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A grounded theory study: Exploring health care professionals decision making when managing end stage heart failure care

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Abstract

Aim: To explore how healthcare professionals in an acute medical setting make decisions when managing the care of patients diagnosed with end stage heart failure, and how these decisions impact directly on the patient's end of life experience.

Design: A constructivist grounded theory approach was adopted.

Method: A purposive sample was used to recruit participants that included 16 registered nurses, 15 doctors and 16 patients. Data were collected using semi-structured interviews and focus groups over a 12-month period of fieldwork concluding in 2017. The interviews were recorded and transcribed and the data were analysed using constant comparison and QSR NVivo.

Findings: Four theoretical categories emerged from the data to explain how healthcare professionals and patients negotiated the process of decision making when considering end of life care. These were: signposting symptoms, organizing care, being informed and recognizing dying. The themes revolved around a core category 'a vicious cycle of heart failure care'.

Conclusion: Healthcare professionals need to engage in informed decision making with patients to break this 'vicious cycle of care' by identifying key stages in the terminal phase of heart failure and correctly signposting the patient to the most suitable healthcare care professional for intervention.

Impact: This study provides a theoretical framework to explain a 'vicious cycle of care' for patients diagnosed with end stage heart failure. This theory grounded in data demonstrates the need for both acute and primary care to design an integrative end of life care pathway for heart failure patients which addresses the need for early shared decision making between the healthcare professional, family and the patient when it comes to end of life conversations.

KEYWORDS

end of life care, end stage heart failure, grounded theory, healthcare professional, heart failure, nurse, nursing care, palliative care, recognizing dying, vicious cycle

1 | INTRODUCTION

The National Institute for Cardiovascular Outcomes Research (2019) defines heart failure as the pathophysiological state in which an abnormality of cardiac function is responsible for the heart's inability to pump blood sufficiently to meet the body's metabolic requirements. The impaired cardiac function occurs as a consequence of damage to the heart tissue caused by, for example, a myocardial infarction, cardiomyopathy, valve disease and/or hypertension. They go on to say that the most prevalent form of heart failure is characterized by poor contraction of the left ventricle, termed heart failure with a reduced ejection fraction (National Institute for Cardiovascular Outcomes Research, 2019). However, heart failure can also be caused by reduced filling of the left ventricle referred to as heart failure with preserved ejection fraction.

Heart failure is estimated to affect 23 million people worldwide, including 10 million people in the USA, 15 million people in Europe (Lawson et al., 2019) and over 900,000 people in the UK (Conrad et al., 2019). In addition, the cost of managing heart failure accounts for 2% of the UK healthcare budget and has been shown to be responsible for 5% of unplanned Emergency Department admissions (Cowie, 2017). The unpredictability of the disease-trajectory means that some patients will live well for several years before requiring hospital admission (Sobanski et al., 2020). However, worsening symptoms and reduced quality of life can often ensue with around 50% of heart failure patients dying within 5 years of diagnosis (Taylor et al., 2019). Patients diagnosed with end stage heart failure who are admitted to hospital with symptoms of acute decompensation have high mortality rates: up to 1 in 6 patients will die in hospital or within 30 days of discharge (Dhamarajan et al., 2015; Parenica et al., 2013). Many of these patients will not have had the opportunity to have end of life conversations and as a consequence have limited access to palliative care services (Hill et al., 2020; Jaarsma et al., 2009). It is therefore imperative that end of life conversations between healthcare professionals and the patient begin well in advance of clinical deterioration (Asano et al., 2019) to ensure that appropriate end of life plans are discussed.

2 | BACKGROUND

Despite a plethora of guidance documents (Department of Health, 2008, 2010, 2015; NHS Improving Quality, 2014) aimed at improving end of life care for patients diagnosed with heart failure there appears to be little improvement in this area of heart failure care. Decisions are made too late in the disease trajectory or not made at all, leaving the patient and their families unable to make informed choices (Allen et al., 2012; LeMond et al., 2015). As a consequence many of these patients die in an acute hospital bed (National Institute for Cardiovascular Outcomes Research, 2019) rather than their preferred place of care. In the hospital, patients are rarely given an opportunity to discuss their preferred end of life choices with a heart failure nurse, cardiologist or indeed a palliative care consultant

(Wiskar et al., 2018). Equally concerning is that little is known about the decision making of these professionals when caring for such patients (Meyers & Goodlin, 2016). End of life decision-making research has traditionally focused on primary care and barriers to communication with very few studies exploring the decision making of healthcare professionals in acute medical environments (Barclay et al., 2011; Selman et al., 2007).

2.1 | Advance care planning and heart failure

In 'Ambitions for Palliative and End of Life Care' The National Palliative and End of Life Care Partnership (2015) proposed a framework detailing six ambitions for the delivery of excellent care to the dying and their families. The main purpose of this document was that each person should be seen as an individual and have access to fair care which is coordinated and reviewed regularly by staff who are competent. For those patients diagnosed with a non-malignant illness this was a major step forward in recognizing the need for equal access to palliation.

However, the disease trajectory for heart failure, unlike many cancers, is not linear and therefore it makes it very difficult to prognosticate and plan end of life care. Heart failure often follows an unpredictable course with periods of stability interrupted by exacerbations which may lead to instability and ultimately death (McIlvennan & Allen, 2016).

Once diagnosed with heart failure the patient often overestimates their own survival making it difficult to engage in conversations about end of life care planning. In a study comparing patient predicted life expectancy and model predicted life expectancy, patients overestimated their life expectancy by 40% (Allen et al., 2008).

Advance care planning (ACP) is a "voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline" (NHS End of Life Care Programme, 2008, p. 5). The aim of the ACP discussion is accurately to document individuals' concerns, record care planning goals and to clarify preferences and wishes towards the end of life.

