding how customers interact with a product or service.<sup>8</sup> In planning for this study, it was adapted and simplified for use in health to capture a day-in-the-life of healthcare consumers. Patients and caregivers were asked to list and comment on the self-care activities they carried out over a usual 24-hour period at home, starting from waking up in the morning through to the following morning. The interviewer documented activities and emotional responses (verbatim quotes and perceived emotions) either side of a long line drawn on A4 paper representing the 24-hour period. Frequently reported self-care activities were clustered alongside other participant responses, and the emotional responses within each cluster were thematically analysed and summarised. A poster was created representing the main activities conducted in the morning, afternoon, evening and overnight period. Alongside each activity is a defining quote and corresponding emotional response either negative, positive or neutral (figure 2).

### Stakeholder Map

Content related to other persons involved in self-care activities was extracted from each participant’s empathy map and journey map. This included who and to what extent that person was involved. In creating the visual representation of these findings and to differentiate the two main stakeholder groups, a colour-code was applied to personal stakeholders (green) and professional stakeholders (blue). The extent to which a stakeholder was involved in self-care activities was represented through the size of the circle corresponding to that stakeholder, i.e. the

**Table 1. Needs and insights of patients with heart failure**

Dominant characteristic	Needs	Insights
Controlling	<ul style="list-style-type: none"> <li>Tracks weight</li> <li>Updates written medication lists</li> <li>Carries medical file to appointments</li> </ul>	<ul style="list-style-type: none"> <li>Frustration with treatment changes</li> <li>Misplacing documentation and poor information sharing is a stressor</li> <li>Caregiver: Likely to support structured/organised approach</li> </ul>
Trusting	<ul style="list-style-type: none"> <li>Fosters interpersonal relationships with healthcare team</li> <li>Pursues reassurance and support</li> <li>Seeks tips and tricks from healthcare team</li> </ul>	<ul style="list-style-type: none"> <li>Respects and trusts doctors and nurses' recommendations</li> <li>Avoids detail on heart failure and treatments</li> <li>Caregiver: Fosters relationships and rapport with healthcare team</li> </ul>
Concerned	<ul style="list-style-type: none"> <li>Reassurance from others</li> <li>Strategies to manage anxiety</li> <li>To be informed 'what to do'</li> </ul>	<ul style="list-style-type: none"> <li>Poor communicator and planner when unwell</li> <li>Sub-optimal decision making</li> <li>Caregiver: Likely to advocate and seek care due to feelings of hopelessness</li> </ul>
Symptom-laden	<ul style="list-style-type: none"> <li>Quality sleep</li> <li>Know symptom self-management support strategies</li> <li>Education regarding link between treatments and symptom management</li> </ul>	<ul style="list-style-type: none"> <li>Feels controlled by symptoms</li> <li>Frustrated and exhausted by the presence and severity of symptoms</li> <li>Caregiver: May feel useless or experience grief; not identify deterioration due to ongoing severe symptoms.</li> </ul>
Accepting	<ul style="list-style-type: none"> <li>Focus on the 'big picture' including striving for good quality of life</li> <li>Work/hobbies/nature contribute to wellness</li> <li>Seeks community engagement and interpersonal relationships</li> </ul>	<ul style="list-style-type: none"> <li>Suboptimal understanding regarding details of heart failure and self-care</li> <li>Frustrated by poor communication between healthcare providers</li> <li>Caregiver: Likely to be insightful, loving and grateful; strives for balance between caring duties and living their own life</li> </ul>

larger the circle, the more involved the stakeholder (Figure 3).

## Results

Seven patients (4 female, 3 male) and four family caregivers (3 male, 1 female) chose to participate. Two married couples and a parent-child pair were included in this sample. The age range of patient participants was 51 to 89 and family caregivers was 56 to 82. Five participants were from metropolitan Sydney and six were from a rural area or another city. The experience of heart failure from the perspective of patients and their family caregivers is represented in a needs and insights summary, a journey map and a stakeholder map. These findings are detailed below.

### *Needs and insights*

Consistent with the design thinking methodology, the needs and insights elicited from empathy map content were collated to five patient categories each with a dominant characteristic (Table 1).

For patients exhibiting *control* over their health information their needs consisted of keeping updated medical documentation with them in a folder or diary, tracking their daily weight and step count, stating 'I want facts and figures; I know where I stand'. Patients were likely to become frustrated with changes to treatment plans and stressed by misplacing documentation; 'My diary is my external memory storage device. If I lose it I go into panic mode'.