Studies undertaken in both primary and secondary care suggest that there is several barriers to initiating ACP which may be precluding patients and families from having these important conversations. De Vleminck et al.'s (2014) qualitative study involved five focus group interviews of General Practitioners (GP) ($n = 36$) with the aim of understanding barriers to initiating the ACP. This study suggests that barriers occurred more frequently with heart failure patients due to a lack of familiarity of the GP with the terminal phase of the illness. The surprising lack of patient awareness about their diagnosis and prognosis was cited by the GPs as a further barrier to initiating ACP conversations (De Vleminck et al., 2014). Similar findings were reported by Ahluwalia et al. (2013) who, in a prospective observational study, set out to evaluate the extent to which physicians working in a busy out-patient department engaged in ACP with heart failure patients.

Data analysed included audio tapes of patients aged 65 years and older ($n = 52$) and their physicians ($n = 44$). The findings concurred with De Vleminck et al. (2014) that physicians were reluctant to engage with ACP because of lack of time, not knowing what aspects of ACP to discuss and a lack of skill and confidence in having end of life discussions (Ahluwalia et al., 2013).

2.2 | Decision making and heart failure

End of life decision making in acute care is complex, involving difficult choices which can often be emotionally demanding for health-care professionals, patients and their families (Barclay et al., 2011). The prognostic uncertainty of heart failure makes it extremely difficult for physicians to know when is the best time to involve the patient in the decision-making process.

Nurses are recognized as having particular insight into patients' wishes as they spend much more of their time with patients and their families and as a consequence can develop a trusting relationship (Puntillo & McAdam, 2006). The unique relationship between the nurse, the patient and their family can allow information to be shared and can broker the gap between the patient's lack of understanding and the doctor's potential over-medicalization of the dying process (Costello, 2001; Hockley et al., 2005). In theory, the nurse's therapeutic proximity and the close relationship with the patient can assist in signalling the patient's readiness to discuss end of life issues.

Making this less likely is evidence which suggests that patients may currently prefer to play a passive role in decisions about their care and treatment, especially at the end of life. Rodriguez et al. (2008) conducted a telephone survey of 90 adults diagnosed with heart failure. Using the 'Control Preferences Scale' the researchers showed that 48% of patients preferred a passive role, with just 21% hoping for an active role. Similar findings were reported by Matlock et al. (2010) who interviewed 22 patients with symptomatic heart failure using semi-structured interviews. Questions posed were "Can you tell me about any important or difficult decisions you have had to make about your heart condition"? Two distinct styles emerged: active decision makers (55%) who were able to consider treatment options and consider impact on quality life and passive decision makers (45%) who did not identify difficult decisions and were happy to trust in the physician to make treatment choices. Both Rodriguez et al.'s (2008) and Matlock et al.'s (2010) studies are limited in that they had relatively small sample sizes. In both studies, the patients recruited were predominantly male and white with a mean age of 65 years so although these results are not widely generalizable they are indicative of key elements of the population of people with heart failure.

2.3 | Palliative care in heart failure

Despite claims that modern hospice and palliative care services extend to all people with an incurable disease (Sobanski et al., 2020)

the reality is that people with heart failure rarely access these services in numbers.

A survey undertaken in the UK by Cheang et al. (2015) with 499 respondents reported that 47% of palliative care providers received <10 referrals of patients with heart failure annually and only 3% received more than 50 referrals. According to Selman et al. (2007) the lack of palliative care models for heart failure in primary and acute care may explain why service provision remains woefully inadequate.

In a detailed review of the situation, Puckett and Goodlin (2020) make a strong case for the integration of palliative care into the management of people with heart failure. They illustrate the extent to which heart failure patients endure breathlessness, anxiety, depression and significant ischaemic pain, with more than 50% of people having four or more comorbidities. They suggest that it is not inconsistent to integrate palliative care principles within an approach which also aims to modify the course of heart failure as both have relief of symptoms as the aim.

Improvement in quality of life at its end is clearly important and there is consensus that it reduces demand on acute health-care services. Evidence suggests that this needs to coincide with the preferences of patients and their families and that this is by far the best option (Metzger et al., 2013). A large cohort study ($N = 113,540$) in Ontario comparing the use of health services towards the end of life in cancer and non-cancer patients demonstrated that, in heart failure (and other non-cancer terminal illnesses) palliative care was associated with a 12% reduction in emergency department visits and hospital admissions and 41% diminution in intensive care unit admission (Quinn et al., 2020).

In summary, a wide international literature makes clear that, despite some reluctance to refer patients arising from interdisciplinary boundaries, heart failure patients being involved in decisions about their care has good outcomes for both patients and health services. Studies seem to suggest that good outcomes for the patient include optimal symptom control and improved quality of life at the end of life, and for the health services a reduction in hospital costs due to reduced hospital admissions (Greener et al., 2014; Sahlollbey et al., 2020). Our study aimed to examine the extent to which this is happening and what participants' attitudes and experiences were.

3 | THE STUDY

3.1 | Aim

To explore how healthcare professionals in an acute medical setting make decisions when managing the care of patients diagnosed with NYHA III and NYHA IV heart failure, and how these decisions impact directly on the patient's end of life experience.

3.2 | Design and setting

A constructivist grounded theory design (Charmaz, 2006) was employed to understand how healthcare professionals made decisions when managing the care of patients diagnosed with end-stage heart failure. The setting for this study was an acute medicine department in a 524 bed District Hospital in the North West of England.