*Trusting others* in the heart failure journey comprised the need for ongoing, interpersonal relations with reassurance and practical support from healthcare team members. While patients respected treatment recommendations provided by their healthcare team, suboptimal understanding may follow; 'I don't try to understand; these blokes get paid enough to know. I'm happy enough they're fixing me up.'

For patients constantly *concerned* and worried about their condition, reassurance, being informed about 'what to do' and strategies to manage anxiety, are important. Due to ongoing anxieties for example, demonstrated by the

comment ‘I worry about everything. I hope everything’s alright’, these patients are unlikely to identify, communicate and plan self-care due to the overwhelming concern impeding their decision-making capabilities.

Similarly, those with many interacting *symptoms* need education on symptom self-management support strategies. For example, proper functioning requires quality sleep as one participant explains, ‘Things are getting beyond me’. Insights from patients with many symptoms include exhaustion by the presence and severity of the symptoms experienced, limited ability to attend to daily activities and frustration that symptoms can’t be adequately treated by their healthcare team.

The final category was patients who are *accepting* of their condition. These patients focussed on striving for quality of life through leveraging what makes them happy such as hobbies, work or getting out into nature, stating ‘I have to play the cards I’ve been dealt...I try to find ways to make life enjoyable’. Insights from this patient category include suboptimal understanding regarding the detail around self-care treatments. They also expressed frustration regarding the poor communication of medical information between health service providers.

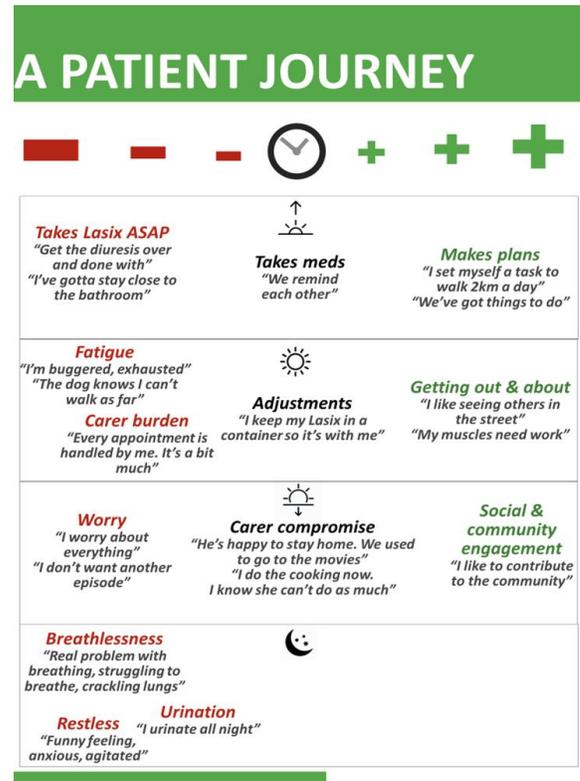
Family *caregivers’* response to each patient group varied. Some caregivers mirrored the traits of the patient, supported self-care and built rapport with the healthcare team, while others struggled for a balance between caregiving and living their own life. Some reported feelings of helplessness and feeling overwhelmed; ‘It’s a bit much’. Advocacy came in the form of caregivers seeking medical assistance on behalf of the patient feeling they were ‘hesitant to make a fuss’.

### Journey map

The patient and caregiver journey over a 24-hour period is represented by a list of common self-care activities carried out in the morning, afternoon, evening and night alongside the emotional response to these activities (Figure 2). A negative emotional response is represented in red on the left-hand side of the figure while positive emotional responses are represented in green on the right-hand side. Neutral responses are represented in black text.

The *morning’s* activities consisted of taking medication (particularly diuretic medications which cause the kidneys to produce more urine) and planning the day. Organising, swallowing and remembering to take morning medications were reported by the patient and caregiver by the comments; ‘Have you taken your tablets?’ and ‘Mum takes her tablets herself’. Taking diuretics was known to cause inconvenient diuresis associated with delays in planning their day; ‘[I must] get the diuresis over and done with. Can’t plan the day until the diuresis is complete’. The inconvenient effects of the morning diuretic medications

Figure 2. Journey map: Daily self-care activities, caregiver involvement and scaled emotional response



was noted by a caregiver; ‘[We’ve] gotta get the effect out of her’. Participants reported their positive attitude and sense of control to plan for daily activities, like exercising; ‘We’ve got things to do. We chat about what we’re doing’ and ‘I set myself a task walking 2km a day’.

In the *afternoon*, positive participant experiences were demonstrated through physical activity and getting out of the house; ‘I like seeing others in the street’. Adjustment to a new level of capability, was demonstrated in the tennis example; ‘If a ball comes in reach, I whack it’ and walking the dog; ‘The dog knows I can’t walk as far’. Condition-related activities such as attending medical appointments and filling scripts at the pharmacy often occurred in the afternoon. Navigating these activities together with local health staff was noted; ‘[I have] two chemists [in town]; if one is out of stock they call the other and get it sorted’. Planning for these afternoon activities was noted in carrying lunchtime medications with them for the day and doing groceries ‘after 3pm when the school kids are working to help put groceries in the car’. Fatigue was commonly reported in the afternoon through the patient statements ‘I’m buggered, exhausted’ and ‘I can’t keep my eyes open’. Similarly, family caregivers reported specific carer-related challenges and concerns predominantly in the afternoon. Statements such as ‘every medical procedure is

handled by me - It's a bit much'; 'it's frustrating when mum doesn't give me warning [that her scripts are running low]'; and 'should I call the doctor or not?' illustrate the caregivers' challenges and concerns.

In the *evening*, positive activities for patients and their caregiver often involved community and social engagement; 'I play bridge with friends' and 'I like to contribute to my community'. For others however, exhaustion caused a decrease in social activities; 'The sick person is happy not to see people. We used to go to the movies [but not now]'. The compromise of the caregiver was noted through contributing more around the house with one participant commenting 'I'm aware she struggles, can't do as much' while another commented on doing more cooking. Reports of anxiety were higher in the evening exemplified by the patient comment; 'I worry about everything. I don't want another episode', requiring medication at times; 'For a crisis, if stressed or anxious, she takes a Valium [diazepam] before bed'.

The *overnight* period presented only negative emotional responses from participants focused on breathlessness, restlessness and the urge to urinate. Participant comments demonstrated anxiety, agitation, breathlessness, crackling

lungs, inability to lay down flat and constant urination. Caregiver responses focused on concern for their loved one through the comments 'I listen to her struggling for breath', 'He's gasping for air' and there's 'nothing more comforting to me than waking up and hearing her breathing beside me - I always worry'. Family caregivers reported sleep disturbance; 'It's annoying. I can't sleep'.

### Stakeholder map

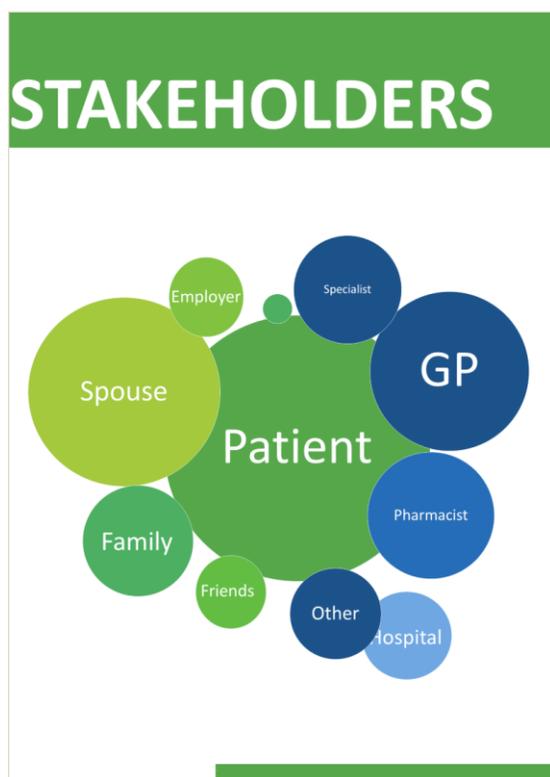
Personal stakeholders are represented in green with larger circles representative of more involvement in every-day life. Blue circles correspond to health-related stakeholders (Figure 3).

The spouse was the most involved *personal stakeholder*. The spouse was most likely to be the greatest support person, demonstrating love and commitment to the health of the person living with heart failure and contributing to housework. They were involved in medication, organising medical appointments, had insight into the patient experience and navigated caregiver challenges aiming for a balance between having their own life and assisting. Other family members were highly valued, but it was uncommon for them to be involved regularly in self-care activities. A child caregiver was actively involved for a widower patient while some didn't see their family at all. Friends provided a social outlet and were not involved in self-care activities. Friends 'don't understand' heart failure nor see them as 'physically ill' which contributed to omitting heart failure-related discussions in the social setting. Furthermore, friends recommending alternative medical treatments frustrated participants at times. Employers were only relevant for a few participants while some discontinued paid employment for health reasons. Nevertheless, many told stories of their previous professional roles, speaking positively of their contribution to the workforce reflecting a strong work ethic. Financial pressures due to stopping work was a common research finding, as well as balancing paid work with caregiver responsibilities. With many participants seemingly community minded, other stakeholders were distantly involved such as the church community, neighbours and volunteer organisations.