3.3 | Sample and participants

47 participants were purposefully recruited to the study over a 1-year period concluding in 2017. The sample included registered nurses ($n = 16$; Table 1), doctors ($n = 15$; Table 2) and patients ($n = 16$; Table 3). Three patients declined to participate, no reasons were given. Patients were included if they had a diagnosis of heart failure confirmed by echocardiography and they were experiencing marked limitations in their physical activity due to fatigue, palpitations or dyspnoea, were at NYHA functional classification stage III, or experiencing symptoms of heart failure at rest, NYHA classification stage

TABLE 1 Characteristics of the nurses

Pseudonym	Grade of nurse	Gender	Clinical area
Ella	Staff nurse	Female	Care of elderly
Joanne	Staff nurse	Female	Acute medicine
Danielle	Staff nurse	Female	Acute medicine (respiratory)
Bob	Staff nurse	Male	Acute medicine (respiratory)
Jade	Staff nurse	Female	Acute medicine
Liz	Ward sister	Female	Cardiology ward
Debbie	Ward manager	Female	Acute medicine
Ann	Ward manager	Female	Medical Assessment Unit
Pauline	End of life co-ordinator	Female	Acute medicine
Sarah	End of life specialist nurse	Female	Acute medicine
Jane	Cardiology specialist nurse	Female	Cardiology
Steve	Heart failure specialist	Male	Cardiology
Rebecca	Palliative care nurse		
Jenny	Trainee advance practitioner	Female	Acute medicine
Kelly	Trainee advance practitioner	Female	Acute medicine
Mary	Trainee advanced practitioner	Female	Acute medicine

IV (The Criteria Committee of the New York Heart Association, 1994). Patients were included in this study if they had an ejection fraction $\leq 35\%$ (Ponikowski et al., 2016; Table S1).

Patients were identified following daily checks of the Electronic Records System along with bi-weekly reviews of echocardiograms. There was twice weekly attendance at the board rounds in the Medical Assessment Unit by the heart failure nurse, plus weekly attendance by KH on the cardiology ward rounds. The age and gender profile of the sample was broadly in keeping with the UK heart failure population (British Heart Foundation, 2020); there were 12 males with a mean age of 70 years and 3 females ($n = 3$) with a mean average age of 67 years (see Table 3). Healthcare professionals were included in this study if they were a registered general nurse or a medical doctor working in acute medicine. The registered nurses ($n = 16$) included; staff nurses ($n = 5$), ward managers ($n = 2$), ward

TABLE 2 Characteristics of the doctors

Pseudonym	Grade of doctor	Gender	Clinical specialism
Shabib	FY1 (foundation year 1)	Male	Medicine (cardiology)
Fiona	ST2 (speciality trainee)	Female	Medicine (care of elderly)
Tim	ST2 (speciality trainee)	Male	Medicine (care of elderly)
Liam	StR1 (specialist registrar year 1)	Male	Medicine (cardiology)
Andrew	StR1 (specialist registrar year 1)	Male	Medicine (cardiology)
Steve	StR1 (specialist registrar year 1)	Male	Medicine (care of elderly)
John	StR2 (Specialist Registrar Year 2)	Male	Medicine (care of elderly)
Paul	StR2 (specialist registrar year 2)	Male	Medicine (care of elderly)
David	StR2 (specialist registrar year 2)	Male	Medicine (care of elderly)
Amina	StR2 (specialist registrar year 2)	Female	Medicine (cardiology)
Ahmed	Consultant	Male	Medicine (cardiology)
Geoff	Consultant	Male	Emergency department
Simon	Consultant	Male	Palliative care
Siddiqui	Consultant	Male	Medicine (care of elderly)
Patel	Consultant	Male	Medicine (care of elderly)

sister ($n = 1$), palliative care nurse ($n = 1$), end of life coordinator ($n = 1$), end of life specialist nurse ($n = 1$), heart failure specialist nurse ($n = 1$), cardiology specialist nurse ($n = 1$) and trainee advanced practitioners ($n = 3$). Similarly, the doctors ($n = 15$) included FY1 (foundation year 1) ($n = 1$), ST2 (speciality trainee, care of elderly medicine) ($n = 2$), specialist registrars (years 1–6) ($n = 7$), consultant cardiologist with a specialist interest in heart failure ($n = 1$), consultant in care of elderly medicine ($n = 3$) and a consultant in emergency care (consultants were generally qualified over 9 years). A palliative care consultant ($n = 1$) was recruited to the study who was based in the local hospice and provided two sessions per week for the hospital. There was one GP who worked primarily in the community who had a special interest in emergency care medicine.

3.4 | Data collection

Over a period of 12 months fieldwork such as attendance at relevant clinical meetings, ward rounds and training events was undertaken.

Semi-structured interviews were undertaken with the doctors, nurses and patients with the aim of exploring their experiences of decision making when managing or receiving heart failure care at the end of life. Initially, questions were open-ended (Table 4) but became more focused as transcripts were coded. Codes were compared with categories until themes began to emerge. During each coding stage theoretical memos were written to focus further data collection as well as to inform and refine the developing theoretical analysis (Charmaz, 2006).

The patient interviews were conducted on the ward, either at the bedside or in a quiet room adjacent to the nurses' station. The healthcare professionals' interviews were undertaken in a place of their choice on the hospital campus. For a small group of healthcare professionals, it was more convenient to be interviewed together. Two focus group interviews were arranged on separate days. A total of 12 doctors and 3 trainee advanced practice nurses were recruited as follows. Focus group 1 ($n = 7$, acute medicine) had two ST2 specialist trainees, two consultant physicians (care of elderly) and three specialist registrars. Focus group 2 ($n = 8$,

TABLE 3 Characteristics of the patients

Pseudonym	Gender	Age	Ethnicity	Diagnosis	Ejection fraction	NYHA
Barry	Male	63	White	HFrEF	<20%	4
Graham	Male	71	White	HFrEF	<35%	3
Maggie	Female	92	White	HFpEF	<35%	3
Fred	Male	84	White	HFpEF	<35%	3
Patrick	Male	70	White	HFpEF	<35%	3
Eric	Male	70	White	HFrEF	<25%	3
Paul	Male	64	White	HFrEF	<30%	4
Frank	Male	75	White	HFrEF	<30%	4
Pauline	Female	68	White	HFrEF	<20%	3
Heather	Female	50	White	HFpEF	<35%	3
Allan	Male	74	White	HFrEF	<20%	4
Peter	Male	78	White	HFrEF	<27%	4
Brian	Male	63	White	HFrEF	<20%	4
Flo	Male	78	White	HFrEF	<14%	4
Jo	Male	65	White	HFrEF	<18%	4
Tony	Male	85	White	HFrHF	<35%	3

Abbreviations: HFpEF, heart failure with preserved ejection fraction; HFrEF, heart failure with a reduced ejection fraction.