In relation to *professional stakeholders*, the most involved was the general practitioner (GP). GPs were reported as being accessible, helpful, providing personalised care and an initial contact point for health-related concerns.

Management of blood thinning medication (warfarin) with the GP however, was considered burdensome. Specialists, namely cardiologists were highly respected, set treatment and medication plans but were less frequently involved than the GP. Medication changes were a reported cause of stress for many participants and negative encounters with specialists were not forgotten by participants many years on. Respecting their experience and instructions were common themes alongside not needing to understand details. Pharmacists were regularly involved, often on a

**Figure 3: Stakeholder map: Heart failure related personal network (represented in green) and health professional network (represented in blue)**



weekly basis offering helpful advice, providing education and assisting with medication variations. Visiting the local pharmacy was a positive weekly or fortnightly event often associated with an outing, walk and opportunity to talk with others in the community.

A physiotherapist was involved with one patient, positively reflecting on a supervised exercise regime. The freely available multidisciplinary heart failure service was appreciated and considered accessible through phone calls to the nurse practitioner, but infrequently accessed in this participant sample. Many participants disliked the in-patient experience. The health system was commented on by a handful of participants. They expressed disappointment with the poor collaboration between health professionals stating that ‘some doctors don’t have each other’s mobile numbers’ and frustration regarding the lack of connection of information between health services especially for rural patients. Phlebotomists, paramedics and palliative care specialists were briefly mentioned.

## Discussion

The research findings have been presented in three forms each representing a different component of the patient and caregiver experience. An empathic approach requires learning the needs of others<sup>6</sup> with the user perspective a valuable asset to identify the *actual* needs rather than the *perceived* needs of patients.<sup>1</sup> Using this approach, much of the findings regarding the patient and caregiver experience regarding heart failure self-care is consistent with three recent systematic reviews on the topic<sup>1-3</sup> but also adds important context-specific details relevant in this population. First in this discussion, the patient experience data is compared to the wider literature on heart failure and self-care practices. Second, the creative representation process is critiqued for suitability of use in intervention design.

### Needs and insights

Heart failure self-care can be seen as a lifestyle adaptation focused on maintaining independence and quality of life.<sup>2</sup> Harkness et al<sup>2</sup> discovered that many patients accepted the possibility of maintaining a good quality of life with heart failure, however this process involved the re-evaluation of what was truly valued by them as individuals.<sup>2</sup> In this study, this was observed in the execution of self-care activities throughout the day, with patients and caregivers seeking a balance between sickness and wellness. Patients accepting of their condition particularly demonstrated this capability.

Further to *knowledge* as a recognised need in this patient group, applying this to every-day life remains challenging. Many patients from previous studies lacked the basic knowledge to conduct self-care effectively.<sup>3</sup> Knowledge deficits particularly related to medication, diet, fluid management and appropriate help-seeking.<sup>3</sup> Even when

patients understood self-care recommendations, the real challenge was overcoming the difficulty of conducting self-care in the context of day-to-day life with fluctuating symptoms.<sup>9</sup> This was consistent with the insights uncovered in the current study specifically for symptom-laden patients whereby symptoms became an exhausting interruption to the daily routine. As important considerations for intervention design, the literature reports promoting self-efficacy, ongoing learning and facilitating adaptation to life patterns<sup>1,3</sup> to facilitate positive patient outcomes<sup>3</sup> in self-care.

### Journey

Journey map findings emphasised the daily challenge of integrating self-care recommendations and heart failure knowledge into every-day life.<sup>2,3</sup> Once again knowledge reappears as a common enabler/barrier from the literature on daily activities carried out by patients with heart failure. Knowledge gaps affect the capacity to engage in specific self-care activities like salt reduction, medication adherence, weight monitoring and physical activity resulting in confusion, delays in care seeking and uncertainty about the future.<sup>1</sup> Further, terminology misconceptions about ‘sodium’ and ‘salt’,<sup>3</sup> challenges with meal preparation and issues with grocery shopping have been uncovered in previous studies.<sup>1,2</sup>