TABLE 4 Example of interview questions

Healthcare professional questions	Patient questions
<ul style="list-style-type: none"> How would you approach end of life discussions? How do you involve the patient and families in those discussions? How are you developing your heart failure service? Do you actively engage patients in user groups? What do you understand about advance care planning and Gold Standard Framework? Would you consider the tool to be easy to use and to navigate? Do you think it is relevant to patients diagnosed with heart failure? 	<ul style="list-style-type: none"> What do you understand about the term long-term condition? What do you understand about the term heart failure? Did you have the opportunity to discuss what was important to you in the management of your heart failure? Have you been involved as much as you wanted in the decision about your care and treatment?

cardiology) included one consultant, two stR year one registrars, two stR year two registrar and three trainee advanced practitioners (see Table S2). An interview guide was used to provide continuity and to act as a prompt when asking more probing questions (see Table 3). Participants were encouraged to discuss their experiences freely and so the interview guide was used flexibly to allow for open discussion. Questions were reviewed regularly as concepts and themes began to emerge from the data (Charmaz, 2014). To enable all participants' voices to be heard in the focus groups several strategies were employed. Firstly, the focus groups were held over a lunchtime period and medical representatives kindly provided lunch. This created a welcoming environment and generated a more relaxed atmosphere. Secondly, careful redirecting of questions allowed those more junior participants in the group to participate and share their own experiences of decision making. Thirdly, checking in with participants helped to clarify points of discussion which often led to further debate. Field notes were kept of substantial involvement in day-to-day meetings and activities. Diaries were used in capturing day to day personal reflections and observations. The diaries, field notes and memo writing were an integral part of the constant comparison of data and only ended once it was evident that categories had been saturated and no new themes emerged. All interviews were recorded using the researcher's voice memo application on the iPhone and immediately post interview downloaded into a file on a password protected PC.

3.5 | Ethical considerations

Ethical approval was granted for this study by the National Research Ethics Service Committee-North West (13/NW0483), University Ethics Committee and the Hospital Trust's Research Governance Department. All participants, who were clear about the role and background of the interviewer, provided written informed consent before the interviews were undertaken and were told that they could withdraw from the study at any time. Although some patients were quite ill, participants were able to consent freely in writing. Professional support was available for any participants who became upset or distressed during the course of the interviews. All data were stored electronically on a password protected computer.

3.6 | Data analysis

Interviews lasted on average 40–60 min and were digitally recorded, then transcribed verbatim into a word document. The process of initial coding was undertaken manually to remain close to the data and to avoid the risk of making conceptual leaps. During this initial coding process 'in vivo' codes were used to capture participants' meaning, views and actions (Charmaz, 2014). The second stage of analysis involved focussed coding. To manage this stage of coding the transcripts were uploaded into NVivo 10. The initial codes were

sifted, sorted and synthesized to identify those codes which were considered to have theoretical reach (Charmaz, 2014). Axial coding provided a way to identify relationships between concepts and categories and involved constantly comparing transcripts with field notes, diaries and memos.

3.7 | Rigour

Several recognized strategies were employed to enhance credibility and trustworthiness of this study's findings. Once the categories began to emerge from the data these were shared with participants to see if they resonated with their own experiences and if the emerging theory made sense. This constant going back and checking with the participants confirmed that the theory in fact was grounded in the data. The constant comparing of data, field notes and memos helped in this checking process and assisted in directing the questions until all categories were theoretically saturated and there was no further exploration of the phenomena. In addition, we had input from a patient charity 'Pumping Marvellous' which provided the patient voice in the initial design of this study. We believe that the depth and detail gained are sufficient to lend substantial validity in terms of credibility and relevance to the categories generated (Long & Johnson, 2000). This study was conducted with COREQ qualitative criteria clearly in mind (Tong et al., 2007).

4 | FINDINGS

Four categories emerged from the data to explain the core phenomena; recognizing dying, being informed, organizing care and signposting symptoms. Each of these categories grounded in data were found to be integral to the 'vicious cycle of care' and as a consequence found to influence the heart failure patients' care pathway.

The core category 'negotiating the vicious cycle of care' (Figure 1) was an in vivo code which emerged to explain how participants in this study negotiated decision making within the cycle of end stage heart failure. The theory suggests that this turbulent 'vicious cycle' of care for heart failure patients disabled the shared decision-making process between healthcare professionals and the patient resulting in a delay in transitioning patients to palliative care. To try and negotiate this cycle of care participants were found to adopt several different strategies which were neatly packaged within the four theoretical categories.

4.1 | Recognizing dying

The healthcare professionals were often resigned to the fact that heart failure was difficult to prognosticate and that the unpredictability of the disease could lead to unexpected deaths.