Nonetheless, patients with heart failure have demonstrated the ability to learn from previous experiences to develop intentional strategies in their self-care activities.<sup>2</sup> These learned experiences were evident through examples within the journey map, for example, the early morning administration of diuretic medications to lessen their effects during the main part of the day. Patients have also learned how to pace their daily activities and optimise their ability to do physical activity through modifying their daily activities.<sup>2</sup> This was consistent with participants in the current study planning their day in the morning, then re-evaluating activity throughout the remainder of the day based on fatigue and breathlessness. The journey mapping revealed that this ongoing ‘juggle’ to balance self-care and daily activities<sup>1</sup> has been shown to become a normal part of a patient’s daily routine.<sup>2</sup>

### Stakeholders

The research findings concur with previous studies; family caregivers are heavily involved and this can be tiring for them. Overall, caregivers are seen to facilitate adherence and foster independence,<sup>1</sup> assisting on an everyday basis through organising medications, buying groceries, preparing meals, monitoring symptoms and navigating the healthcare system.<sup>2</sup> Caregivers have detected variations in the patient condition which the healthcare professional and patients themselves didn’t seem to identify.<sup>1</sup> Nevertheless, negative feelings of social isolation, distress, fatigue and ill preparedness of caregivers have been demonstrated leading to recommendations to increase

support for this stakeholder group.<sup>1</sup> Daily caregiver activities were similar in the current study and emotional responses to these activities uncovered equally challenging themes in relation to navigating the healthcare system, fatigue and distress.

Participants reported interacting with their GP more frequently than noted in the literature. The review by Harkness et al<sup>2</sup> referred to physicians as the main healthcare professional involved for patients who reported increased vigilance in symptom monitoring and adherence because of feelings of anxiety, fear of dying or fear of hospitalisation. Patients from previous studies reported uncertainty in developing a relationship with their primary healthcare professional.<sup>2</sup> Further, physicians tended to focus on clinical indicators rather than how the patient 'felt' within themselves which was not necessarily shared with their physicians.<sup>3</sup> This participant group predominantly spoke of positive interactions and open relationships with their GP which is the main differentiating factor to the aforementioned reviews.

### ***Creative representation***

As the number of people living with chronic conditions increases, creative service redesign is needed<sup>10</sup> to accommodate community requirements without compromising quality and safety. Alongside exploring ways to listen to consumers, their voice needs to be heard in healthcare forums.<sup>10</sup> Rapid design methods can be an important tool to capture and incorporate the patient experience in redesign efforts. This practice can give voice to the patient experience, their frustrations, challenges and existing support structures in a clear, visual format. This research demonstrated they can be used successfully in heart failure self-care.

The strength of this approach is not the collection of the experience data but the use of visualisation techniques that help make the data meaningful. In the context of collaborative intervention design the visual representations disseminated the research findings beyond written data alone, widening accessibility to non-traditional audiences. In this case, the needs and insights summary, journey map and stakeholder map were presented in poster format to a diverse group of providers and consumers in participatory design workshops to develop a novel mobile health intervention for heart failure self-management.<sup>11</sup> The use of colour and short quotes added an emotional component to the journey map and the linear nature of time was reflected in the layout. Challenging patient experiences are easily identified in the journey map, emphasising for example, the negative emotional response to all health-related activities in the overnight phase, namely breathlessness, restlessness and urination. Similarly, the use of colour and shape emphasised the frequent involvement of the spouse and GP in health-related interpersonal relations in the stakeholder map. Previous research has shown patients with heart failure define self-

care not only by the activities they conduct for their health but also their emotional response.<sup>2</sup> As a single tool, the journey map captured a more holistic participant experience, adding subjective information to common self-care activities.

### ***Limitations***

While common themes from this research study, the findings are not necessarily generalizable to the wider heart failure population. The impact of participant self-selection on the findings is a limitation of the study. Further, the inherent potential biases of the project lead (first author) in operationalising this qualitative, creative work is to be acknowledged. In the pursuit to completely understand this phenomenon, an observational study, designed to objectively detail daily activities might complement the self-reported data presented in this paper. However, this would impact on the rapid nature of the design methodology.

### ***Conclusion***

Current research on the experience of heart failure is two dimensional and doesn't provide us with enough contextual details to design effective patient-centred interventions to support self-care. Rapid design methods provide tools to gather the patient and caregiver experience within a certain context. The three tools used in this study allowed the identification of needs and insights, emotional responses to daily self-care activities and stakeholders in heart failure self-care. These rapid design methods allow researchers to incorporate the diverse and complex nature of the patient experience through merging data with creativity.

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