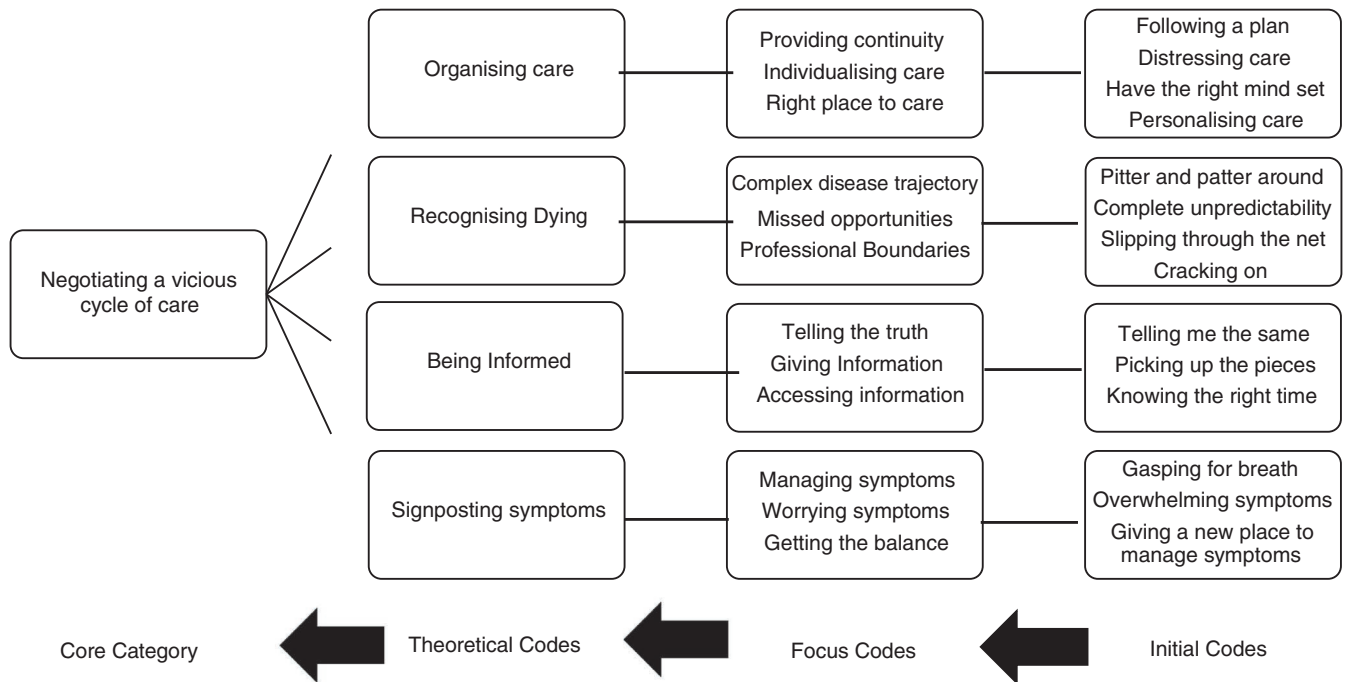


FIGURE 1 The evolution of the core category 'negotiating a vicious cycle of care'

They will just try everything they can medically off-loading the fluid you know to the point where the renal function is impaired, probably because the disease trajectory is so unpredictable. Even the cardiologists don't like to commit to days or weeks. I know people who I have seen in the clinic on Tuesday and they sadly passed away on the Thursday. I would be thinking what's wrong with them but they are either going to die from pump failure or an arrhythmia so it's what gets you first unfortunately." (Steve, Heart Failure Nurse)

Despite the availability of the New York Heart Association functional classification score to assist in the decision-making process, very few doctors were observed recording the patient NYHA classification in the medical notes. The reason given for this was: 'it isn't very helpful', 'patients find it difficult to understand' and '(it's) not always as reliable as blood tests and echocardiogram' (Ahmed, Consultant, Cardiologist). There were very few nurses both on the cardiology and acute medical wards who understood NYHA or knew about the classification.

"No, I never see that on the ward but I think the nurses do ask some of the questions, but maybe not all of them. For me they are either out of breath or not out of breath; they are either breathless when walking or not out of breath when walking." (Liz, Ward Sister)

The withdrawal of the Liverpool Care Pathway (Neuberger et al., 2013) and the lack of clarity surrounding the implementation of the individualized end of life care plan (Leadership Alliance for the Care of Dying People, 2014) had made some doctors nervous about

diagnosing dying and so there was a tendency to prescribe potentially unhelpful treatments for the patients. The continuation of these futile treatments occasionally led to patients' lives being unnecessarily prolonged; this was distressing for both the patient and their families.

"I think that is our failing, I think it is the medics' failing, ... from my point of view. This patient in particular, we really have to be sensible about this and how long do we sensibly have to continue doing things for this gentleman which is inappropriate and we have to bear in mind what he wants. Does he want to spend his last days in a hospital or does he want his symptoms looked at in an appropriate setting, and I think yeah, and I think other than that we can all reflect and improve." (Liam, Registrar)

The barrier to expert end of life care was perceived by some doctors involved to be the lack of clear guidance. For many doctors having defined guidance provided the necessary support and assurance to know when to refer onto the palliative care team. In heart failure patients this lack of certainty in recognizing dying and referring them for palliative care often delayed the patient's transfer and consequently the patient died unnecessarily in a hospital bed. The cardiology doctors often referred to this as being the 'vicious cycle'.

"...We don't have a policy of guidelines to recommend co-operation with the palliative care team ... so you know if a patient is going to die very soon with severe LV (left ventricular) dysfunction 20 or below of ejection fraction, 20 or below with lots of symptoms, (it) would be beneficial if the palliative team were involved

and the heart failure nurses. One patient was here for 6 months. She was in the side ward and we were not doing anything ... we hardly made any changes ... it is a vicious cycle ... and it was difficult to get her out of the hospital ... these patients are very costly." (Andrew, Specialist Registrar)

4.2 | Being informed

'Being informed' was found to be multi-factorial and revealed different emotions in both patients and healthcare professionals. For example, it was important for patients to be informed about what was 'going on' by a healthcare professional whom they considered to be trustworthy. For the healthcare professional 'being informed' was about balancing the risks and being able to deliver safe and effective care. We found 'giving information' to patients about their end of life care to be dependent on several factors; the expertise of the person giving the information, professional status, suitability of the information and how the information would be received by the patient and their families. Nurses described patients falling into two categories; 'those who could handle' the information and those who 'couldn't handle the information'. Occasionally nurses would refer to this intuitive knowing which was described as 'a gut feeling' that patients were ready to receive information.

"I think you can come across some patients who you would get the feeling, who you know can handle the information you are going to give them and they are to handle it well and they are going to take it on board, but there are other patients; how are they going to respond to this?" (Bob, Staff Nurse)

Often nurses were found to link this 'intuitive knowing' to their years of clinical experience and an ability to sense when it was the right time to give information to the patient and their families.

"I can remember saying to a student nurse this patient I can't see going out of hospital. She said how you know that? I said it's just intuition, it's just experience ... you just know when the right time is to give information." (Debbie, Ward Manager)

To avoid upsetting the patient nurses would initially use the family as a 'sound board' to test the patient's understanding about their terminal condition. This technique was well-rehearsed and meant nurses could avoid unintentionally upsetting the patient. It was not clear what nurses considered to be the accepted or the right time to give end of life information to the patient. Generally, information was observed to be given on a need to know basis. The only time nurses would deviate from this practice was when a direct question was asked by the patient. The rationale given for not giving end of life information was that patients would 'not want to know', it would be too upsetting or 'they

couldn't handle it'. This practice was observed amongst the more senior nurses who took a gatekeeper role in keeping the patient emotionally safe.

"Yes, probably more so I think with spouses than with the patients themselves, I think somebody who is very close to somebody can see that they are not getting better and they want to know the answers and they want to know what is coming. They don't always want to discuss that in front of the patient but they want to know the answers and I think sometimes possibly the fear with patients, they almost don't want to know. They won't ask the question because they don't want to know the answer. I think there is a slight element of that sometimes." (Jane, Specialist Nurse)

In contrast, palliative care nurses took a different approach to information giving; there was an understanding that the patient had a right to know their fate. It was accepted that 'being sad' and 'being upset' were part of a normal response to being given a terminal diagnosis.

"I have seen over a thousand patients ... I must have done ... most people, yes they are sad but they are ok ... they are ok ... yes of course they are sad they (are) approaching the end of their life ... but they are ok." (Rebecca, Palliative Care Nurse)

A consensus amongst some healthcare professionals was that information was not given because of a 'lack of confidence'. This was observed in non-cardiology areas like care of the elderly and respiratory medicine where healthcare professionals were considered 'not the experts'.

"I think it is a confidence thing with the person who is giving that information because sometimes you see it yourself; people sitting on the fence a bit and sort of what you think, well this is ... they need to know the facts." (Kelly, Trainee Advanced Nurse Practitioner)

In this study, both nurses and doctors stated that they found the task of explaining the diagnosis and prognosis to the patient very challenging. They spoke about the 'need to be honest' about the seriousness of the condition and were mindful that this could raise patient anxiety. To avoid giving information to patients about their terminal condition emotional blockers were used like 'I don't want the patient 'to lose hope.' (Specialist Registrar, Cardiology). This left many patients in a situation of 'not knowing' and having 'false hope'.

"Really it's a problem to be honest. We should tell them everything at that time but we just don't want to upset them all in one go and then go: 'you're going to die.'" (Shabib, FY1)

4.3 | Signposting symptoms

It was common for patients to present initially to the GP with acute symptoms of decompensation (failure of the heart to maintain adequate circulation). Patients spoke about making multiple visits to their GP where their medications would be reviewed and then being sent home.

"I went to doctors because I couldn't breathe. At times they gave me some tablets which they said take for 10 days so I took them for 10 days. They worked to an extent because it all settled down. Once I stopped taking them it went back up again ... I went back to doctors they gave me the same again only for longer and they didn't seem to do anything at all. Next thing I know 2 more weeks down the line I'm going back getting another load of tablets twice as strong as the last lot and I mean, you have seen my legs." (Patrick, Patient)

There were common 'markers' or 'signposts' which the patient would describe. Often these markers or signposts would be described 'gasping for breath', 'swollen legs', 'loss of appetite' and 'lack of sleep'. Often patients were observed self-referring to the emergency department when symptoms became progressively worse and the markers or symptoms were not picked up by the GP.

For the doctors responsible for the care of the elderly 'signposting symptoms' involved treating the acute episode of decompensation. It involved controlling symptoms rather than acknowledging or trying to change the patient's prognosis or referral to palliative care. In some cases a patient's symptoms would improve to allow discharge home. For many patients it was common to be readmitted with worsening symptoms only weeks after being discharged back home. This 'vicious cycle of care' would then be repeated over and over again; treatment, review, discharge and readmission.

"If patients are stage 3 and 4 they are usually on maximal medical therapy and are never going to get any better so it's about symptom control as opposed to like making their prognosis any better. They are probably going to die in the next 6 months but they continue to come back into hospital because they become more breathless. We tinker around with the diuretics and then they go home and then they come back with acute kidney infection because the Frusemide has been upped, so it is a recognition that the person is probably dying and that it is symptom control." (Fiona, ST2)

This type of medical model of managing heart failure patients was considered by doctors to be "sticky plaster medicine" (Geoff, Consultant) and that often it was just a case of "cracking on until the end" (Shabib,

FY1). It was unanimously agreed amongst the doctors that conversations about end of life should already have been initiated with the patient before reaching the end stages of the disease. This was felt to be the responsibility of the heart failure team but in many cases is just did not happen.

4.4 | Organizing care

Patients did not always have access to a community heart failure nurse so relied on the GP or practice nurse for advice and support. If symptoms did not improve the GP would refer the patient to the on-call physician or the emergency department. For the patient, this cycle of care often resulted in readmission to hospital within weeks of discharge.

"Oh, I had swollen legs a bit then but they still sent me home and I went downhill a bit, I was sick like. Before I had my breakfast this morning I was heaving and bringing up all different sorts of stuff so I knew I was going down really as I said to them "I am not blaming anybody" because it's bad enough (to) report to higher authority here, and they want to know why I was sent home in the first place and why I have come back again". (Patrick, Patient)

The emergency department was considered by healthcare professionals to be the lowest common denominator when it came to patients being readmitted back into hospital. The healthcare professionals often commented that the department was often used to provide 'crisis intervention' for patients which was seen as unsatisfactory. This often meant treating the symptoms of decompensation and then discharging the patient either to a ward or back home into the care of the GP. Often opportunities to engage in end of life conversations or refer to the palliative care team was missed.

"I don't think there is any joined up thinking. Patients with long-term conditions whether chest, heart, whatever, they are given their treatment, they go home with it and then as they deteriorate and when there is a crisis the lowest common denominator is Emergency Department and MAU (Medical Admissions Unit). In the acute phase it's just sticky plaster medicine you get them over the hump and discharge them home but there is not much in the way of follow-up, what's the long-term plan, is palliation an option?" (Geoff, Emergency Department)

Furthermore, there was recognition by the emergency care team that meeting the government four hourly wait target meant for some heart failure patients being discharged from the department without having the opportunity to be seen by the cardiologist or palliative care team.

"Meeting the four hourly ED target means patients once reviewed will need to be discharged either home or into beds ... we probably keep people with severe heart failure 48-72 h till they are over the worst then get them home but if there's a 4 day wait for a cardiology bed then they don't make it we do refer them all to the heart failure nurse... (Geoff, Emergency Department)

5 | DISCUSSION

We believe that this is the first study to illustrate in detail how health professionals often fail to negotiate modern, open, communication and decision making with patients within the cycle of end stage heart

failure (Figure 2). Our findings show how the absence of a structured management plan and a fragmented care system leads to the disabling of the shared decision-making process between healthcare professionals and the patient, resulting in a consistent failure to transition patients to a palliative care approach as might more often happen in cancer care, for example, where prognoses are in many cases more certain. We describe this as a 'vicious cycle' of care.

To try to negotiate this cycle of care participants were found to adopt several different strategies which were neatly packaged within the four theoretical categories; signposting symptoms, organizing care, being informed and recognizing dying. These themes identified by the participants and grounded in data were found to be important landmarks in the negotiation process and assisted participants in making sense of each stage of the cycle.

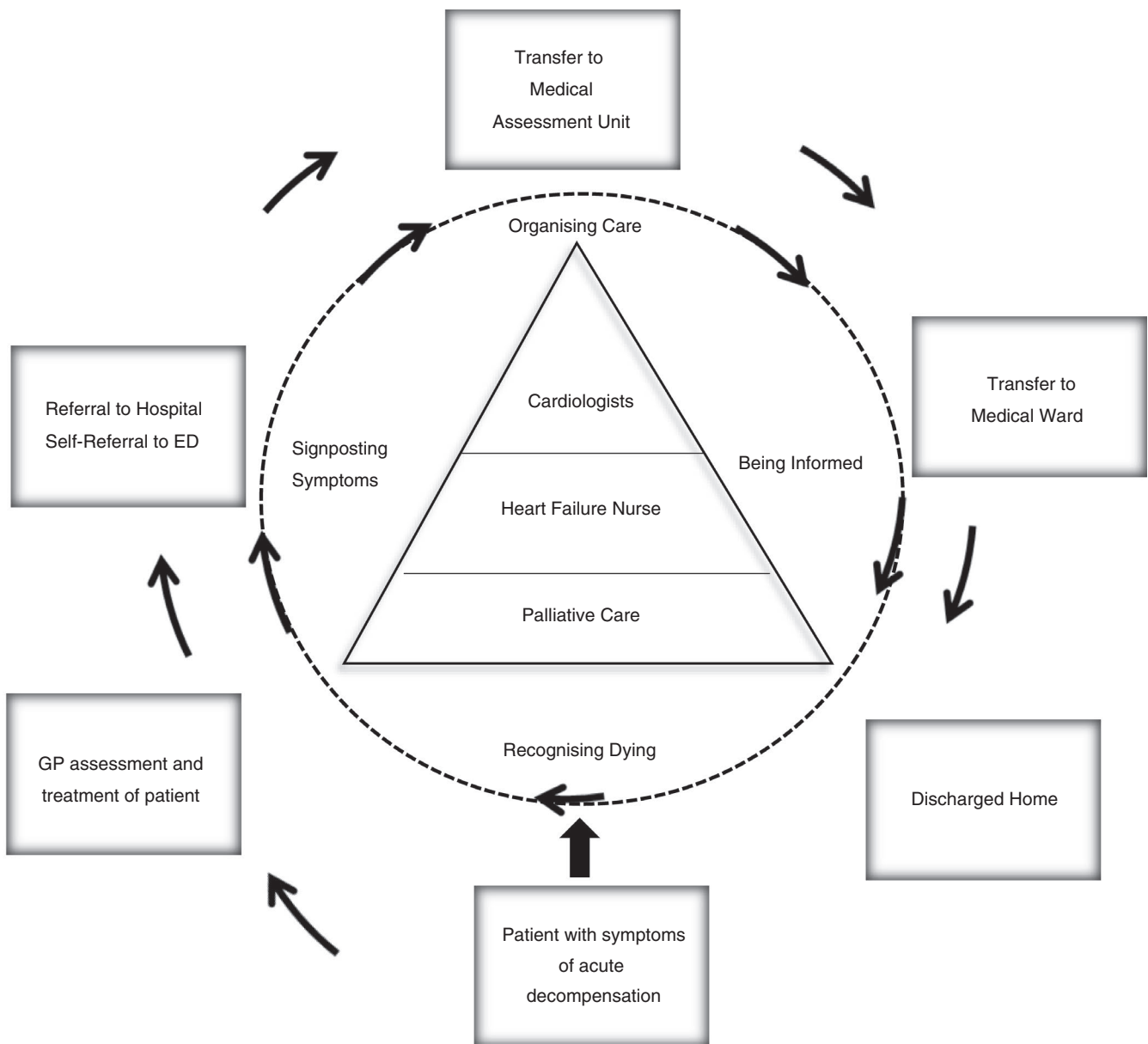


FIGURE 2 Vicious cycle of care for heart failure patients

The findings suggest that for the nurses knowing when to give information to the patient about their heart failure condition was enabled by a process they described as 'intuitive knowing'. This process of intuitive knowing was seen by the nurses as a way of protecting the patient from any information which could potentially cause any harm or distress. Equally, intuitive knowing was what the nurses used to decide the patients' readiness to receive information. This process was carefully orchestrated to allow the nurse's time to flag any concerns to the doctor and suppress what may be perceived unwanted information. These findings are congruent with Taylor et al. (2017) who found that nurses and doctors used an iterative process, which involved intuitive knowing, collecting clinical data and the use of prognostic models to inform the diagnosing dying decision.

There was a genuine concern by the doctors that giving patients too much information could result in the patient giving up hope. These findings supplement those of Clayton et al. (2007) and Brighton and Bristowe (2016) who found that doctors were reluctant to disclose prognosis because they wanted to preserve hope and avoid harm to the patient. The principles of non-maleficence and beneficence (Beauchamp & Childress, 2008) were important to the doctors in this study who described the giving of information as a careful balancing act between meeting patient expectation and avoiding harm. Gordon and Daugherty (2003) argue that these principles may be misguided and that beneficence would ideally still entail full disclosure of prognosis without necessarily causing harm. Likewise, nurses were of the opinion they would be more comfortable raising discussions and giving prognostic information if it was perceived to benefit the patient and their families. A moral framework privileging autonomy, in this case the meeting of patient and family preferences and the relief of suffering might perhaps play a stronger role in the future.

Interestingly, in this study very few patients were observed proactively seeking out information from healthcare professionals, they preferred to take a more backstage passive role in the process of being informed. Literature around the topic of health information seeking behaviour seems to suggest that avoiding information is a common strategy used to protect oneself from the burden of knowledge (Klindtworth et al., 2015). Other factors observed to influence patients' information seeking were found to be the physical symptoms of heart failure, for example breathlessness, which made it difficult for many patients to engage in questioning or conversation.

The demise of the Liverpool Care Pathway along with an unpredictable disease trajectory were reasons given by the doctors for delaying or avoiding end of life discussions with their patients. There was a belief held amongst some of the doctors that recognizing dying was equivalent to failure and so they felt morally justified in continuing to provide medical intervention. Several doctors recognized that prolongation of life was not right but at times felt obliged to meet the treatment expectations of both the patient and their families. The difficulties in recognizing end of life have been highlighted in the literature where doctors have failed to recognize dying and been overly optimistic with treatment plans (Momen & Barclay, 2011; O'Leary et al., 2009; Willard & Luker, 2006). In the

present study, the delay in recognizing dying led directly to delays in referring patients to the palliative care team. Consequently, patients were unable to make informed decisions with their families about their end of life care.

In this study, the Emergency Department was observed to be the most common point of entry into the cycle for patients presenting with acute symptoms of decompensation. This was particularly evident for those patients without community heart failure services. For the healthcare professionals this cycle of care was recognized as being unsatisfactory. The competing demands of resources and pressure to meet government targets meant that patients were often pushed through the cycle without any time to organize care and refer to either a cardiologist or community heart failure services. Moreover, many healthcare professionals recognized that the opportunity to refer patients to palliative care was lost because of the need to meet government targets. Several studies concur with this finding agreeing that Emergency Departments could provide the initial assessment and referral to a palliative care team potentially reducing the number of potential re-admissions (Lipinski et al., 2018; Pang et al., 2014).

6 | LIMITATIONS

The transferability of these study findings should be evaluated in the context of its geographical location and its modest sample size. The sample recruited to this study was limited to only one District General Hospital in the Northwest of England, therefore these findings may not be transferable to other healthcare organizations. However, it could be argued that the process of gathering rich and contextualized data on the human experience complements and adds to existing literature on the topic of end stage heart failure. This study was undertaken in a location of ethnic diverse cultures and yet the sample recruited were all white participants. This was not intentional and this issue was raised as a concern to the cardiologists who were aware that ethnic minorities in the area were not attending the outpatient clinics. It will be important to investigate this issue in relation to various minorities such as South Asians who are known to be particularly vulnerable to heart disease (Davis et al., 2020). The aim of this study was not to provide a theory specific to one participant but one that could be applied or compared with data across other similar settings. Therefore, it is important to consider that this substantive theory will in the future provide a platform for further research to explore cycles of care with patients diagnosed with end stage heart failure from a range of setting and communities.

7 | CONCLUSION

In this study, the vicious cycle of care for heart failure patients was found to be a product of a healthcare system where organizational demands and organizational rules do not always facilitate the

delivery of best care. The cycle allows the patient to enter and exit the cycle randomly without any barriers leading to the patient moving back and forth within the cycle until the patient's untimely death. The knowledge about cycles of care in heart failure is limited and so further work needs to be undertaken with multiprofessional teams across primary and secondary care to develop a truly integrated care pathway which delivers on quality of care but facilitates shared decision making at the end of life.

8 | IMPLICATIONS FOR PRACTICE

Whilst we understand that further research is necessary and that these findings can only be applied to the hospital in which the study was undertaken, there are some practical changes which could impact positively on the care and management of the heart failure patient. These are as follows:

An integrated care pathway which includes primary care, secondary care and tertiary services. This pathway needs to include a clearly defined decision-making algorithm to optimize the patients' and families' experience throughout the episode of care and can clearly identify the need for palliation.

A flag system similar to that adopted by cancer services has to be adopted by the electronic patient records systems for heart failure patients to allow healthcare professionals to identify quickly if the patient is at the end of life and has, or should have, an advance care plan in place. This flag system could be incorporated into the integrated care pathway. The early identification and alert will prevent the patient being missed and avoid inappropriate cycles of care.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.14852>.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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